

Guide for parents after the diagnosis



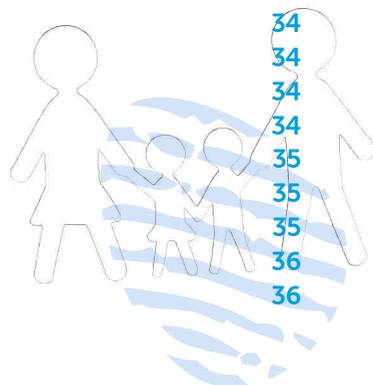
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Your newborn child is finally here, but when you discover that all is not as it should be, what do you do?



Guide for parents after diagnosis

You have a child with a (rare) disease and you do not yet have a (correct) medical diagnosis. But then, you finally get the medical diagnosis. And then ...

What rages through you as parents? "What does the future look like for our child and us? What can or can't our child do later? What is the life expectancy of our child? What is the impact of this on our family? Will our child be able to live independently and have a nice life?" And so on.

This series of articles provides practical support to anyone who is dealing with a child who has a (rare / chronic) disorder.

The following main topics are described in this series:

1. Introduction.
2. A roller coaster of emotions.
3. The impact on the entire family.
4. What you can do yourself.
5. All therapies in a row.
6. How others can help.
7. Additional information.

This series of articles was developed on the basis of 'guide for parents after diagnosis' by author Johannes Verheijden and with his permission. Johannes is one of our regular speakers and he is our workshop leader during our global member conference in the Netherlands.

The content of the articles is based on Dutch culture and social security. We realise that these may be different in other countries. However, we believe that most of the content can be applied in other countries and cultures.





1. Introduction

This guide is for parents who have just heard that their child has been diagnosed with a handicap or chronic illness.

After the initial shock

- What does this diagnosis mean?
- What can I expect?
- Is it okay to feel the way I feel?
- How do I deal with it?

After hearing the diagnosis of your child, you will have a lot of questions and / or you will go looking for help, understanding and support. That is very normal.

In this series of articles you can read what you need to know, what you can do and most importantly: that you, as a parent, are not alone. If you have just heard that your child has a disability or chronic illness, you embark on a long, often emotional, journey. You enter a completely new world, full of doctors, therapists and rules that you have probably never heard of. To ensure that you find your way in this, it is good to find out as much as possible about the condition that makes your child – and therefore your life – special.

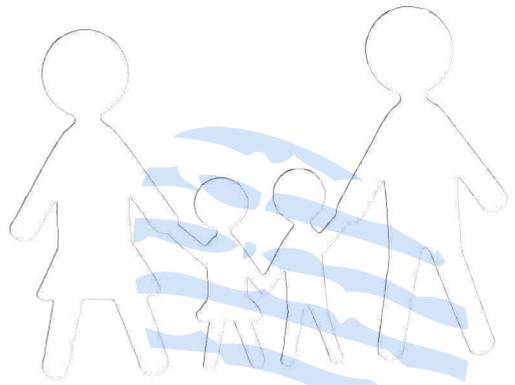
Some parents don't remember anything about the first time after the diagnosis. Others describe it as "a black bag" that was pulled over their head or a knife that was inserted into the heart.

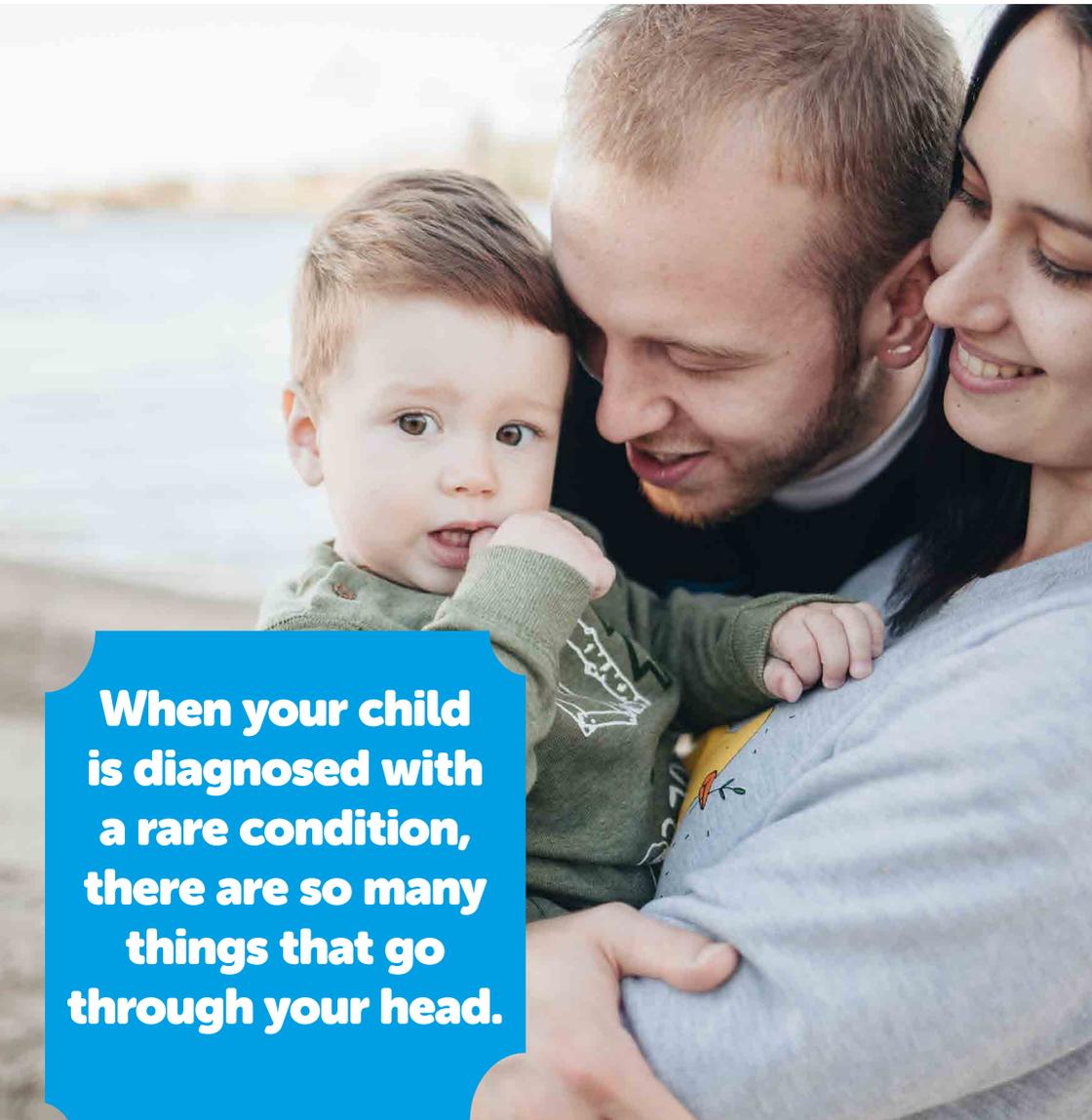
But there are also parents who experience relief because, after years of diagnostic searching, they finally receive an answer to their question. Some parents do not experience any of the above. They are not sad, their world is not collapsing, but they have received confirmation of something they have had an (indefinable) feeling about for a long time.

In short, how you experience hearing the diagnosis is very personal. Fortunately, there are plenty of resources that can help you get through this period properly, should you need it. The realisation that you are not the first and certainly not the only one to experience this, for example, is hopefully a consolation. That is why we describe how parents can react differently and give practical tips and advice, so you don't have to reinvent the wheel.

Every child is different and every parent is different, so what you

read here may not exactly refer to your situation. Nevertheless, we hope that this article answers questions that you may have and that it offers enough tools to help you lead a normal, happy life with your child. Though it may be hard to imagine, there will come a time when the first thing you notice when you look at your child, is the amazing and unique individual, and not the disease or disability.



A photograph of a family of three. A young child with light brown hair is in the center, looking towards the camera with a curious expression. The child is wearing a green sweater and has their hand near their mouth. To the right, a man with short brown hair and a beard is leaning in, smiling warmly at the child. To the left, a woman with dark hair is also smiling, her face partially visible. They are outdoors, with a blurred background of water and trees. A blue text box is overlaid on the bottom left of the image.

When your child is diagnosed with a rare condition, there are so many things that go through your head.

2. Rollercoaster of emotions

There you are, in the hospital corridor, with the diagnosis still echoing in your head. Maybe you already expected it, maybe you are in shock, but the big question is: how do you deal with this and how do you tell your family such as grandfathers and grandmothers? In this article, we try to answer those very first, sometimes overwhelming questions.

So many feelings ...

You may feel enormously protective and loving towards your child but you are extremely angry because your child has this condition or chronic illness. You may continue as if nothing is wrong, or act as a “stand-by” zombie. All these feelings are very normal. It could take a month to give your child’s disability or chronic illness a place in your life, but also years. Yet parents say that the intensity of grief diminishes over the years. You will have good days and bad days, but most will be normal, just like in any other family. It is very normal to have feelings of:

Denial.

Confusion.

Powerlessness.

Disappointment.

Rejection.

Denial

“The doctor must be wrong.”

