

# GUIDE TO SUPPORT PARENT'S



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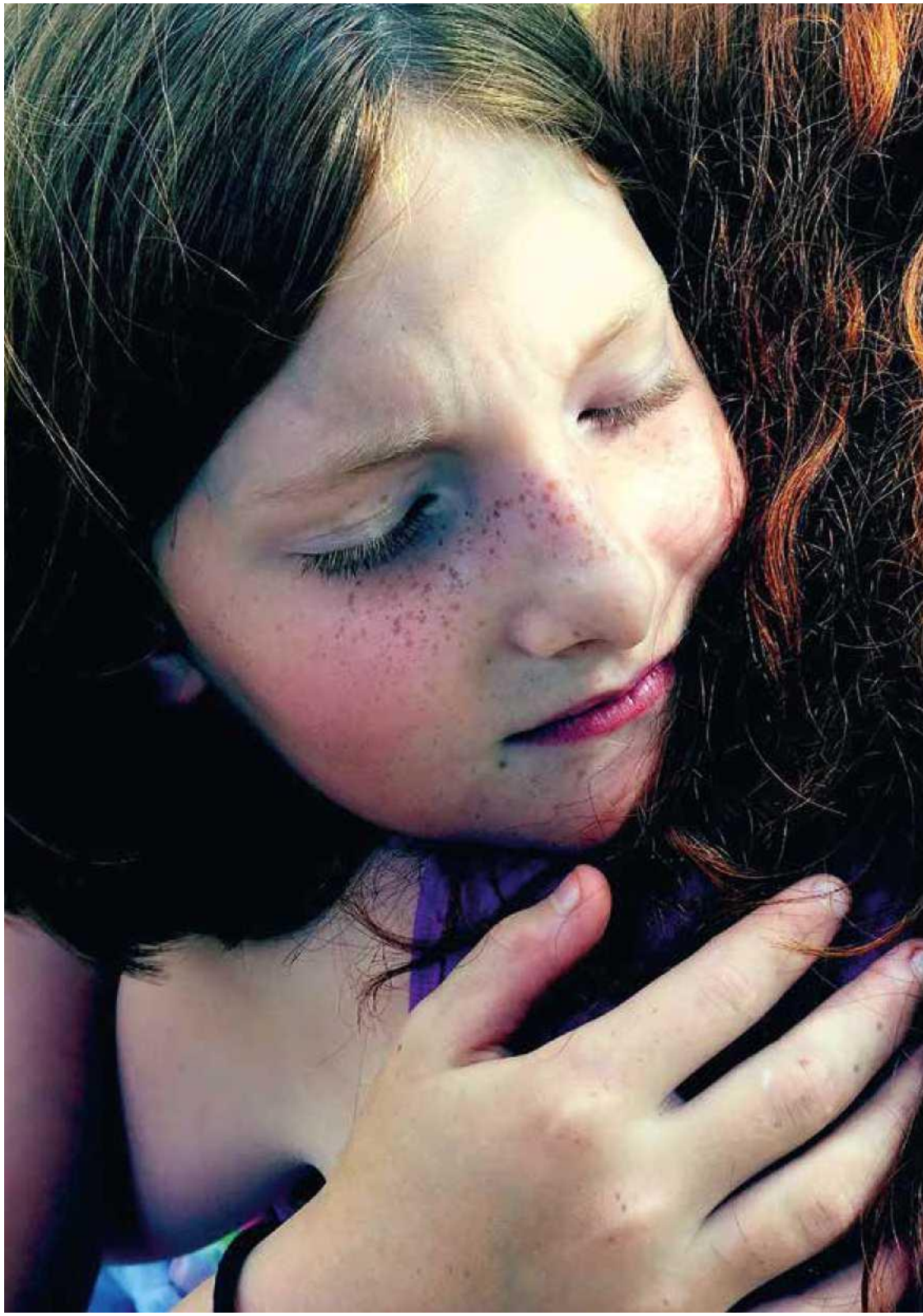
**GROWING  
A CHILD WITH  
A PATHOLOGY  
RARE**

Being parents of a child with a rare pathology, during his early years of life, can be an intense experience and a wide range of emotions — such as fear, anxiety and concern — can take over. As parents, it is natural that you want your child to reach its maximum potential, developing key competences in both social and emotional life.

This guide offers strategies and advice to help you enhance social and emotional well-being during your child's early years. These are the most formative years for a child, to become totally dependent on parents or those who care for them and want to find out what will be his way in total autonomy.

