

OPPRATAT

**Guidelines for parents, grandparents and professionals who
work with children with a functional impairment
and their families**

Engelska

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Opratat.se – prevents ill health

Opratat.se is a tool for helping people to talk about thoughts and emotions which are seldom mentioned in families with a child with a functional impairment. With the help of films, stories, picture books and games, children and adults can find out how another person thinks and feels in various situations. This can be the start of a conversation. Opratat.se is aimed at children aged from 4 to 12 years, their family members and other adults with whom the family comes in contact. The aim is that everyone will find something they can identify with.

This is opratat.se

- **Animated films** about topics people don't talk about and why they don't talk about them.
- **Stories** that provoke thoughts and give examples of ways to make it easier to talk about difficult topics. The stories are based on the experiences of children with a functional impairment, their siblings, parents and grandparents.
- **Picture books** that can initiate conversations about emotions that can arise in the situations described in the books.
- **Games about emotions** – the games are intended to be good fun but they can also be used to talk about feelings. What emotions can I find in the pictures on the pieces used in the game? How do those different emotions feel? How can one and the same person feel different emotions? Can different people feel the same emotion? The games are intended for the youngest children.

The content in the films and the stories is based on interviews with 160 children with a functional impairment, their siblings, parents and grandparents, and on meetings that have been held as part of a project organised by the disability rights movement.

Why opratat.se?

When children with a functional impairment and their families protect each other from being sad, anxious or angry, they don't talk about topics that are sensitive or difficult. Children can sense their parents' uncertainty but they don't understand why their parents are behaving strangely. Because nothing is said, children try to guess what the parent is thinking and then they think up their own explanations, which are sometimes worse than reality.



That is why it is important to talk to one another. With the help of the films, stories, picture books and games on opratat.se, children and adults can realise that they think and feel the same way in a certain situation. They are not alone. If you can identify with something, you may dare to talk about topics that are not usually discussed.

Children know and understand much more than we adults think and children are experts at being children today. However, at the same time, children need help and guidance from their parents.

Hampus, 10, said: "You have to get out what's inside you. Otherwise you get a stomach ache." Tuva, 8, said: "Sometimes I think my parents argue because I am being difficult. But it doesn't have to be like that. Sometimes you just imagine things."

The children who were involved with the opratat.se project often said that they want to know how things really are – and they want to talk.

The films are about eight different themes

The narratives of the 160 children showed us what sort of topics are difficult to talk about and we have categorised that material into eight themes.

I've got something

Is about the functional impairment. Children with a functional impairment want to know what they have. Their siblings also want to know. They want to understand and know about possibilities and limitations. The children say "I'm the one who's got something".

Parents want to protect their children and also themselves from strong emotions such as sadness, anxiety, anger, shame and guilt.

Grandparents want the parents to dare to talk to their child about his/her functional impairment but they find it hard to raise the issue because of the risk of spoiling their relationship to their own children and to their grandchildren.



I don't talk about how I'm feeling

Children and adults don't talk about how they are feeling or they play it down. They want to protect themselves and others and they are afraid of inducing emotions such as shame, guilt, anxiety, grief and anger.

Always needing help

Is about dependence. The children feel they are in the way and that they are demanding. They refrain from doing activities so as to avoid that emotion.

Is it my fault?

Is about being a nuisance. The children are worried that they are the ones who make their parents tired and that they are the cause of other difficulties in the family. They think that they are too demanding, stealing time and energy from their siblings. The children feel “it’s my fault”.

Only the children with a functional impairment brought up the topic of being a nuisance. No siblings, parents or grandparents mentioned that.

Are they ashamed?

Is about the attitudes of other people. It is hard for children and siblings to know what to do when other people stare or make insensitive comments. Parents worry about how their children will be affected if other people are intolerant or don’t understand so they avoid certain situations or don’t talk about the child’s functional impairment in some contexts.



Taking responsibility for other people’s emotions

Children and siblings are sensitive and can sense how their parents are feeling. The children see themselves as being the cause of other people’s sadness, anxiety or anger. They refrain from doing some things so other people won’t have to worry. The children take responsibility for other people’s feelings. The siblings take care of and protect their brother/sister in various ways.

The future

Siblings often worry about what will happen when their parents get older or die. Who will look after my brother/sister then?

Parents want to protect their child from anxiety and don’t want to destroy dreams. For example, they may find it hard to talk about heredity and what that can imply for the future. Will their child be able to have a family and children of their own?