Confusion

You do not understand what has happened and what is going to happen. You may not understand what the doctor or specialist is talking about, worry a lot, sleep poorly and therefore have trouble making decisions during the day. In short, you are confused and that is very understandable.

Powerlessness

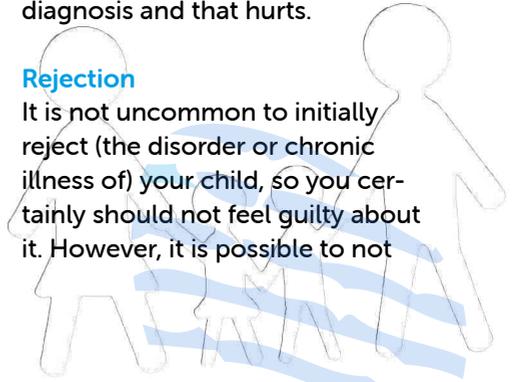
Your child has this condition or chronic illness and you cannot do anything about it except incorporate this fact into your life and adjust your life accordingly. However, you would like to know what you can do and in your opinion, you do not get enough tips from professionals.

Disappointment

Of course you are disappointed because this has to happen to your child, or because your child got this diagnosis and that hurts.

Rejection

It is not uncommon to initially reject (the disorder or chronic illness of) your child, so you certainly should not feel guilty about it. However, it is possible to not



only reject your child, but also your family, friends or specialists.

How do you deal with your emotions?

Everyone has their own way of handling violent or emotional situations. We call that 'coping' strategies. You will find that some ways of handling things work better than others. If you notice that a problem or worry is diminishing instead of getting worse, you know that something works.

Talk

Cry

Rea

Pray

Contact with other parents

Talk

For many people, talking and sharing helps to process the diagnosis. This can be with your partner, but also with family, friends, or a social worker. Talking to other parents who have just heard the diagnosis can also help.

Cry

Many parents suppress their feelings because they see it as a sign of weakness. However, even the strongest parents of children with a disability or chronic illness should not be afraid to show their emo-

tions. So don't be afraid to cry if you feel like it. Learn to deal with natural feelings of bitterness and anger. It is normal to feel this when you have to let go of your wishes and dreams that you had for your child. Recognize that anger and try to let it go. If this does not work, seek help. Even though you cannot imagine it now, life will get better and you will feel more positive again!

Read

Some parents read everything about what is wrong with their child. They Google around a bit, visit a Mytyschool and ask professionals thousands of questions. Collecting information about the condition or illness and preparing yourself for the future is a great way to deal with the diagnosis. But some parents also choose to limit the flow of information to what they can handle. So don't feel cowardly or weak if you don't want to confront the future.

Pray

In addition to praying or meditating, actively talking to a spiritual supporter can also help. Call, write or visit the person you trust or get along with well. It is nice to share your pain with someone who is positive about life. Do not feel bad

that you “normally” do not actively practise your religion and now suddenly ask for help. A minister, pastor, rabbi, imam, or pandit is there for you unconditionally and can give you the support you need.

Contact with other parents

Sometimes it is nice to talk to parents who have an older child with the same disorder or illness as your child. They can tell you what they encountered in the beginning and how they solved practical or emotional issues. Select someone as a “mentor” to help you through the most difficult periods. Blowing off steam or receiving a pep talk over a cup of coffee or over the phone can make the difference.

This can also be a parent of a child who has a different disability / illness, because care, processing and practical problems are often the same. They understand you in a way that your best friend, parents, brother or sister can never do. After all, they have been in the same position once ... And of course, you can always contact a patient interest group that can get you in contact with other parents.

How do you tell your environment?

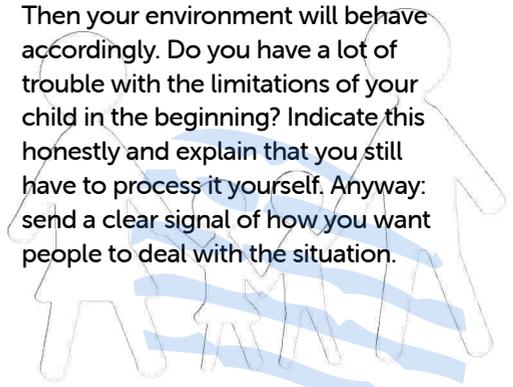
When you hear the diagnosis, first of all you will feel sad about it. But

the people who love you usually feel the same pain, fear, confusion and disappointment. They worry even more than you sometimes. Therefore it is not always easy to inform family and friends and to take them with you in the process. Your own parents, brother, sister or close friends can disappoint you. For example, because they are afraid to pick up or babysit your child.

That’s a shame, but remember that this happens in all families. Part of that disappointment is also in the grieving process of these family members, such as the difficult denial and anger. The best thing you can do is clearly tell what is wrong with your child and how you want to deal with it yourself. For example: “He is likely to develop slowly and may not be able to do everything, but we love him and treat him exactly like our other children.”

Send photos just like you would with a “healthy” child. Make it clear to everyone that you have a nice child that you are happy with.

Then your environment will behave accordingly. Do you have a lot of trouble with the limitations of your child in the beginning? Indicate this honestly and explain that you still have to process it yourself. Anyway: send a clear signal of how you want people to deal with the situation.



Professional support

Are you deeply troubled by the diagnosis or do you notice that you can hardly complete any daily tasks like working or looking after your family? Then you probably need more than extra support of another parent, friend or family member. Fortunately, a lot of professional help is available. In the article about how others can help, we discuss who you can turn to if you can't handle it anymore. From the general practitioner and psychologist to special bodies.

Allow yourself some time

Crying, laughing, talking, praying ... everyone chooses their own way of coping. For example, your partner may respond in a completely different way than you do. Remember one thing: there is no right or wrong way to handle your child's diagnosis and sometimes it takes years before you can come to terms with it. Allow yourself some peace and the time to find out what works best for you. How do you deal with the environment?

The people who love you and sympathize with you, feel many of the same emotions that you feel: pain, fear, confusion, disappointment or worry. Finding a way to provide information to family and friends

without being overwhelming, is not always easy.

Creating expectations

It is useful to teach family members how to see change / progress in your child. Because he/she may respond, but not always, unlike the other children they raised. Only when they understand – and learn to wait for – reactions that might come slower or differently than with other children, and learn to see your child's subtle signals, will they become less frustrated. Communicate clearly what the diagnosis will cause for your child and include them in your child's development.

Ask family for help ...

Remember that family members are also "extra" eyes, ears and hands. They might surprise you with their ingenuity as your baby or child grows and needs certain things, such as toys that you can operate with one hand. These may come from the shed of that handy uncle or from the sewing machine of that sweet aunt! But also think of a babysitter if your child cannot go to school again.

... and ask people you don't know for help too

As soon as your child develops differently or looks different, you

will also have to “raise” strangers. A simple question like “What’s the matter with your child?” can be very annoying on some days. You may receive even more confrontational are comments such as: “Oh well, it could have been worse,” or “You get the child you can handle.” Always remember: people mean well, but they just don’t understand. They do not understand that even though it could have been worse, you must deal with what could have been better at this time. They do not understand that you do not know at all whether you can handle it and they don’t understand that sometimes you want to scream or flee from them. And what do you say when they ask ‘What does your child have?’ That depends on the moment, whether you have time to answer and whether you want to answer. Because you don’t really have to be a saint, you can choose not to answer and walk away.

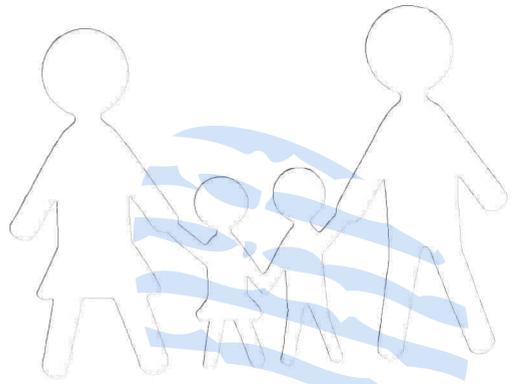
Decide how to deal with others

Perhaps it deeply touches you how people respond to you or your child. But many people’s reactions to serious problems are caused by a lack of understanding or fear of the unknown. Many people do not know how to behave when they see a child with a (visible or audible) disability or visible aids. Sometimes

they say something strange because they’re nervous. Although you cannot determine how people react, you can determine how you deal with looks or questions. Try not to worry about people who are unable to respond in ways you might prefer. As a parent of your child there are better ways to use your energy.

You don’t have to explain anything

No matter how you decide to respond in a certain moment, remember that nobody wants to teach the rest of the world. The condition or illness is a part of your child, just like the color of their eyes or hair. However, it says nothing about who your child is.