IN THIS LEAFLET YOU WILL FIND TIPS ON HOW TO:

- Strengthen your self-esteem
- Help him make friends
- Strengthen your school experience
- Help him talk about his pathology
- Listen to her emotions
- Talk to other people about your pathology
- Give support to brothers and sisters
- Build a parent support network.



## DEVELOP YOUR SELF-ESTEEM



Self-esteem means feeling good with yourself, recognising your value and being proud of your strength, skills and achievements. Parents and adults are a key part in the positive development of their children's self-esteem, and can do so both through gratifications (on their uniqueness and qualities more visible), as well as supporting the development of social skills and emotional awareness.

As your children experience positive social experiences, they will be able to internalise their value and grow more confidently, feeling proud of themselves and how they are moving, recognising the right thing for them.

### **Praise your son**

Children bloom when they know they are appreciated, loved and therefore praised. Be precise with your compliments, specify what you liked and what you are praising, appreciate their strength, highlight their successes and positive traits of their personality, help them understand what you love in them.

### **example**

*"When you talked about your mole to your friend you were really good, you made him understand everything clearly, I'm proud of how you behaved", or:*

*"I saw you smiling and asking that child to play with you, were you super nice, did you see that he then started playing with you? It seemed like you were having fun!*

### **Help your child develop a greater**

### **awareness of self and others**

Watching other people carefully and their characteristics can help your children focus on something else when someone is staring at them. Encourage your children to notice and describe how other children behave through simple questions: "What do you see?" or "What do the other children like to do?", and again: What do you think they think when you play football?

Help your child to explore above all his strength and characteristics: what are your interests? Is there a game or activity that is particularly passionate about it? What is he most capable of? Put in order? Read books? Art? Sport?

### **Self-encouragement**

Children born with a rare pathology may be very cautious in making new friends, especially if they have already experienced unbelievable experiences. But the way we think also affects the way we think ourselves. Research shows that the higher expectations and positive thoughts, the higher the chances of experiencing positive experiences.

Fears or negative experiences experienced can lead the child to think "I'm afraid" or "No one likes me".

Ask your child to concentrate only on positive experiences; find optimistic messages to give your children so that they can use them in unpleasant situations. These selfaffirmations allow you to face negative thoughts that may arise when your child meets other children, allowing him to improve his self-esteem and self-confidence.

Here are some examples of positive

remarks that your child can remember:

- It's their problem, not mine.
- I don't have to listen to them, I can always leave.
- "My friends like me the way I am"
- "I'm good at this game, I'll find someone who wants to play with me."

## HELP YOUR CHILDREN MAKE FRIENDS

Friendships are tightened through observation and being observed. Children usually look so much, perhaps with more curiosity and interest; they can ask some questions or on the contrary look away because they do not know how to answer. Equipping your child with a simple explanation of his rare pathology and helping him to move the conversation to another subject will allow the curiosity of others to pass over, allowing your child to learn the dynamics of making friends.

Although you will have become accustomed to answering your children's place or anticipating questions by giving explanations, you will not always be with them, so they will have to learn how to deal with these situations on their own.

### **Give your children the chance to speak independently**

Your children, each of them, are watching you, so they learn how to respond from your way of approaching questions about giant snow. In time they will get used to these explanations, using them for themselves when they feel ready. You can encourage this step by looking closely and giving them the opportunity to answer these questions or any glances or comments.

If another child asks your child: "What is that stain?" do not intervene immediately answering the question, instead remain silent to see if it answers. You might also try to encourage him: Do you want to answer that? If you do not feel it, give you a brief explanation and encourage him to present himself and then play together or any other proposal that could lead to a simple and natural communicative exchange.

### **Help your children find the right explanation**

Sit down with your child talking about the words he likes or does not like; throw down some possible answers, including an explanation pattern and examples of how to move the conversation to another topic and practice them aloud, all together. Let your child choose his favorite phrase, he can then write it on a sheet to keep in his pocket or attach it to the wall of his room.

Remind him of who to trust when living in a difficult situation or feeling alone; as it grows you will be able to step aside, allowing it to respond autonomously and to feel more and more secure and relaxed with its condition.

**Learn essential social skills** When your child succeeds in conquering the following skills, they will be able to take the initiative when they have to stay in company and make new friends at school:

- Greet people by their name;
- Introduce yourself to others;
- Establish eye contact and smile;
- Ask other children to play with them;
- Propose a game or activity;
- Start a new conversation;
- Move the topic with a question.

