

SUPPORT FOR THE WHOLE FAMILY

Family activities

A child's illness affects the whole family: siblings, parents, and relatives.
Sharing mutual experiences with families who have gone through the same thing helps to cope.



4/2021

The Finnish Kidney and Liver Association offers support to those suffering from illness and recipients of organ transplants, as well as their loved ones. The association shares reliable information on diseases and their treatments. At the association's family activities and member associations, you can meet others who have gone through the same experiences and receive peer support.



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Family activities organised by the Finnish Kidney and Liver Association

The children can include those born with kidney or liver disease, those who become ill with it, or those who have received a transplant. A child's illness affects the whole family: siblings, parents, grandparents, and other relatives.



The Finnish Kidney and Liver Association organises activities for families and adolescents. It is possible to participate in the association's events even if a child's illness is not yet at a serious stage.

The association organises courses, family activity days, and peer-to-peer and recreational meetings with funding provided by STEA, Kela, or collected from the parents of the children with illnesses. As a rule, the events are free of charge for participants.

Sharing experiences with families who have encountered the same thing helps to cope. Peer groups provide support in helping the smooth running of everyday life. Peer parenting confidentially supports a family to cope with all stages of a disease.

Through the association, it is possible to arrange for a specially trained nurse for temporary homecare for a child with kidney or liver disease or who has received an organ transplant.

The association supports adolescents on their way to adulthood by organising events and group trips where the young people can meet others in their age group who have experienced the same illness and practise becoming independent in a safe manner.



"Through my child's illness, I have made new lifelong friends who are there to walk alongside me. Even though our communication is not daily, knowing that I can contact them at any time helps me to cope."

– Feedback from a parent who participated in the association's family activities

Diseases and organ transplants

Kidney disease

Serious diseases leading to kidney failure in children are rare. In Finland, approximately 30–40 children develop severe kidney disease each year. The disease can be caused by a congenital structural aberration of the kidneys or urinary tract (e.g., blistering kidneys or posterior urethral valves) or glomerulonephritis (e.g., nephritis related to Henoch-Schönlein purpura or IgA-nephropathy). The disease can also be hereditary, such as congenital nephrotic syndrome of Finnish type (CNF), which causes massive amounts of proteins to be excreted in the urine.

Kidney disease can lead to severe kidney failure, which is treated with a kidney transplant.

Approximately 10–15 kidney transplants are performed per year for children and adolescents in Finland, and the kidney transplants come from either living or brain-dead donors. A living donor is usually the child's parent and in some cases a grandparent or other relative. The aim is to perform a kidney transplant from living donors, and their number has increased over the past decade. Today, more than 50 per cent of kidney transplants in children have come from relatives.

In recent years, approximately 20–30 per cent of kidney transplants in children and adolescents have been performed proactively, i.e., without prior dialysis treatment. However, this is not always possible and roughly ten children per year are given dialysis treatment. Dialysis treatment is carried out daily as a peritoneal dialysis treatment at home or as haemodialysis treatment carried out 2–4 times a week in a hospital.

Liver disease

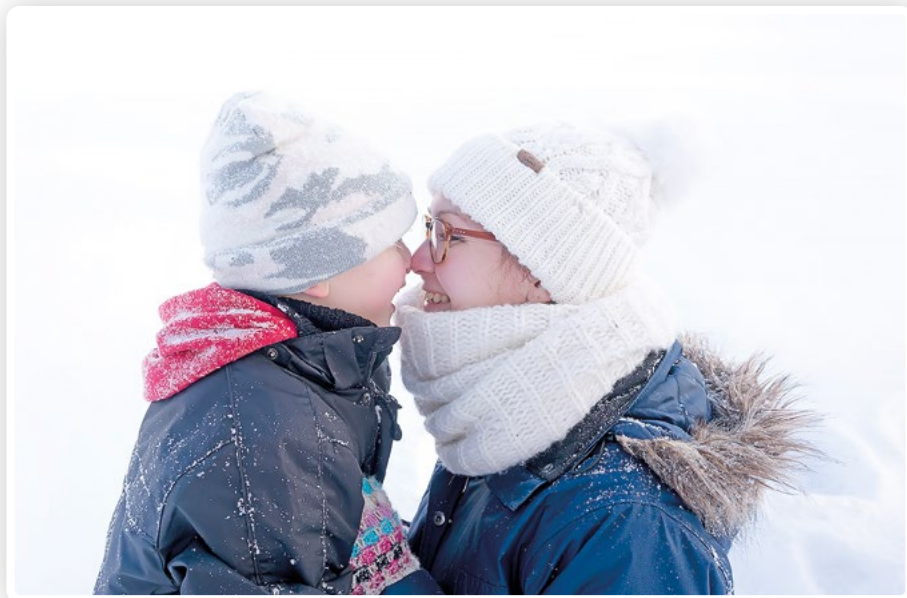
Approximately ten children are diagnosed every year with severe liver disease requiring a liver transplant. Most commonly, liver damage is caused by congenital biliary atresia, i.e., a deficiency of external bile ducts in the liver. The liver can also be damaged by a severe viral disease, liver cancer, or some rare metabolic disease such as hyperoxaluria. A rather large proportion of liver diseases in children are congenital and are already manifested in infants. Approximately 150 liver transplants for children have been performed in Finland.

Other severe diseases

Idiopathic nephrotic syndrome is a disease typically found in children of between 3 and 12, causing abundant excretion of proteins in the urine. Approximately 20–50 children contract the disease every year.