Tips for dealing with your feelings

- Live day to day. Don't let the fear of the future paralyse you. Live day by day and try to enjoy what is going well today. Worries about the future can exhaust you, and you already have less energy than other parents. Moreover, it is a waste of time, it is impossible to predict the future.
- Keep talking to each other. Over the years it appears that many parents do not talk about their feelings. Sometimes they make themselves appear stronger than they are (especially towards each other). But the better couples (and their other children) can communicate in more difficult times like this, the greater their joint strength.
- Be realistic. Try to accept life as it is. Recognise that there are a number of things that you can change and some things that you cannot change. The trick is to learn which things you can change and then only do something about these things. You can let go of the rest.
- Avoid pity. Self-pity, pity from others, or pity for your child is

actually always a hindrance. Pity always points out the negative. If you notice that someone (or yourself) is constantly emphasising how sad you or your child are, say something or do something about it. Sympathy for the nasty and the fun moments is, of course, nice, but make sure that those feelings are balanced.

“Stupid” questions you can expect

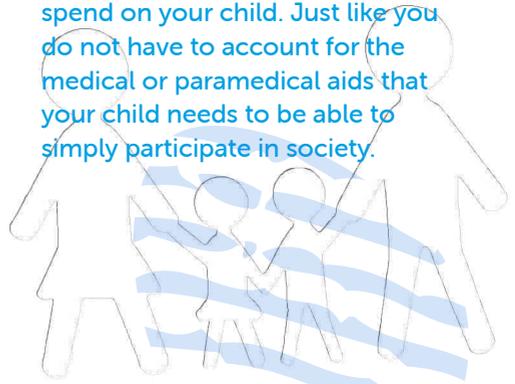
- What's wrong with him? Children in particular will often ask this on the street if the restriction of your child is (becoming) clearly visible. For example if your child is going to use an aid. It is handy to have a standard simple answer ready. For example: “His muscles do not work well, but he just understands everything.” Or: “He understands less than other children. But he is very happy.” Or: “He gets tired a little faster, but he is very happy!”
- Isn't it great, all the things they come up with nowadays? Of course you are also happy that there are all kinds of technical possibilities for your child, if necessary. But many bystanders think that everything will be fine thanks to the technology. Don't feel like nodding “yes”? Then let it be understood that you really don't have to be extra thankful for effective

technology: "Well, we couldn't live without our laptop or Google Maps anymore, could we?"

- Did you not know that in advance? Many people think that you "should prevent" getting a child with disabilities. You can still perform all kinds of tests during your pregnancy, right? Before you know it, you end up in a complex discussion after such a question. Fortunately, it is easy with various diseases / disorders, which you cannot detect at all in the belly. So "no" (and just keep walking).
- Will you be reimbursed for everything? It might sound stupid, but with such a question it seems a bit like they are asking about your salary slip. Although it is often asked out of concern, you do not have to explain your financial situation. You can answer honestly: "That depends on the Social Support Act civil servant or the municipality."
- Is that YOUR child? If you walk on the street with your other child or children, nobody will ask if they are yours.
- That would be an absurd question to just ask a father or mother.

As soon as you push a wheelchair or walk with a child who is "different", it is apparently permitted. The best way to answer is to ask a question, like "Yes, why?" Or "Why do you ask that?" You make people think about what they actually asked about.

- Do you get paid for it? If people know that you receive a Personal Bound Budget you can get this question thrown at your feet. Unfortunately, we know from experience that if you answer this question with yes, you can quickly get a skewed relationship with the person asking the question. What bystanders can also express are comments such as "You get a lot of tools for free." Some people unfortunately only see the "benefits" of a disability or chronic illness. For convenience's sake, the disadvantages are sometimes forgotten. However, you do not have to be ashamed or accountable in any way if you receive financial support for the many hours you spend on your child. Just like you do not have to account for the medical or paramedical aids that your child needs to be able to simply participate in society.



N.B. The answers above are just examples. Find answers for yourself that are close to your situation and that suit you. And always remember that you do not have to answer if you do not want to and that it is also fine if you sometimes do not answer so “politically correct”.

Tips for getting over the initial shock

- Time is on your side. Fortunately, the cliché is true: time heals many wounds. Of course, it may not be the case that your child’s life will go without its challenges, but over the years you will discover different ways to deal with these challenges.
- Take care of yourself. In times of stress, everyone reacts in different ways. However you respond, the most important thing is to keep taking care of yourself. Get plenty of rest, eat well and take time for yourself. It is equally important to create a good network of people you can rely on. This can be a good friend, family member or a fellow parent to talk to.
- Stay positive. Staying positive in spite of everything is your best “weapon” against the challenges you will face. By focussing on the positives rather than the negatives, you will find that you will far more easily cope with any difficulties that come your way.



- Enjoy your child. The fact that your child is different from other children does not make your child less special. Your child is a unique individual, so enjoy the love you share for each other as well as spending quality time together.
- www.schouders.nl: Experience Center for parents is an umbrella foundation with a cross-disorder platform for and by parents of care children (children with a physical disability, mental disability, chronic illness and/or developmental disorder). Many questions within these families are not limited to disease-specific themes. Disorder-transcending themes that these parents struggle with
 - and have found solutions for – often relate to the family situation, relationships, finances, relaxation and education. Within the Parents Experience Knowledge Center, parents can benefit from each other's experience and the group can target group needs.



A young child with dark hair is lying in bed, wearing a light-colored patterned dress, and drinking from a clear plastic sippy cup. An adult's hands are visible, holding an open children's book. The book's left page shows a blue sky with a yellow sun and a blue whale, with the text "He had a dream about the ocean...". The right page shows a green landscape with a house, trees, and a red deer, with the text "I travel Monday...".

Your child's illness affects not only your child but the whole family.

3. Impact on the family

“You are never alone when you have a disability or illness,” people sometimes say. Your child’s diagnosis also has an impact on everyone in the house. When it comes to your first child, you will need to find a new balance as husband and wife. If you already have children, the whole family will have to get used to the new situation. Fortunately, most families quickly find a nice balance again.

You want to help your child develop fully. You may give 100% of yourself for that, but if you focus all your energy on one person in the family, nothing else remains. Therefore, make sure that you create a harmonious home in which everyone receives the love, attention and support that he or she needs, including you!

How do you deal with it together?

If you react differently to the diagnosis than your partner does, it can cause tension. If one of you reacts more emotionally and the other prefers to be more practical, give each other plenty of room and keep telling each other how you feel and whether you want to talk about it.

It is also very important to accept

each other’s way of processing the diagnosis. Don’t get angry if your partner just cries or if he or she just can’t stop ‘Googling’. Decide together how best to care for your child and family. Make sure that you are clear about your expectations of each other, and keep doing fun things together, even without children. That way you will become a strong team.

How do you explain it to your other children?

When you come home with your new child, the other children may sense from you that there is something wrong and may become a little alarmed to hear that their new baby brother/sister has a disability or is unwell. How do you explain this to them? Of course, everyone parent must find their own way to do this, however, here are a few tips that may be of help:

Be honest

Be clear

Toddlers

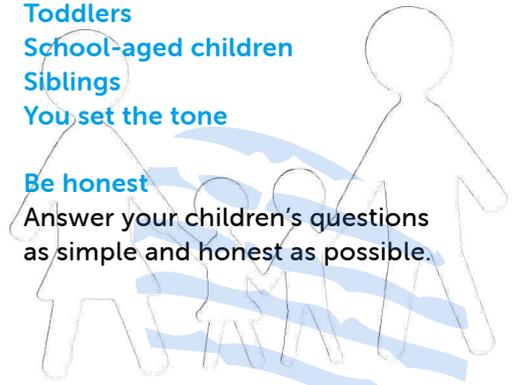
School-aged children

Siblings

You set the tone

Be honest

Answer your children’s questions as simple and honest as possible.



Don't know the answer?

Then just say that. Children pick up everything that happens around them, so shielding them is not a good idea. If you do not explain why you are sad, children will become more concerned, think they have done something wrong or think something terrible is going to happen.

Be clear

Don't know where to start explaining? Then keep the following set-up:

1. A "this is it" statement: "Your brother's kidneys are not working so well and that is why I feel sad and worried."
2. Explanation of what is going to happen: "She is not sick and will not die, but she does need help to learn things and that is why we go to the doctor so often."

Toddlers

How children react to a brother or sister depends on their age. For toddlers the whole world revolves around them. It may be that they are more involved with their toys than their brother or sister. At the same time, they may feel that it is their fault that the baby is "sick." As a parent, you often feel when you have to leave your toddler alone or explain at his level what it is like.

School-aged children

Older children can react a little differently. Of course, it depends on the sensitivity of your child, but often you see that an older brother or sister is very protective. Incidentally, this concern can just as easily turn to shame about their brother or sister.

Sometimes even on the same day, children are simply erratic. The following also applies here: keep talking about what's going on. Your "that's it" sentences help your child accept the situation and accept their brother or sister.

Siblings

Your other children are "brusjes", or brothers and sisters of a child with a disability or chronic illness. This group of children, who of course are a bit special themselves, receives more and more attention and all kinds of fun initiatives are created for them, such as the Facebook group on www.facebook.com/brusjes. Especially when your children grow up, it can be instructive to read a book about it which contains advice from psychologists, brusjes or other parents.

You set the tone

Both with your "normal" children

and with your “special” child, the following applies: you set the tone when it comes to emotional behaviour. How you deal with your child’s disability / illness is a statement and inspiration for the people in your household. The more normal you deal with the situation, the less traumatic or dramatic it will be for them. It is understandable that you cannot always be cheerful, you are only human. And you certainly don’t have to pretend. Just try to stay positive and help your children to live the most pleasant life they can.