Some children will learn these skills simply by observing them, while others may need more step by step encouragement, such as:

### **Phase One:**

Start with the simplest skills, such as smiling and greeting. Let them try to greet people by smiling, asking what they notice of their reactions. Nine times out of ten people will smile in turn and that will lead him to want to try again, as we all do when we get a positive reaction!

The next step will be to let your child know that he was good, encouraging him to try again for himself next time: it is essential to let him know that smiling can make him and other people feel comfortable, thus making him more master of the situation.

### **Step Two:**

When it's more relaxed, talk to your child about how he can learn to make friends. Ask if at school there are other children who want to know: what do these kids like to do? This could be an aspect your child can exploit. You could ask a question or just comment: You're really good at drawing! Another possibility could be to ask you to play together: What a nice game! Can I play too?".

The teacher could help your children acquire some of the social skills listed above by asking them to notice how many times other children do the same things. When you feel ready, with your teacher you could decide which skill to test first and set a weekly goal, this could help you create a safe environment to develop these new skills. He may then be able to develop these same skills in other contexts with more self-confidence.

### **Support your child more**

- Invite her friends for an afternoon games;
- Encourage your child to join groups or start some sports, both to build friendship, but also to consolidate self-confidence and increase self-esteem.
- Let your child know other children with his own characteristic.

## **TALK TO YOUR SON ABOUT HIS RARE PATHOLOGY**

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Your child might ask why your legs or arms are different, then suddenly change perspective and ask: Why is my skin different? By answering these questions concretely and easily will help your child to know his/her pathology:

- Feeling accepted and valued
- Increasing confidence and self-esteem
- Answering questions in a direct and concrete way.

Some parents think it is better not to mention the pathology for fear that their child may be upset or frightened. The children we talked to have confirmed that they are not afraid to talk about their characteristic, I prefer to talk about it rather than deny everything.

The following tips can help you develop methods of converging with your child about snow, with further explanations for brothers and sisters, friends and other children.

### **Why talk to your son about his condition?**

Children are by nature curious about what is

different, this curiosity leads them to ask questions about aesthetic diversity, be it their snow or another diversity of other people.

Children's comments or questions may surprise you and turn out sometimes rude, yet with these questions they rediscover themselves and the world in which they live. If you are able to find the words to talk to your child about his pathology, you are also able to prepare him to manage the curiosity of others with confidence. A child who speaks to his parents about his pathology will be easy to answer directly: I was born like this, it doesn't bother me or anyone who knows me.

**Building a positive image of self** It is likely that your child, at some point in his life, will clash with reactions of curiosity, surprise or even contempt. Speak of his pathology as a fact, strengthen in him the awareness of being able to greatly appreciate his aesthetic diversity.

Building a positive image of yourself, including both the rare pathology and his talents and the positive traits of his personality, will help your child feel more confident in social situations. In this way, negative thoughts on the pathology that do not correspond to the







his vision of himself will be discarded to leave room for positive thoughts and images he has created for himself.

### **Calm your child's fear and worries about pathology**

Children can gather information about their pathology about what they see and feel around them; whether through the hospital environment or through spills on the rarity of the pathology, he could collect and process details about his condition. Children reason differently from adults; if they don't talk to you about the snow, they may begin to analyse themselves and generate more fear or worries than they should.

Talking about his condition will reduce his fears and help him feel safer and comfortable with his characteristic. A stable communication will allow him to turn to you to share every thought, feeling or fear.

### **Preparation for the curiosity and questions of other people**

As your child grows up becoming more and more independent he will meet new groups of people.

Give him clear and honest information about his pathology and help him build a range of strategies and explanations to use in the face of the growing curiosity of others, will help him answer comments and questions more securely when you are not with him.

This kind of preparation can also help him accept the giant snow as part of himself and not as something to be ashamed of or that embarrass him.

**A special note for rude words** is often

mocked for their diversity and it is never easy to cope with uncourteous words or unjust minds on the part of others, both for your children but also for you as parents.

This guide is intended to support with this type of behavior and no child must be faced in similar situations alone. It is important for your child to know that he can get help from parents at home, school teachers and any other adult responsible in other contexts, such as clubs, gyms, etc.

## **IDEAS AND SUGGESTIONS TO TALK TO YOUR CHILDREN**

- Use honest, simple, and age-appropriate explanations.

The key to talking to your children is keeping everything on the simple; be open and honest, use a language that they can understand.

