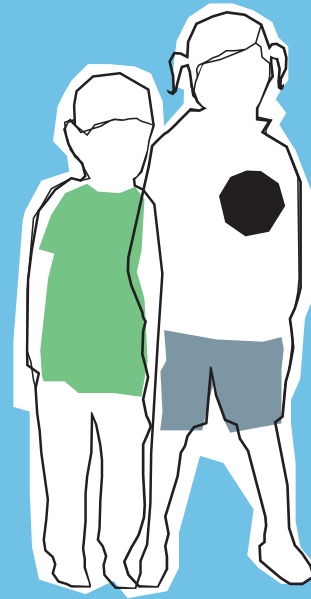


# Children and illness

Children with a seriously ill parent



In families where a parent or other adult is suffering a serious illness or injury, the situation for the children becomes particularly difficult. It is important to give the children attention so that they can continue to feel safe and secure. According to the Swedish Health and Medical Services Act, children have a right to information and support when an adult family member suffers an illness. The health service offers support from social workers, doctors, nurses and psychologists.

Asking for help as an adult can reduce your own anxieties and make it easier to deal with thoughts and questions from your children.

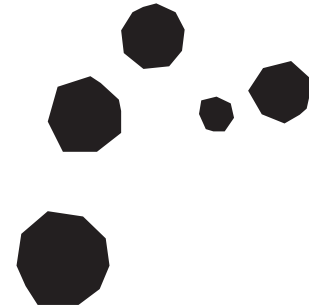
# Let the children be involved

Since children notice when things are different, it is important to explain what is happening, otherwise they will be left to their own anxieties and imagination. A child's ability to understand and handle the situation is different at different ages, which is important to bear in mind when talking to them. Children of all ages fear the death of a close relative and losing the security that the family provides. Children therefore need to continue being taken

care of and to feel that most things will continue as usual. Children also need to know that they can trust the adults, who will continue to explain what is happening and will pay attention to the children's questions, thoughts and feelings.

Treatments and hospital visits mean that the parent is more absent and less able to spend time with the children in the same way as before. Letting children be involved in what is

happening and letting them do what they can to help can enable them to handle the situation better. However, they must not be burdened with adult tasks.



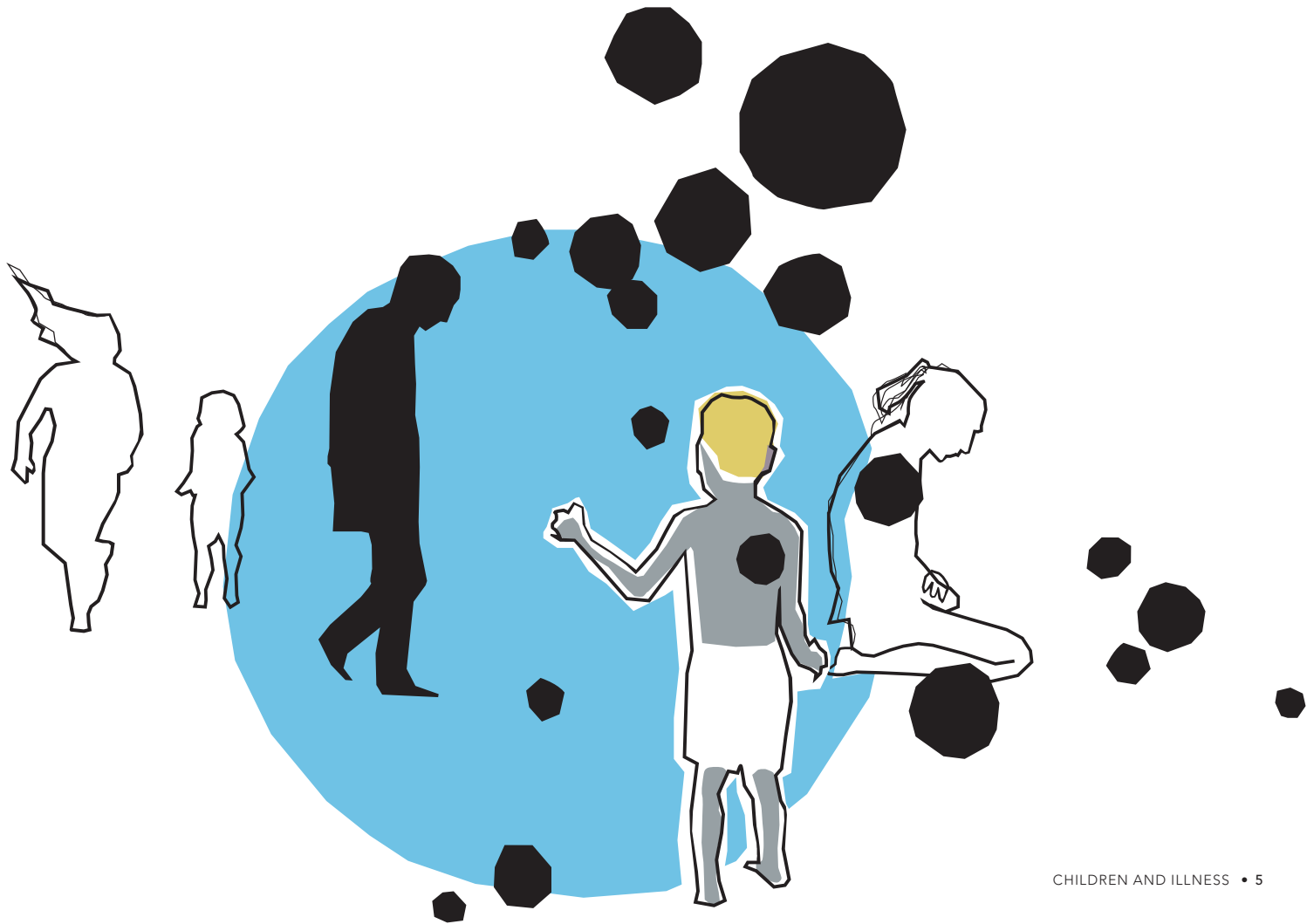
# When should children be informed and by whom