What now?

The world does not stop turning and you are not a terribly insensitive parent if you adjust the rhythm of your child to the needs of the rest of the family, including yourself! Make sure your child participates in daily life as much as possible. Sometimes he/she will have to adjust to (the speed of) his/her brother(s) and / or sister(s), and sometimes the other children will have to wait a little longer for their turn. But don’t worry, the happiest and most successful adults with disabilities or chronic illness say that their parents treated them just like all other children in the family.

Practical tips

Personal attention

Spend time with every child, even if it is only ten minutes a day. Every child needs undivided love and attention to feel special. Give them your undivided attention and show that you listen and understand your child, by repeating what they tell you.

Be flexible

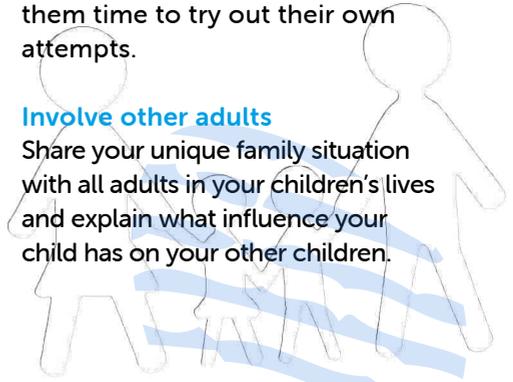
Balance the needs and wishes of your child with those of other family members. Can you not swim with the disability or illness (because of the cold water or anything else)? Then look for an alternative family outing that everyone can join.

Let your children help

Involve your children in the care of your child who has special needs. This reinforces your children’s empathy and will strengthen the relationship. Let them think along to help your child and give them time to try out their own attempts.

Involve other adults

Share your unique family situation with all adults in your children’s lives and explain what influence your child has on your other children.



This will make others understand your child better.

Arrange good childcare

Sometimes you cannot have your child taken care of by your normal babysitter. In this case, make sure you have various childcare options. You can get special babysitters via organizations such as MEE, the national help guide or Per Saldo. Also think of a call among students of physiotherapy, occupational therapy, nurse education or orthopedagogics. Another possibility is to investigate whether you can solve this through the

Personal Budget, such as babysitting by nurses.

This may be pricey, but it can be an enormous reassurance and you don't have to arrange anything. Through the interest group, you can get in touch with other parents, who may have tips on how to handle special childcare. Links of the relevant organisations are listed in this series of articles.







**Thankfully,
there is plenty
that you can do
to help you and
your child.**

4. What can you do yourself?

For the most part, life continues “as usual” after hearing the diagnosis. Your child needs attention, love and care, perhaps more care than other children of their age. What is the best way to provide this care? You will learn this over the coming months and years with the help of counsellors, doctors and / or therapists.

Your child is more than the condition

The best thing to do is to treat your child in the most normal way possible. Your child can be sweet, mischievous, happy and curious, but sometimes angry, grumpy and rebellious. In short, they have the same range of emotions other children their age has. Be careful not to only see your child’s medical condition, your child is so much more than that. They are unique little people with their very own personality, gifts and interests.

Playing is learning

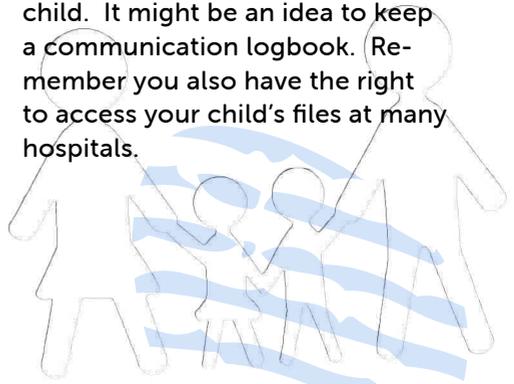
Interact with your child as normally as possible. Challenge them to move, play and explore without focussing too much on their medical conditions. Play with your child as you would with any other. Small daily activities, such as brushing your teeth, washing

the dishes, cooking or walking the dog can also be fun learning moments.

How do you deal with doctors and therapists?

There will be times when you feel that your child is being surrounded by different professionals all wanting to help and it can feel overwhelming at the beginning. There may be times when you feel that you are not in control of the situation but remember that this is not the case. It is important that you feel happy with whatever is happening around your child, make sure that you have the information that you need to take care of your child at home.

Sometimes communication between professionals themselves can be unclear, so it is vitally important when communicating with a large group that everyone is clear about their own responsibilities and communicate clearly how to support you and your child. It might be an idea to keep a communication logbook. Remember you also have the right to access your child’s files at many hospitals.



Keep control yourself
Stay informed
Ask for clear communication
Educate yourself
Let doctors and therapists help you

Keep control yourself

It may be that the professionals more or less 'take' your child. You may feel that they suddenly have everything to say about your child. Of course, nothing could be further from the truth! Therefore, make sure that you are in control and discuss how you can take care of your child at home.

Stay informed

Sometimes communication between the professionals and towards you is not always clear. While that is very important, with such a large group of people who have to work together. Here too, keep in control. Some people do this, for example, by keeping a communication log. You can also access your child's file at many hospitals.

Ask for clear communication

The language used in reports can contain terms that you do not understand. This is very normal, but not useful if you want to know exactly what treatment your child is receiving. Do make sure that you

are included in all discussions and decisions about your child. When speaking and writing to you, ask doctors to communicate with you in simple language and without the use of medical jargon.

Educate yourself

To be well prepared in the consultation room, do as much as you can to learn everything about the disability/condition of your child. Learn about the challenges they will face and rights they have.

Government websites are a great source of reliable information. In addition, you can also visit the website of the patient organization for information about the condition or illness and / or get in contact with other parents for educational experience stories.

Let doctors and therapists help you

Nowadays it is no longer the case that doctors and therapists just decide everything for you and your child. Professionals and parents work together as much as possible. There are various ways for professionals to support you:

Handing over your child

There may be occasions when you need to be more of an observer than a participator, allowing the medical experts to take the lead.

Let them coach you.

Ask the professionals to explain clearly to you how you can support your child in their development. Not all professionals may have the skills to be a good coach, but this will help you to stay in control more easily and allow you to manage your own child with more confidence. Knowing how to stimulate and to manage your child's needs will mean not having to leave your child with outsiders as often. It will also make you feel closer to your child.

As a parent of a child with a disorder or chronic illness, it is natural to feel over-protective of them. However, it is very important to encourage your child to be as independent as possible. Allow your child to make their own mistakes and to learn from these experiences.

Give your child the opportunity to reach their full potential. On the site www.opeigenbenen.nu you will find a growth guide (click on toolkit / young people / growth guide).

On the parent's website there is also a handy tool: Take Care, which can be a very useful resource for parents.

Don't forget to raise your child

As a parent of a child with a disorder or chronic illness, you probably tend to do too much for your

child and demand too little, while you should really do everything you can to make your child as independent as possible. From an early age, try not to protect your child more than is necessary. Children should be allowed to have their own experiences so that they can learn from their mistakes. On the site www.opeigenbenen.nu, a growth guide is available (click "toolkit/jongeren/groeiwijzer") that can help you work with your child on his/her independence and identity. Also, on the website of (Sch)parents, there is a handy tool "Take Care", which discusses various topics of importance, some of which may require more of your attention.

You can translate these Dutch websites by means of Google Translate.

Tips to take action yourself

Practical tips:

Organise yourself

Organise your house

Set realistic goals

Write down your questions

Make a booklet



Organise yourself

Knowledge is power. Collect and use information so that you can be a strong advocate for your child. Use a ring folder with tabs to store information about your child's condition / illness, challenges, legal rights, and treatment plans. Having this information at hand can reduce stress, help in daily and longer-term planning and improve communication with care providers.

Ideas for topics / tabs in your folder:

- Types of medication and dosage.
- Medical materials such as brands and types of catheters, Mic-Key
- Your child's doctors / therapists.
- Results of laboratory tests, tests and letters.
- Diseases, operations and hospital admissions.
- Vaccinations and allergies.
- Appointment schedules.
- Treatment calendar.
- Learning material.
- Legislation and regulations concerning children with a disability / chronic illness.
- Contact information of special services and support.

Organise your house

If a lot of materials and / or medicines are needed for your child, it is useful to keep them together in one cupboard. Maybe you even need small or large adjustments at home. You can think of bobbins under a normal bed so that the hospital atmosphere disappears, or a kitchenette, so that care can be made easier.

Set realistic goals

Every parent wants their child to achieve the highest possible goals. That is no different for you as a parent of a child who has a chronic illness or disability. Always remember that your child will go through the various stages of development at their own speed, depending on the severity of the disability / illness. Consult with doctors, therapists and teachers to see how they can help you achieve your goals. Also, remember not to talk down to your child. Fatigue can also result in your child not getting the right cognitive challenge.