Parents of younger children may want to use a special name to describe their child's pathology, to help him feel more confident about his aesthetic diversity. Some children, therefore, use particular names such as:

- Chocolatey spots;
- Angel's kiss
- Special stain
- Neo
- Black spot

When it begins to grow, it is right to use words that describe how the real aspect of the giant neo is actually. Think about color, shape and size. It is important to identify which keywords are most pleasing for your child; sit down and talk to him and his brothers and sisters to decide the words you

all want to use to describe the pathology.

### example

'I was born with a stain; all they have in but mine is bigger';  
"I was born with a stain on my cheek, it's called"...";  
I put the cream on my mole because sometimes it's dry and pinch.

Once your child feels comfortable adding more information, he will feel safer in answering any snow-related questions before shifting attention to other interactions such as getting to know new people and playing with other children.

**Prepare your child to explain how pathology affects his life** Who meets your child might think that pathology negatively affects his life. It is worth discussing with your children about the impact the pathology has on them; this will allow them to develop adequate vocabulary to explain to others.

### example

You were born with a big stain on your skin. That's all that sets you apart. You like to play and have fun just like everyone else.

### Use medical terms

Your child is likely to have heard the medical terms you used when talking to doctors, nurses, friends or relatives; so you might wonder what their meaning is.

Explaining the specific terms will help you gain more confidence in using medical words when it will be larger.

### It is important how parents communicate

The body language and the tone of the voice have an essential meaning in communication, so it will be important to train to speak in a relaxed and relaxed way, also through visual contact. We all understand body language and when this does not coincide with what is said, we tend to look at non-verbal signals; if you can talk to your child about his condition with confidence and concreteness, he will have a positive example to follow.

### Talk about forces and similarities

So far the suggestions have focused on explaining a rare pathology, but your child is much more than his pathology, so many are the aspects that make him unique and loved, just like all other children. It is important to highlight what he has in common with others, especially because this will become important as he approaches adolescence.

When talking about his friends, mention similarities, such as what he likes to do with them. He points out that he does not like mathematics but loves sports, answering that others like the same or not. You could say: I'm the same at your age and I still don't like math but I try to help you with your homework anyway.

### Take some time to compliment when your child makes right choices

Children feed on positive comments, help them build their identity, outline what they are able to do and how they feel good to do it. Children who have an image of themselves with a thousand facets disturb themselves less in front of a negative comment, because they know they are so

valuable.

### example

Enter his room and see your child brushing his hair in the mirror. You could take the initiative, get closer and say: "I really like my blue eyes, my smile, but a few days I hate my nose. What about you? What are the things you love about you? Because you don't like me, don't you?"; you could also comment on what you appreciate about him/her, the things he likes or what makes you and others smile.

**Find time to talk** by growing up your child will begin to understand more and more things and therefore ask more and more questions. Perhaps you will feel the need to sit down and talk a little. Find out when your child is in the right mood, and if you succeed, think about what you want to say and what he might ask you.

Although he is interested in knowing more about his pathology, children (the older they might get more nervous about it directly, so it's right to speak in a "safe" place where they don't feel at the center of attention. For example during a car trip, or while preparing lunch, maybe looking at photos or during the bathroom, or while expecting a brother or sister to leave school, etc.

If you want to start converging, you could start like this: I was thinking about what you could say to children at school when they see your mole. Why don't we think together what to say?

### Talking not only with parents

It is natural that, by approaching secondary

school, your children want more and more independence, and so it will be spontaneous for them to share less and less things with their parents. Encourage them to talk to those who support them and those who support them in the face of their feelings, experiences and concerns; it could be a friend, a family friend, a school counselor or a representative of the association (a patient, etc.).

## TALK TO YOUR SON ABOUT HIS FEELINGS



A natural instinct of parents is to protect their children by avoiding certain situations that can disturb them, like going to public spaces where people can stare or comment.

Yet, no matter how much you can protect them from the reactions of others, at some point in their lives they will collide with these reactions. The great variety of negative feelings such as anger, sadness and nervousness are essential components of life and it is right that children learn to know and live them. Talk to them, answer their questions with appropriate words, perhaps starting with observing what your child's mood is at that time; it will be extremely useful to connect their body language and facial expressions to these feelings, help them identify these emotions and understand how to express them.

### for example

You have a huge smile, your eyes shine!

You look happy today";

You were silent today, you didn't really

want to talk. It can happen when

something happens that makes you

nervous. If you want to talk, I'll be happy

to hear you.

By offering descriptions of his feelings, you are giving your child the opportunity to share his feelings with you openly.