Is he going to die?

Children want to know how things are but it is hard for adults to know how much the child understands. Children and siblings often know a lot but they don't always understand all the implications.

Thinking about death induces strong emotions, both in the people who are going to explain and talk about it and in the person who is ill. Death is abstract and hard to explain.

How Opratat.se can be used

Together with the child – for family members and professionals

Before showing a film, it could be a good idea to explain that the film is short and then talk a little bit about it. If the child doesn't want to watch any more, just turn it off. Be guided by the child.

Be patient and wait for the child's reactions. Don't talk about your own adult thoughts straight away. You can use the same method with the stories.



One way of starting a conversation is to ask questions about the people in the film or story. What is going on? How do you think the different people are feeling? Why do they feel like that? What do you think they are thinking? What would you have done in a similar situation?

Talking about the people in the films and stories may make it easier to talk about one's own situation. When you understand that other people can think and feel the same way as you do, it is easier to come in contact with your own feelings. Be curious together, share your experiences and talk about how you perceive different everyday situations.

Use words that are as concrete as possible; listen and make sure you have understood things correctly. Answer the child's questions and acknowledge the child's feelings. That will help the child to learn to trust his/her own sensory perceptions and describe and explain them to other people.

An emotion is never right or wrong, unreasonable or justified. An emotion simply exists.

Jimmy, 11, said: "People think, or many people think, that small children don't understand and that they don't have views or thoughts." I know that when I was

four years old, I had many, many thoughts, just like I have now." Anna, 9, said: "In these films, you can put yourself in a situation and you realise that there are other people who understand how that feels and that you are not alone."

At the work place – for professionals

There are several ways in which professionals can make use of opratat.se.

- As a means of support and a way of finding out what sort of topics it is important that children, siblings, parents and grandparents discuss.
- As a starting point for discussions with other members of staff. This may make more people interested in using the tool at the work place.
- As a tool for individual counselling sessions by raising topics that are not easy to talk about, for example, the child's functional impairment.
- In group sessions with children with a functional impairment.
- In group sessions with siblings, parents or grandparents.
- When giving advice/hints to children, siblings or parents.
- When training or guiding personnel to make it easier for them to talk about difficult topics.

One social worker said: "As a professional, you can sometimes be overcome by your own helplessness and so you dare not ask about their situation and how they are feeling."

Others who have used Opratat.se

Comments from professionals on individual and group sessions

"We showed films from Opratat for parents who had not met before. We have never experienced parents beginning to talk so quickly and so openly." Personnel at a4 habilitation centre

"If we begin by talking about the child in the film, it is easier for the child to start to talk about himself/herself." Personnel at a respite care home

"The content is good for breaking taboos. Parents are still not getting help with how to talk to their child. But that help is needed. The material shows that it's not dangerous to talk; on the contrary, it is good to talk." Teachers and class assistants at a special needs school

"I always have Opratat in my back pocket, at the back of my mind. It's easy to bring up and use when a situation arises." Social worker at a habilitation centre

Comments by children and parents on the films

The film **The Climbing Frame** was shown to a group of children and a group of parents at the same time but in separate rooms. The children were very familiar with the situation portrayed in the film. They talked about how they get angry and upset when they are not allowed to do things that are exciting and that they would be able to do. The children also understood that the father was afraid. The parents could also identify with the film. They discussed daring to "let go" more and have confidence in their children.



A group of children at a preschool watched the film **The Puzzle**. The children said: "It seems a bit hard for her.", "She cried because the others were faster, she cried because she wasn't fast as well, she was sad because she has something wrong with her.", "She was too late, she wasn't allowed to play with the others".

Parents' comments on talks with their children

Opratat.se has become a concrete tool for parents which opens up for different kinds of conversations. Most of the parents like the fact that the films and stories are short.

One parent said he/she was going to show the website to the staff at the child's preschool. Another parent described a conversation with a social worker. The daughter had been at the Child and Youth Psychiatry centre (BUP) and during the visit there, she had talked about how she felt guilty because of being a nuisance to her parents. That had made the parent feel guilt emotions. The social worker showed them opratat.se and said: "We know that many people feel and think like that. Children protect their parents in that sort of situation." Being told that made the parent feel some relief - he/she was not alone.

To conclude, one father said: "I need help to stay calm, confident and open about different topics, and not be afraid of my child's emotions."