Remember that you know your child best and that your child's abilities may change over time. Be flexible, set challenging goals, but not so challenging that it becomes frustrating. Offer, as

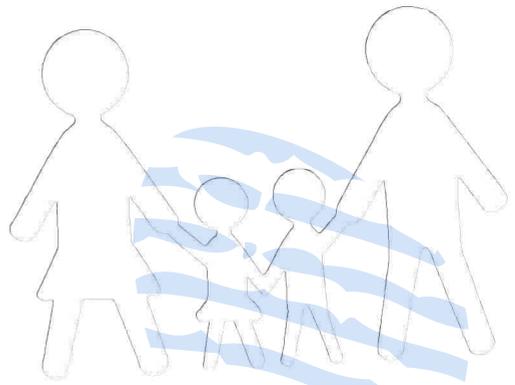
soon as somewhat possible, choices that are in line with your child's experience. The freedom to choose will give your child confidence and help you feel as independent as possible. Cheer on all your child's attempts to develop! Write down your questions

Doctors and therapists are eager to help you and generally do so on the basis of a request for help, so that they allow you as a parent to regain control and not to come up with things yourself. But, certainly in the beginning, you are not at all concerned with that, or do you not realise that you can request help at all. In any case, start by continuously recording questions that arise. After a while, you see a line in the things you encounter. A specific request for help in collaboration with professionals can be realised then.

Make a booklet

It's perfectly fine to mourn the loss of a dream. This is discussed in more detail in the "Profits Verliesspiegel" which you can find on the shoulders/parents website. Yet you can try to celebrate every special moment of your child with gratitude and pleasure. Therefore, try to keep a booklet with your child's photos and crafts. Their

performance may be different than in a "normal" baby book, but the result remains a beautiful memory that radiates parental love and pride. It will be nice to show to others and read again later.



A photograph of a family of four enjoying a day in a park. A man in a tan jacket is on the left, holding a red and white volleyball. A woman in a purple vest and tan pants is in the center, smiling. A young boy in a red jacket is on the right, reaching out. A black and white dog is in the foreground, looking up. The background shows trees and a white car with its trunk open.

There are a whole arsenal of therapies and organisations available to you out there.

5. Possible therapies

This article discusses the various possible therapies and instances that you may encounter. The situation in the Netherlands is discussed here so that the situation in other countries may be different.

In the field of therapies, the following are discussed:

Physiotherapy

Occupational therapy

Speech therapy

Pre-verbal speech therapy

Complementary therapies

Possible therapies

Physiotherapy

Physiotherapy (for children) is primarily focused on motor development. Your child is supported in learning motor skills. The emphasis is mainly on gross motor skills.

Furthermore, the exercises are aimed at reducing underlying disorders by improving muscle tension, for example, keeping the muscles at the right height and improving strength, coordination and condition. In addition, the physiotherapist can help you request the necessary aids, such as a walking aid, special chair or wheelchair.

Occupational therapy

Playing is very important for your child. However, this will always be just a little, or even completely different, than for children without a disability / illness.

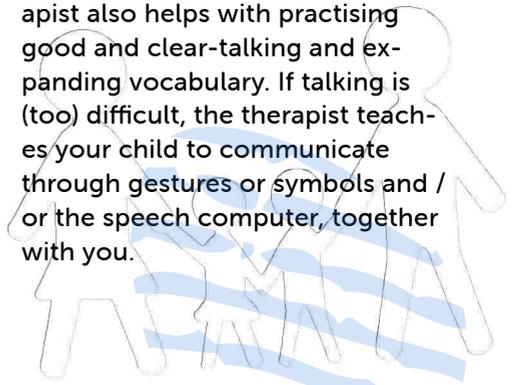
The occupational therapist helps your child with this. They specialize in improving independent behaviour at school, at home and in leisure time. Occupational therapy exercises are focused on daily (fine motor) activities such as dressing and playing, but also writing at school for example.

Just like the physical therapist, the occupational therapist can help you request the necessary aids. This usually happens in consultation with the other therapists.

Speech therapy

The speech and language therapist offers help with swallowing, eating and / or drinking, or excessive saliva loss.

The speech and language therapist also helps with practising good and clear-talking and expanding vocabulary. If talking is (too) difficult, the therapist teaches your child to communicate through gestures or symbols and / or the speech computer, together with you.



Pre-verbal speech therapy

If a child has problems drinking from the breast or bottle, eating from a spoon, drinking from a cup or learning to chew, pre-verbal speech therapy can be given.

This is always done through a referral from a doctor (for example, a general practitioner or a paediatrician). The latter is important because it must first be checked whether there are any underlying medical problems causing difficulties in the mouth area. Starting communicative development is also important in early development.

Complementary therapies

From dolphin therapy to therapeutic horse riding to ... There are a lot of (international) therapies that can benefit a child. Sometimes they are reimbursed by your health insurance company, but often they are not. Usually, these types of therapies consist of short (very) intensive treatments or training sessions.

In general, the effect of these training is short-lived and in many cases, the adventure is costly – especially the treatments that are only given abroad.

Of course, you want the best for your child, and you have to try out what feels right for you.

Just remember that traveling with your child abroad means that your child is taken out of the social structure, misses school and cannot play. We, therefore, recommend that you consider any therapy outside the regular circuit in close consultation with your doctor.

Which authorities do you have to deal with?

In addition to the various doctors and therapists, you may be confronted with (some of them are specific for the Netherlands):

- Consultation agencies
- Integrated early aid
- Hospitals
- Rehabilitation centers
- Further professional help
- Your doctor (general practitioner)
- Social worker
- Family therapist
- Psychologist
- Remedial educationalist
- Foundation MEE
- Center for Youth and Family
- Respite care
- Family support

Consultation agencies

The consultation office is a practice, with a doctor and one or more district nurses. They ensure that infants and toddlers are invit-

ed to participate in periodic check-ups and vaccinations. The purpose of the control examinations at the consultation center is to identify diseases and developmental disorders as early as possible so that they can be treated on time. In addition, the youth doctor or nurse can support you with tasks that fall outside the scope of the hospital, such as upbringing, support of sibling, choice of school, daycare (nursing). In addition, they are connoisseurs of the social map in the neighbourhood and can offer support in familiarizing your child with this.

Integrated Early Aid

A number of organizations (such as MEE, child rehabilitation and daycare centers) work together at Integrale Vroeghulp. It is precisely this collaboration that makes Integral Early Aid very valuable. Everyone brings his or her own expertise; your child will be looked at from all perspectives. Here you can ask all the questions you have about your child. In some municipalities, the Center for Youth and Family, for example, is responsible for this. The consultation office can help you with this.

Hospitals

Some appointments and examinations, such as having a pediatric neurologist make an MRI, or

appointments at a paediatrician, pediatric urologist, a pediatric nephrologist and the like can only be done in a hospital. Your doctor will be informed of all procedures and examinations.

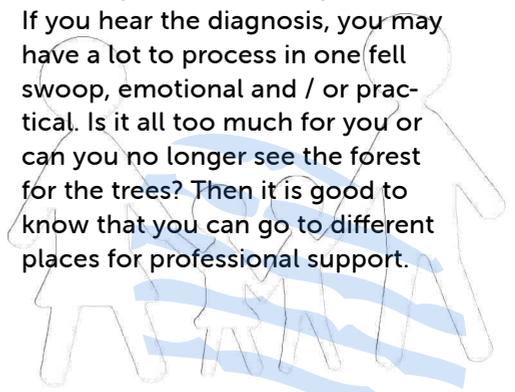
Rehabilitation centers

Depending on the diagnosis, you will go to a rehabilitation center with your child for the first years of therapy or daycare. Physiotherapists, occupational therapists, speech therapists, rehabilitation doctors, remedial educationalists, social workers and psychologists work together under one roof and often in a team.

The rehabilitation centers work closely with hospitals, nursing homes, general practitioners, primary care and home care. If your child goes to special primary education, they usually receive therapy at school and you no longer need to go to the rehabilitation center.

Further professional help

If you hear the diagnosis, you may have a lot to process in one fell swoop, emotional and / or practical. Is it all too much for you or can you no longer see the forest for the trees? Then it is good to know that you can go to different places for professional support.



Your doctor

Your doctor is primarily there for health problems, but an important task of the doctor is also to monitor the entire situation of patients. They know more about you and your family than other professionals and therefore they can help to coordinate all care around your child. It may be that you need to “remind your doctor” about this. Your doctor can also tell you exactly when he should refer you to a specialist.

Social worker

At the hospital, the rehabilitation center or possibly later at the special school of your child, you will be assigned a social worker. If not, ask for this! This is a permanent person who can help you with everything that you encounter regarding your child, both practical and emotional. The social worker knows all about healthcare and your personal situation and can advise, mediate or refer you to the right body.

Family therapist

Do you notice that your relationship or the entire family suffers from the new situation with your child? Then do not hesitate to engage in a relationship or family therapy. Such a therapist offers

therapy where both partners or all family members are present together. Everyone’s problems are central to therapy. That way you work together on a new balance.

Psychologist

A psychologist helps people with psychological challenges. This can be uncertainty, worries about the future, feelings of guilt about the past, relationship problems or problems at work. A psychologist first explores the problem and then proceeds to handle the complaints. This often happens in a very practical way, such as with writing assignments, role-playing games, practical exercises or relaxation techniques. After all, improvement does not occur automatically and requires time and practice. Going to a psychologist certainly does not mean that you are “crazy” or “weak”. By doing so, you demonstrate that you take responsibility for solving your problems. A psychologist can also be very supportive.