### **Help your child express his feelings**

It is important to give your child the opportunity to express what he feels in relation to his or her appearance. If, for example, he said: "I hate my Neo!" let us know that it is natural what he feels, also because we all don't like something about ourselves. Even just expressing one's feelings will in some way lead to developing a sense of relief. Moreover, being able to freely say "I hate my mole!" allows your child to identify what specifically he does not like, without turning it into a deeper feeling like "I hate me because I am different".

First of all, ask your son what he doesn't appreciate about his condition. The answers could outline practical reasons, like the mole pinch, which can be solved by applying a little cream. If you find it difficult to answer, you may try to ask why, because he does not like his pathology. The answer to this question could highlight the psychosocial impact of having an aesthetic diversity.

### **Parents' feelings**

Many parents feel guilty, angry, sad or tired of having to face and respond to the reactions of others. It may happen that you want to protect your children by hiding your emotions, especially when a person makes a rude comment during the day. Yet, even if they are unable to describe the emotions of others, children are aware of them and

recognise them through body language and facial expressions.

In these situations you will help them if you take note of your emotions, giving an example of how you can handle them. If an external reaction bothers you, you might say: "When I feel like this, I need to talk to a friend. If you need to talk about it, or if you just need a hug, let me know.

### **What if I'm wrong?**

If you can't find the words, write how you would explain the pathology to your son and other people. Then re-read what you wrote to memorise the whole thing, you can always change what you wrote, reread your explanations by adding details and keeping in mind what he and other people might ask you in response to what you wrote.

If you talk to your child about the pathology as you feel that you have not answered all the questions as you would have liked, it is never too late to go back and start over; that's how you teach him certain and valuable skills.

Remember that however you don't have to have all the answers, then it's likely that by raising your child will ask questions that you can't answer. Encourage him to write the questions and then take them to the next appointment with the doctor.

## **TALK TO OTHERS ABOUT THE PATHOLOGY**

- It is normal that, between adults and children, differences are noticed; so, wherever public you go, it's likely that the diversity of your child will be noticed.

The youngest children are extremely

curious, they will look intensely in giant snow, perhaps asking extremely direct questions; adults, on the other hand, could only stare or cast more looks. They might forget to say hello, letting go of some inappropriate phrases like: What happened to your child? Very often parents find themselves unprepared in the face of this curiosity and this could give rise to feelings of sadness, anger and anxiety.

### **The SPIEGA-RASSICURA TECHNICAL-distract you will:**

- Make the first move
- Act in order to make you feel more under control
- Dealing with all kinds of curiosities
- Preserve the self-esteem and confidence of your child
- Be an example of how to respond to this curiosity, to help develop skills to use with new knowledge

### **The SPIEGA TECHNICAL-reassure-distract**

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The general rule is: the more the interaction has an important value to you, the more you will improve the technique.

#### **Scenario 1**

If, for example, you are aware that other people have noticed the NMCG while you are at the supermarket, walking or at the bus stop, there is no need to provide a long and in-depth explanation.

Just try to smile or say "Hello", to reassure them or stop their eyes. Some people may then ask a few questions, at that point a short and coincident answer will satisfy, allowing you to continue to

live your day.

#### **Scenario 2**

When you want to make friends with other parents at school or help your child meet other students in the post-school, you may perhaps find yourself having to explain the pathology in more detail. More in-depth information about the pathology will allow other people to see your child equal to others.

#### **example**

"It's just a mole"

"Tommaso was born with a giant neo";

"I have a giant mole; it's brown, protruding and hairy, but it doesn't hurt."

#### **Scenario 3**

Some comments or reactions may be more difficult to handle, especially if they ask strange questions or come directly to touch your child's mole, who will interact with other children every day at school, so the way you will respond to other children will help him manage and deal with the reactions of his peers. The following explanations are great for distracting, shifting attention from the pathology to another topic.

#### **example**

This is Matthew, he has a special stain that you can't remove. What's your name?

He's just a big mole on his eye, it doesn't hurt. You want to go to the swing?

#### **Scenario 4**

There will be times when you won't want to explain to others what the NMCG is.

Try to focus and use the “Distrarre” technique, asking them questions about them or moving the conversion to another theme.

### example

“I don't feel like talking about it, I'll tell you everything again. What did you do this weekend?”

### Scenario 5

Keep in mind that people might do other reasoning about the pathology, such as: “Is it contagious?”, “Do you need help?”, “Do you have mental delays?”