Once a serious illness or injury is confirmed, it is a good idea to talk to the children as early as possible. It is not necessary to give much information initially, but explain what has happened and what is going to happen in the immediate future. It is good if the very closest adults are present when the children are told about the situation. Beforehand, consider who is the best person to give the information.

It can sometimes be helpful to have a doctor or other health-care worker present for the talk. This gives the children an opportunity to ask questions directly if there is anything they want to know about the hospital treatment or the illness.

It is not a problem to be sad when talking to the children. Explain that it is okay to be sad and that you will still take care of the children. Say that you will tell them more as soon as you know more.





# What should I say and how?

Think carefully about how you are going to inform your children. It is best if you can inform all the children at the same time, even if they are different ages. If that is not possible, don't leave too long between the talks.

- Speak directly and simply.
- Explain who is ill and what the illness is called.
- Don't use metaphorical language.
- It is not necessary to pass on everything you know, if you are not sure that the child will understand or needs to know, but everything you say must be true.

- Don't use too many words and don't speak for too long.
- Be aware of how long the children can manage to pay attention. Take breaks and give them a chance to do something else. Younger children in particular need to be given the information in very short bursts.
- Wait for the children's questions. Also be open and ready to deal with questions, even if the children can't express them clearly. By all means let the younger children make drawings and then talk about them. This can be a good way to

understand how they feel.

- Don't be afraid to ask the slightly older children what they feel and think. Questions and answers in an atmosphere where the children feel that they are allowed to speak and that there is time for their questions can mean a great deal to them.
- Children will often want to know how the adults feel and it is important to be honest with them. They notice when there is something different about an adult. Explain that there is nothing worrying or strange about you being sad and concerned.

# The children's reactions

The first reaction is not always what you might expect. As an adult, you have an advantage in that you have already processed your knowledge of the illness, and your capacity to understand and deal with stresses is greater than the children's. Some children can appear entirely unaffected and refuse to accept the difficult news. It can take time for the information to sink in. Some may not have understood what a life-threatening illness/injury means, while others don't want to show their feelings. Respect this for a while, if you

think it is best for the child.

Some children have many questions. Don't worry if you can't answer all of them immediately. It needn't be a negative thing to think about the question or say you don't know. Some children ask no questions. The questions may come later or the children may have been told everything they want to know. As long as the children feel okay and have not changed their behaviour too much, there is no reason to try and get a quiet child to ask more questions.

When a parent becomes ill, children may start thinking more about the big existential questions. Why are we here and what happens when we die? It is important for an adult to be there to talk, but books and films can also help to describe the situation.



# Visiting the hospital

Let the children go with you to the hospital. Support them in being willing to cuddle and be with the ill person, let them get up on the bed if possible. If a child is not sure about going to the hospital, find out why. There may be reasons that can easily be overcome.

Explain in advance what things look like at the hospital and in the patient's room. Also explain how the patient looks and why their appearance has changed.

Pay attention to the children's questions and answer them, particularly after the visit.

By all means ask the nurses and doctors to tell the children about the different things in the patient's room and why they're doing what they're doing.







## If the illness gets worse

Children who receive constant, age-appropriate information about their parent's illness are rarely surprised by the death of the parent. The children have had time to start the grieving process. If the family is going to lose a parent, it feels even more important to spend a lot of time together.

Children need to know what the future will be like if their parent dies. If they live with an ill single parent, it is particularly important that the children know who will

be taking care of them once the parent is gone. The children need concrete answers and they need to hear that most things will continue as usual in terms of preschool, school and friends.

In the most difficult situations, it is important to find reason for hope. Even though the children realise the seriousness, they will keep hoping until the end and need to be able to do so. Balance the need for facts and honesty with the child's need for hope.