Remedial educationalist

Every parent of a child who has a chronic illness or disability will sooner or later have to deal with a remedial educationalist. This is a therapist who deals with more difficult learning and upbringing

situations of children and with the education of a child with a disability or chronic illness. If you run into parenting problems (for example if your child is extra demanding, or if they are constantly bored by their disability), the remedial education-
alist can advise you well. There is usually an orthopedagogue in your child's treatment team. Feel free to address them with additional questions.

MEE Foundation (Netherlands)

You can contact the MEE Foundation for advice on practical matters concerning your child. How do you arrange help? What budgets are there for financial support? And where do you request it? Together with you, MEE maps out what is possible and they can, if necessary, help with filling in forms and other paperwork.

Center for Youth and Family

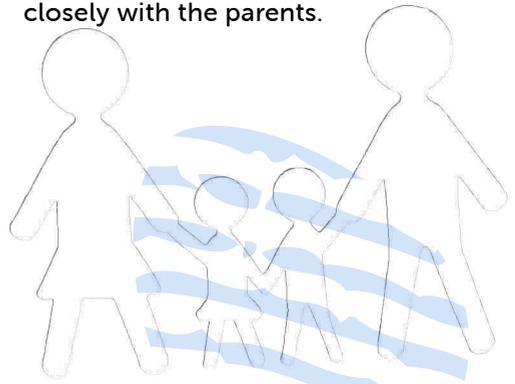
The Center for Youth and Family (CJG) is for all parents and educators who have questions about the upbringing, growing up or health of their child. For information, help, advice and support you can contact the CJG in your area. You can also go here for tasks in which Stichting MEE was previously involved, but which can no longer be offered due to budget cuts.

Respite care

Everyone needs a break when caring for a child who has a disability or chronic illness and that is exactly what respite care offers. In another location or at your home, respite care staff take care of your child while you have the time to do something else. Or just nothing at all! Being alone to charge your battery, do something with your other child or children, do some jobs around the house ... Thanks to respite care, this is all possible.

Family support

Do you have questions about your child's development? Or would you like to talk to people who are experts in the field of disability or chronic diseases? Then family support might be something for you. This home help is intended for children and young people with intellectual or multiple disabilities. The guidance, including the number of guidance hours per week, differs per family and works closely with the parents.



Tips for good collaboration with professionals

Request and find information

It is not about how much information you collect, but how accurate it is. Do not be afraid to ask questions, because that is the first step in understanding your child's disability or illness. Learn to formulate your questions so that you get the information you want. And keep asking until you have received the information and understand it. Remain friendly, but bold.

Learn the terminology

If someone uses a word that you don't understand, stop the conversation for a moment and ask that person to explain it. Especially in conversations with doctors you can, may and must do this. Above all, don't feel "stupid" because professionals are often hard to understand for everyone.

Ask for copies

Ask for copies of all documents from doctors, teachers and therapists related to your child and

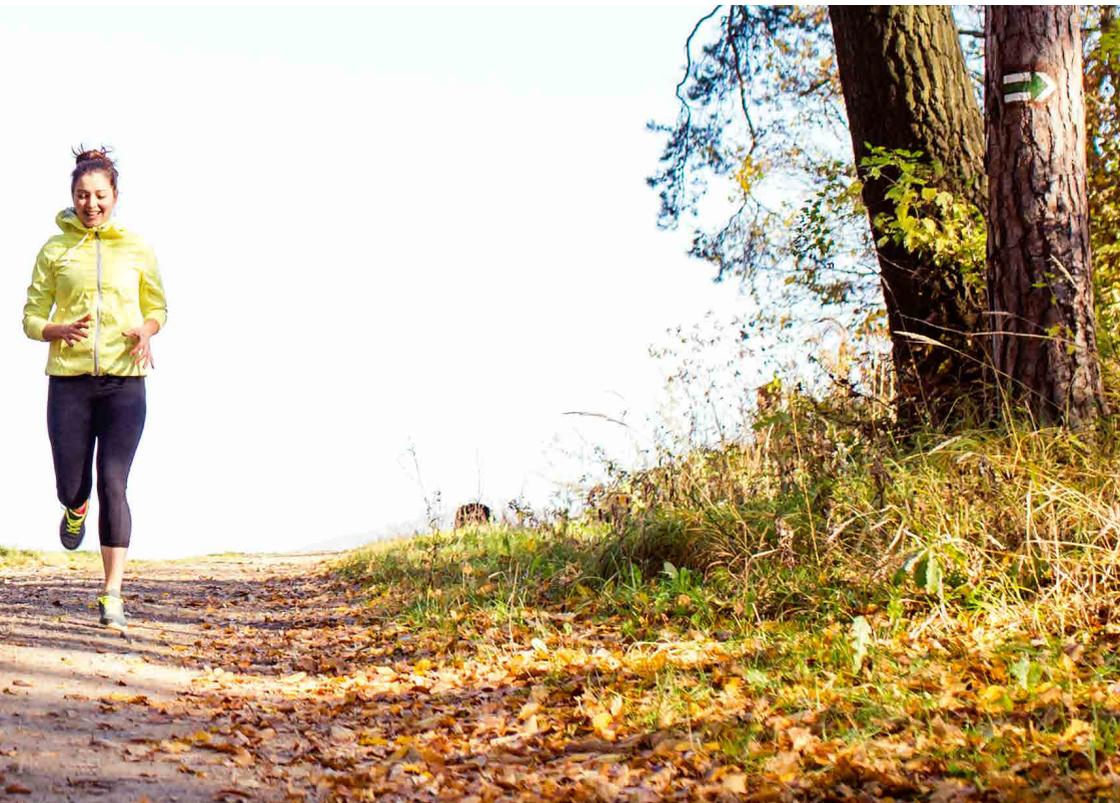


collect them in a folder. Are you not that organised? Then buy a box where you store all the paperwork. If you need something later, at least it is all in one place.

Don't feel intimidated

Many parents feel insecure around doctors and / or therapists due to all their diplomas and, sometimes, because of their professional way of doing things. But it is not necessary at all to feel intimidated by the knowledge or background of anyone who treats your child.

Like you, professionals want you to go home with a good feeling and clear answers. And ... you are your child's expert in the end! Although you can get a lot of information from books and from professionals, that does not mean that all information applies to your child. No two children are the same, so it is important to see what happens to your child.



A young child with dark hair, wearing a blue and orange striped long-sleeved shirt, is seen from behind, holding hands with two adults. The adults are wearing orange and red shirts. They are standing in a lush green field with a blurred background. A blue speech bubble with white text is overlaid on the image.

**You don't
have to be
alone.**

6. Help by others

This section is for friends and family. Many close friends feel uncomfortable asking questions about the development or course of your child's illness. They also often feel powerless because they do not know how to help you. Do you notice that someone who is close to you and cares about you finds it difficult to talk to you or offer help? Then have them read this special article.

The most important advice for the environment of a family with a child who requires more care is: do not be afraid to ask questions about the child's disability or illness. Openly tell them that you want to know more. Follow the development of the child together with the parents. Remember that they have less time to do fun things than before. Do not compare your own children with the child who has a disability / illness. Provide emotional and practical support where possible and make it a habit to regularly call just to say "hello".

How can you respond better?

Parents of children who have disabilities or chronic illness expect that they will be supported by people who are close to them, both emotionally and practically. How can you help?

Emotional support

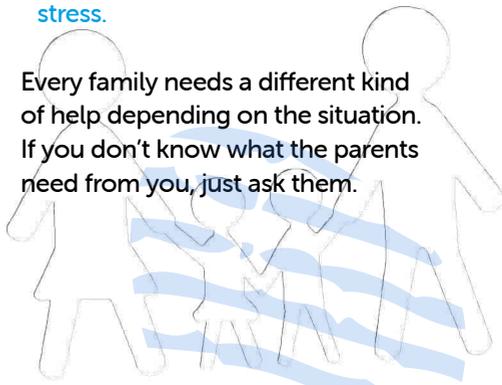
Listening is important. Be available, take the time and listen actively (so ask open questions, reflect and summarise) and be attentive. Make more time than usual to do something with the child. The limitation / illness can mean that tasks take more time and / or can go slower. For example, it may take longer to get in and out of the car or the house. Offer to go to a doctor, therapist or care provider once to get a better understanding of the child and the condition / illness.

Practical support

You can provide reliable help to parents on a regular basis, such as:

- Shopping.
- Taking care of the other children or do household chores.
- "Being there" to take care of the children during an emergency situation.
- A weekly visit at a certain time and doing the laundry, tidying up or helping out in the garden to reduce stress.

Every family needs a different kind of help depending on the situation. If you don't know what the parents need from you, just ask them.