Although some children with the NMCG may need extra help, this is not always the case, so, thanks to the rule of SPECIFICATION-Reassure-Distrarre, you can reassure others and erase any incorrect reasoning.

### example

“Daniele was born with a giant mole. It is not contagious and can do anything like all other children.”

### Manage rude comments

Some people can be rude, make hypotheses or do not know how to approach the pathology. Be asserted through a good answer, explaining everything without attacking or getting angry can be a great example of how to handle these situations. For example: My son was born with a spot on his face, he's a kind of mole.

It is important that you teach your children to be sure when facing the reactions of others, but if someone is rude or annoyed, they must know that it is right to move away and, if they are in school, to

seek help by talking to an adult about what they feel.

## YOU DON'T HAVE TO JUSTIFY YOURSELF ALL THE TIME

The suggestions mentioned may seem difficult to put into practice, but often parents who use them state that, the more they exploit these strategies, the more they feel confident and quiet to get out. Sometimes thinking about options and possible solutions with someone who supports you can help you feel safer and allow you to spend more time with your children.

### Take care of yourself

You can't expect to be able to handle every situation. Some days will be better than others, so it's right to take it slow. On good days you will want to take a tour of the park or make some shopping, feeling totally at ease in answering people's questions. But if you have days when you find it difficult to react to the reactions of others, it may be useful to do something to relax you, have a coffee with friends or simply vent with people you love.

### Self-encouragement

Sometimes you'll have to go out even if it's one of those “no” days. If you do not want to explain or simply need a push, try to remember something to say to you to reassure you. It may seem strange but it has been shown that the more we think and act positively and the more optimistic we



will feel. Among the methods of dealing with negative thoughts is also the self-encouraging discourse: the more you do it, the more our brain gets used to doing it automatically.

If we take for example perfectly normal thinking: "I can't do it anymore!", you could face by recognising the ways you've managed to make it so far and what you could do this time to succeed again.

### example

- We've done it in the past, we'll do it again this time;
- They are my children, I am proud of them;
- I'll ignore who's staring, I'll smile showing them I'm fine.

## SUPPORT BROTHERS AND SISTERS



The fact that your child has a rare pathology somehow affects all members of the family. Most brothers or sisters will do well if they help them understand the aesthetic diversity of the brother/sister, and if they manage to share their feelings and concerns.

However, they will be aware of unwanted looks and comments. They may receive questions about the appearance of their brother or sister so it is important that they are included in the discussions on how to respond to others, so that they too can feel confident when faced with questions or comments.



### example

This is my sister, she has a giant mole. Do you want to play with us?"

"He is my little brother, he has a giant mole. Do you have brothers or sisters?"

## ENHANCE YOUR CHILD'S EXPERIENCE AT SCHOOL



Children spend most of their time in school. During primary school optimising his opportunities to socialise can affect his self-esteem, his ability to establish friendships and to go well at school.

When your child is placed in school, arrange a meeting with the principal and teacher to share with them the following information:

- The name of the pathology and how it affects his life
- Any of your medical needs
- Any other need
- Examples of how to explain the pathology to other children
- Provide the school with leaflets and the various websites.

It is useful to ask the following questions:

- Faced with every particular curiosity about the appearance of your child, how will the school staff act?
- How will they approach any unwanted attention?
- Do they have experience in caring for children with an aesthetic diversity? How did these kids find themselves?
- Will you be informed about your son's progress? And if so, how?
- Will the school accept a training course to support a child with a rare pathology?

### What should the school provide for?

It is vital that all members of the school, including administration and canteen, are aware of your child's pathology, understanding both the social and psychological challenges of having an aesthetic diversity.

Before school starts, require the school to share all the information and needs of giant snow children with all the school staff, a job that should be done with your cooperation, so that you are aware of the information that is shared.

### Teach the SPIEGA- reassure-distrate technique

It is essential that the school knows this technique in order to be able to respond promptly to the curiosity of any child in a direct and simple way. You could help the process by making a list of things to say, so everyone will use the same facilities, both inside and outside school. For example: "Jessica has a mole on her face, we call him Giant Nevo. It's just like a simple mole but bigger. Do you have any insides too?"

## SUPPORT FOR PARENTS



As parents of a child with a rare pathology, you might experience moments when you feel overwhelmed. Many parents find it reassuring and useful to talk to someone who understands to a certain extent what they are going through. It can be really liberating to be able to openly express one's feelings about what it means to have a child with a rare disease.







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# CARING FOR A CHILD WITH A RARE CONDITION

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