# Age-appropriate information

## **BABIES**

Babies sense changes in the mood of their parents. They can't understand anything, but the most important thing for them is a continuation of their comfort and routines. Your voice, tone and how you hold and touch the child shows that you are there for it. Carry your baby and sing or talk calmly to it. Make sure that you maintain the usual routines regarding feeding, sleeping and nappy changes.

## **PRESCHOOL CHILDREN**

Preschool children live in the present and see themselves as the centre of the world. Their ability to interpret and understand reality means that they can easily believe that illnesses or accidents are their fault. The family is the secure foundation of their life and they are frightened about losing that security. Disruption of daily routines can be more frightening than the fact that a parent has a life-threatening illness. Explain what has happened in a simple way and be clear that the illness is not anybody's fault.

## **SCHOOLCHILDREN**

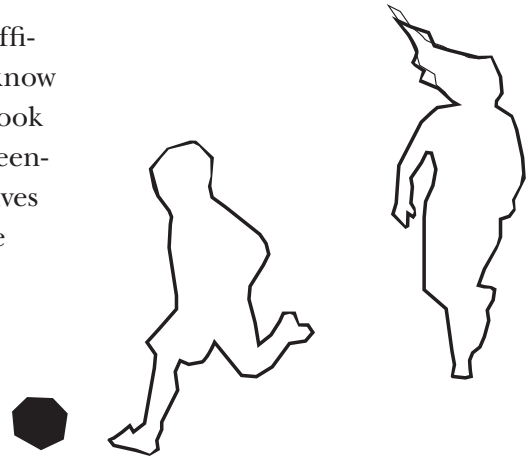
Children of school age are extremely interested in their concrete reality and want concrete explanations for the illness. A great deal of their focus is on making their existence ordered and comprehensible. Children think a great deal about what is right and wrong. They have started to understand that there are risks in life, and death becomes more and more of a reality. Children may worry that someone else in the family or they themselves will contract the illness and you may have to explain several times that serious illnesses are not at all common.

## TEENAGERS

Teenagers understand the full meaning of being seriously ill and also understand about death. Teenagers can become extremely closely tied to the family or they may entirely turn their back on home life. Respect their space, but at the same time show that you are there for them. Explain about the illness and about the treatment. Let teenagers decide for themselves whether and when they want to come with you to the hospital, but try to encourage them to go. Don't force information and

comforting on them and avoid conflicts relating to the illness.

A parent's illness can be difficult to take in. Teenagers know that they are not ready to look after themselves and the 'teenage revolt', freeing themselves from their parents, is made more difficult with a sick parent.



# Warning signs

Children often show their emotions more through behaviour than words. While children will mostly handle the situation reasonably well, you should look out for behavioural changes and symptoms such as recurring stomach ache, headaches, muscle pain, concentration problems, disturbed sleep and problems at school or nursery. Some children become introverted and passive, while others may act out and become aggressive. Don't hesitate to seek professional help

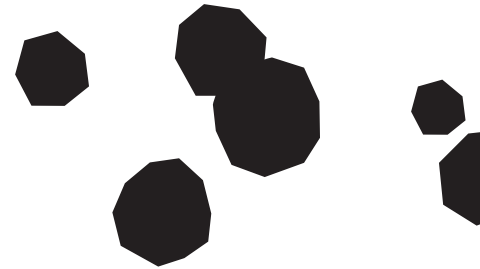
if you believe your child needs it.

Life is about more than just the illness. Keeping to the daily routines helps children to feel secure. Children want their parents to continue being parents. You should therefore continue to set boundaries and make sure not to let your usual rules slip.

Encourage your children to continue with their activities and meeting friends. It offers a neutral environment and helps

them to continue living and developing. It is still okay to have fun.

Don't forget to keep hold of the good things, being able to be happy, to laugh and have a good time together!





# Ask for help

In a situation such as serious illness, a person can feel extremely alone on an existential level. It is therefore important to make clear that help is available for you and your children. As healthcare workers, we also have a responsibility to pay attention to the children involved. Talk to your doctor or nurse about this.

Talk to your children and agree on who is to be told and not told about the situation. It can be important to let teachers know.

The nurse, social worker or psychologist at the school can also provide support. Also make use of your personal network, where other adults or your children's friends can provide good support.



# The books

*"Sorg hos barn: en handledning för vuxna"* by Atle Dyregrov.

*"Sorg, saknad, sammanhang: böcker om barn och ungdomar i svåra livssituationer"* - a summary of good books about children in difficult situations in life by Gunilla Brinck & Anna Lindberg.

These books are available from the hospital library.

PROJECT MANAGER: KERSTIN ÅKERLUND, COUNSELLING AND SUPPORT UNIT

ILLUSTRATIONS: TOVE HENNIX

LAYOUT: KATARZYNA DUCHNOWSKA, MEDICAL GRAPHICS

This brochure can be ordered from Quality and Patient Safety: [kontaktaKP@karolinska.se](mailto:kontaktaKP@karolinska.se)





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