Empathy

Parents don't want sympathy! What they want is empathy and it takes quite some effort from you to understand how they feel and what they go through. Therefore try to "walk in the parents' or the child's shoes" for a while. Perhaps the list below can help you to understand the stress, on top of the daily hassle, as described by parents of a child that requires extra care:

- Frustration due to uncertainty about what will happen to the child in the longer term and difficulties in finding clear answers.
- Feelings of guilt because you have to divide attention between the child who has extra needs and the rest of the family.
- The continuous question why the child has the disability / illness and whether it could have been prevented.
- Dealing with the chronic sadness and loss of the 'normal' child that the parent does not have.
- Worries about whether the child will be accepted by the environment.
- Worries about future plans for adulthood (education, work, family life).
- Worries about the severity of the condition.
- The fatigue associated with the continuous giving and arranging of daily care, which goes beyond the normal expectation pattern for the child for the coming years. Families may have difficulty feeding, dressing, toileting, bathing, heavy lifting, playing, therapy, putting on splints, eating, playing, etc. In addition, arrangements and "battles" with municipalities over facilities, transportation, etc.
- The pressure of attending many therapy sessions per week, plus the appointments with specialists, hospital, results and tests.
- The infinity of it all ...
- Less freedom of choice and freedom of movement because you always have to think about the special needs of the child.
- Sadness and frustration because the child is not going to roll, crawl, sit or walk, or because it is not talking, cannot do everything it wants.

- Possible marital problems because your partner does not accept the child, does not understand you or does not help you plus extra stress such as lack of sleep.
- Dealing with the effects on brothers and sisters. How do they feel and how do they deal with the difficulties?
- Other children cannot understand why mom and dad spend more time on the child with ... Feelings of guilt, rebellion or rivalry.
- Uncertainty about a new pregnancy. Can it happen again with the next child?
- The feeling of being "trapped" due to physical exertion and the extra organisation needed for outings (from simple picnics to longer planned vacations). There are concerns about sufficient space in the car, finding a place with good facilities, accessibility, toilets; accommodation; problems with eating out and specially prepared food. All of these factors make it difficult to plan in the long term and make it less likely for the family to make a spontaneous decision to go out.
- Always putting one's own needs aside to meet the extra needs of

the child.

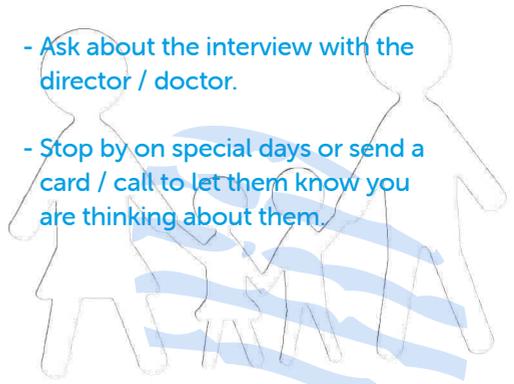
- Financial problems (home modifications, special cars, medicines, facilities, special toys).
- The doubt or inability to return to work due to the treatment and special needs of the child.

What can I do for you?

"What can I do for you?"

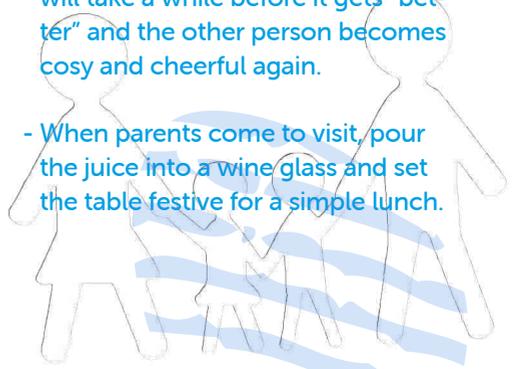
In her book "What can I do for you. Support during mourning", writer Karin Kuiper has collected some wonderful ideas that are very easy to realise and that we would like to share with you:

- You can help by "being there". Call, stop by, go out or a coffee, send a card.
- Take parents with you for walking, cycling, dancing.
- Help out during birthday parties. This way the real hostess / host can catch up with the guests.
- Ask about the interview with the director / doctor.
- Stop by on special days or send a card / call to let them know you are thinking about them.



- Secretly plant flower bulbs in the parents' garden.
- Take the children to buy a surprise for their father or mother or make a beautiful "work of art" with them.
- Offer to go to the recital at music school, the competition at the gym club, the cup competition at the football club or the school musical.
- Offer practical assistance in the form of cheques that can be exchanged at the issuer.
- Send a card with ten self-written compliments.
- It is easy to maintain intensive contact with one person. But for someone with a child with a disability / chronic illness, it is not easy to keep a whole circle of friends / environment happy. Be generous in maintaining the friendship.
- Reach out on wedding days and the children's birthdays.
- Make sure that you are just pleasant company.
- Take a freshly pressed smoothie with you when you come over. Tasty and healthy!
- Talk about the fun and less fun sides of your own life. The world keeps turning and in the end everyone wants to move on with their life. It's nice to stay involved in the lives of others. That way you prevent loneliness.
- Call in the first few weeks after hearing the diagnosis.
- If a parent cries, don't pacify them, but touch them gently to show your support.
- Do not break the friendship without explanation. The children will not understand where everyone went. This will cause confusion.
- Take the dog out for a walk (or take the parent out for a walk).
- Give / borrow the book that you recently enjoyed so much yourself.
- "Being there" means listening without judgment. Listening is paying attention with your mouth shut. Let them cry or get angry. It can be nice to let the emotions go. Listen and offer a shoulder and some recognition.
- Eat together regularly.

- Send a regular message to let them know what's happening in your life. Send photos of holidays, children and grandchildren or places of interest, nice videos or websites.
- Give a medium with your favorite music. Go to a concert together. Give a medium with your Top Ten of tear-jerkers. Forward links to YouTube videos, videos and internet sites to share the music of your favorite artist.
- Ask again how the reports were, whether the exam was passed and whether everyone was "over".
- Spontaneously ask parents for a picnic in the woods or on the beach. Go fly a kite with them.
- Offer long-term disaster relief assistance with leaking gutters, flooding washing machines and defective dishwashers and such. Give a voucher that can also be redeemed in five years' time – then parents will know that they may also ask for help in a while.
- Offer to go to the swimming pool or amusement park – the expedition will really be a trip!
- Arrange an evening of film – and also arrange the babysitter!
- Call on the parents' help every now and then.
- Take over the daily life of the parents for three days and send them out to recover.
- Give something beautiful. A bouquet of flowers, a special photo in a frame, a beautiful plant, a separate postcard, a tea cup with hearts.
- Help with the preparations for birthdays and holidays.
- When visiting a hospital, send a "goodnight" text message, or "a success today in the morning!" – message.
- Mourning and processing are not a bleeding finger that needs a patch, not a wound that is quickly closed or leftover. Take the sadness and the process seriously. Accept that it will take a while before it gets "better" and the other person becomes cosy and cheerful again.
- When parents come to visit, pour the juice into a wine glass and set the table festive for a simple lunch.



- Tell an inspiring story about your “hero” or your hobby.
- Wash their car (unsolicited) for them.
- Offer specific assistance. “Next week / time / holiday I’ll be careful” “Shall I cook for you tomorrow?” “Can I help you with the garden?”
- Provide a warm house and a bunch of flowers, or a Welcome Home card, when you return from the hospital.
- Find a ridiculous photo of the parents or yourself, and show that it can always be worse!
- Give parents the chance to sit on a couch all day long with a book, film, magazine or laptop and a pot of tea. No shopping, cleaning up or care obligation for them.
- Organize an egg hunt at Easter.

How should you not respond?

Of course every comment from a good heart is welcome. Certainly, if you know each other well and know what it means to you.

Yet it is better not to respond in the following ways:

- Deny the disability or illness
- Show anger
- Express fears aloud
- Criticize the chosen therapy / treatment

Deny the disability or illness

A reaction such as “Don’t worry, there’s nothing wrong” or “He’ll grow over it” can hurt parents. No matter how well-intended, you are thereby denying the severity of the diagnosis they have just received. Even “Nowadays there is as much as possible” is a form of denial. Not everything can be solved with medical treatment. It is possible that you deny the seriousness yourself, which is a sign of compassion. First, try to deal with your own sorrow. Or look for “fellow sufferers” in the form of other family members or friends of a family with a disabled child / child with a chronic illness.

Show anger

It is sweet and understandable to get angry about the diagnosis that your friends or family have received. But venting your anger towards the child’s parents, even if it is aimed at a doctor or hospital, for example, has a negative effect. Anger is not an emotion that

parents can use, so try to keep this to yourself.

Express fears aloud

After the diagnosis, there is often one fear that dominates: how should it go later? "What will happen to this child when he is five years old, or twelve, or 21? And what if I am no longer there myself? "Then other questions arise:" Will he ever learn? Will he be able to go to school? Will he be able to love, live and laugh and do all the things we had planned? "Other unknown things also cause fear. The parents fear that the diagnosis of their child might be the worst. Fear can paralyze them. Therefore, make sure that you do not feed the parents in their fear. Listen to it, say you understand, but do not participate in predicting or discussing doom scenarios.

Criticize the chosen therapy / treatment

Because parents often come across "unknown" due to their child's disability / illness, the advice of professionals is very important to them. They can also opt for a not yet known or alternative therapy, or treatment. As a family member or friend, it is important that you support the advice and efforts of profession-

als – trusted and respected by parents – even if you disagree with what they do. Your acceptance and support is necessary and valuable for families with special needs.

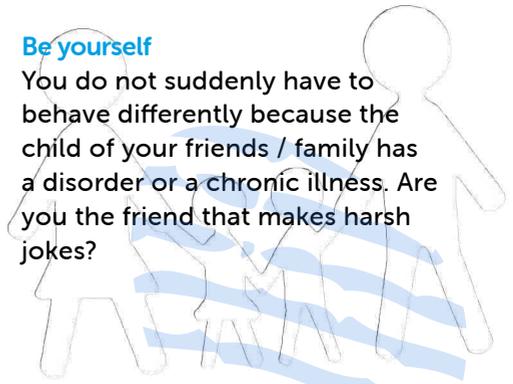
Finally

It may be clear: a child with a chronic illness or disability brings stress, sadness and fatigue with it. Fortunately, parents do not always feel this stress continuously or equally. As in any other family, feelings of happiness, achievement, pleasure and satisfaction are certainly also experienced. The most important message for friends and relatives is to consciously see how life can be for the family. And how you can help by continuing to talk, by offering practical help and by showing the same love or friendship as before. Do's and don'ts for friends and family

What you have to do

Be yourself

You do not suddenly have to behave differently because the child of your friends / family has a disorder or a chronic illness. Are you the friend that makes harsh jokes?



Then you do not suddenly have to be more responsible. Are you the sweet overprotective mother? Then do not suddenly become tough or strong. Try to find your own way in helping the parents. Don't think: "How should I respond, how should I handle this?" But rather: "How do I want to respond?"

Show how you feel

Real love and friendship mean: being happy when the other is happy and being in pain when the other is suffering. By showing your own emotions about the diagnosis or the problems with their child, the parents can feel moved and strengthened. It is not the intention to "saddle them" with your sorrow, (and that they should comfort you instead of the other way around), but you certainly do not have to hold back your tears. This way you show that you understand somewhat what they are experiencing and that you have a lot of sympathy.

Sound the alarm on time

Parents with a child with a chronic illness or disability can feel so much stress that they go beyond their limits without realising it. As a good friend or family member, you can see how things are go-

ing from a distance. Keep in mind that the situation can be ten times more difficult than the parents would have you believe. Do you see that they keep too many balls in the air, are exhausted or almost never smile again? Take them apart to talk about extra help. Whether that is more babysitting or a conversation with a psychologist or family therapist.

What you shouldn't do

Avoid the subject

The child in question can become an "elephant in the room". They can be that subject that is not being discussed, in order not to ruin the atmosphere or because you think it will make the parents unhappy. Sometimes parents actually find it nice not to talk about it for a while, but often talking can be a relief. Just ask: "Do you want to talk about it?"

Think that everything stays the same

Busy parties, joint meals or vacations ... For parents of a child with a disability or chronic illness, those are the moments they often don't like. They are usually more concerned with their child than enjoying the company and socialising, or there are too many in-

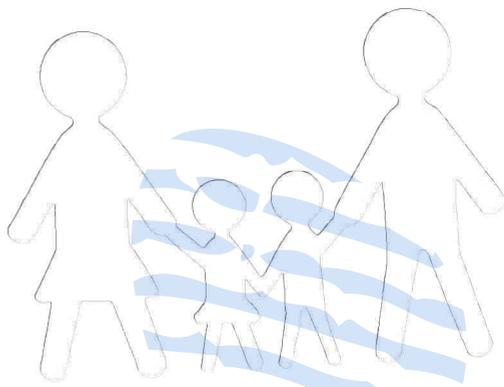
centives for the child. Don't blame them if more and more often one of them doesn't come along or if they just stay at home. Try to find other moments to have a good time together.

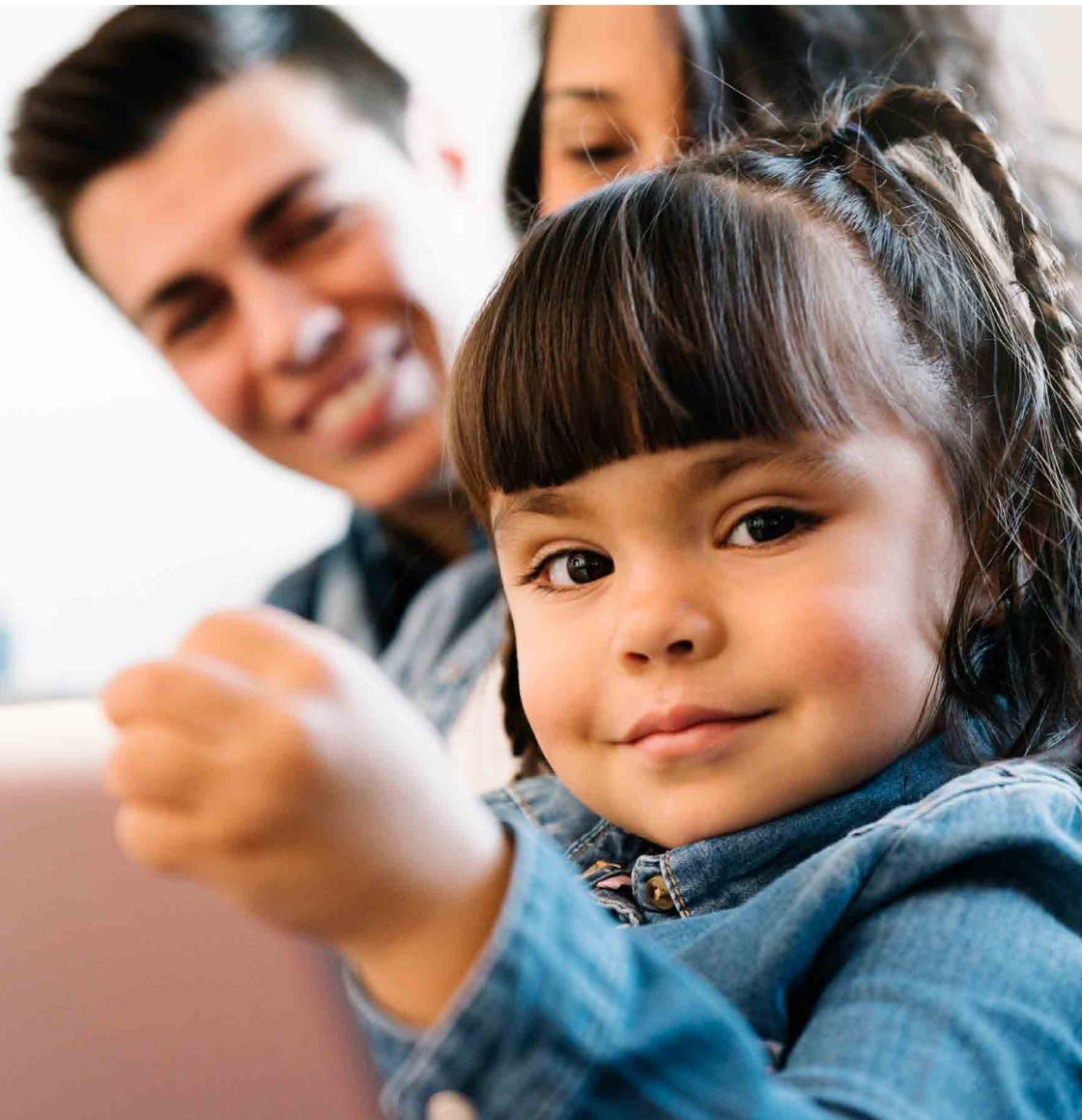
Thinking for the parents

"I won't invite them to my child's third birthday, because that's too confronting for them." 'Parents of a child with a chronic illness or disability can end up in social isolation. Therefore, always keep communicating openly and do not be afraid to get "no" for an answer. At least you have invited them in any case.

Not give a baby shower gift if there is a danger that a baby might not live

No matter how serious the situation is, it hurts when people assume the worst, while parents themselves hope for the best. So, nevertheless give a gift, go on a maternity visit and stay in touch!





Additional information like websites (use Google Translate)

www.centrumvoorjeugdengезin.nl

www.integralekindzorgmetmks.nl

www.integralevroeghulp.nl

www.cosis.nu

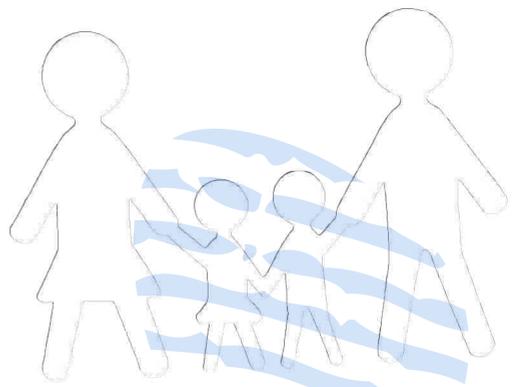
www.mantelzorg.nl

www.mee.nl

www.nationalehulpgids.nl

www.nvn.nl/activiteiten/projecten-lobby-en-meer/empouder

www.pgb.nl/hulp-en-advies/per-saldo-hulpgids



COLOPHON

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