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Cortisone is most commonly used to treat the disease, which usually reduces or completely ends proteinuria. The majority of children with nephrotic syndrome experience relapse, which means that cortisone treatments have to be renewed or long-term anti-relapse medication is initiated in addition. The risk of relapse of nephrotic syndrome is significantly reduced after puberty and rarely leads to a decrease in renal function.

In Finland, a few children are born each year with bladder exstrophy, i.e., a congenital structural deviation of the urinary tract, or some severe bowel disease. Children with bladder exstrophy usually undergo several surgical procedures. The medical and nutritional treatment of these diseases, as well as hospitalisations, are demanding and put a strain on both the child and the child's family. These diseases usually do not lead to organ transplants.

Heart, bowel, and lung transplants

Families with a child who has undergone a heart, bowel, or lung transplant are also welcome to participate in the association's family activities. Approximately five heart transplants are performed on children in Finland every year. The main reasons for heart transplants in children are congenital structural defects and cardiomyopathies, i.e., heart muscle diseases. Approximately 100 children have had a heart transplant in Finland. Bowel and lung transplants have been performed on a few children.

Transplants

A transplant is a treatment option if the organ function of a child with kidney, liver, or heart disease cannot be maintained by other means or if the poor functioning of the organ significantly impairs the quality of life.

Transplants for children began at the HYCH children's hospital in 1986 and since more than 600 transplants have been performed in Finland. After a successful transplant, a child or adolescent without significant associated diseases can live a normal life without major restrictions.

In Finland, children's transplants have been centralised at the New Children's Hospital, where all children waiting for a transplant and who have already had one are monitored until they reach adulthood. The children also visit their own university or central hospital for follow-ups.

Transplants require close cooperation between the healthcare personnel and the parents of the child. Following a transplant, a child's treatment in the hospital usually lasts from three to six weeks. A child's recovery depends on the individual and treatment times vary.

After being discharged, children who have received a transplant will regularly visit an outpatient clinic and ward for check-ups. During the first months following a transplant, the child will be sensitive to infections and rejections to the transplant. It takes about six months to recover, but a child who has received a transplant can return to school as early as two weeks after being discharged, depending on their overall condition. A child can return to day care approximately 2-3 months after the transplant.

In Finland, transplants are of a high standard and the long-term prognosis for children who have received a transplant is good. Following a transplant, a child needs medication to prevent organ rejection throughout his or her life and support for adapting to life with a long-term illness.



Child illness and family

When a child with long-term illness is born into a family, or when a child suddenly falls ill, the whole family and surrounding circles are faced with a major change. In order to adapt to a child's illness, the whole family needs time and diverse support.

The child, the siblings of the child, and other children close to him or her should be informed of the disease according to their age and level of development. It can take time to understand difficult things. It is a good idea to return to the subject from time to time as your child grows up, even if the child does not specifically ask about it – and especially whenever the child seems concerned about it. Talking is a step towards openness, which increases a feeling of security.



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A child with illness also needs safe boundaries, love, affection, and attention. A child is first and foremost a child, not a sick child. Parents may no longer have as much time for the other children in the family. Therefore, siblings of a child with illness may experience jealousy, sadness, withdrawal, or excessive conscientiousness. The solution may be daily one-on-one time with the parent, when the sibling can feel that he or she receives undivided attention. It is also advisable to inform the sibling's day care or school about the family's situation.

When a person faces major changes and concern caused by an illness, it is normal to feel down. A child with long-term illness or disabilities in a family can be challenging for a relationship. Parents need to take care of themselves and their own ability to cope. It is important to make time for oneself when day-to-day life is challenging. For example, it is important to keep up a hobby. If the feeling of being down continues, one should ask for help with coping and, if necessary, express their feelings to a professional.

The family should book an appointment with a social worker at their own hospital as soon as possible to find out about the support possibilities. Often, it can happen that one parent may have to give up their employment, which may cause financial difficulties for the family. One can seek help from the municipality, neighbours, and relatives in taking care of a child, their siblings, and in running everyday life.

The change brought about by illness can also bring positive things to a family. A relationship may become stronger, the values of the family may change, or the family and extended family may become closer. In a difficult situation, new, life-long relationships can emerge.

Activities for families

Courses for families with children

Each year, the association organises five-day adaptation training courses funded by Kela for families where a child has undergone a transplant, a child's is waiting for a transplant, or a child is undergoing dialysis treatment. The aim of the courses is to support the whole family to adapt to the transplant or dialysis treatment and to provide resources for a changed life situation.

In the course, the whole family receives support and the opportunity to meet their peers. The courses have guided, enjoyable things for the whole family to do together. Adults, children, and siblings are also each offered their own programmes in the courses. Adults receive information about transplants, nutrition, and well-being. During the adult programme, trained child instructors supervise the children and the activities. One of the child instructors will be a nurse who is familiar with treating children with transplants and receiving dialysis.

The aim is to organise family courses annually during the summer and autumn holidays. The courses are free of charge for families. To apply for a family course, a doctor form B statement recommending that the whole family participate in the course should be requested. Kela supports parents in the form of a rehabilitation allowance if a parent is prevented from their work during the course. In addition, you can apply for travel expenses from Kela after the course.

Other courses for families with children

Weekends for families with children are weekend courses for families with kidney or liver disease, bladder exstrophy, nephrotic syndrome, demanding bowel disease, or organ



transplants. Over the weekend, there will be discussions and an activity-based programme for children, adolescents, and adults, both in a group together and separately. The programme always includes a lecture by a doctor, dietician, or other specialist. During the children's groups, care for the children is provided by experienced child instructors. Family weekends are funded by STEA and free of charge for the participants.

Family days

The association organises family days and other recreational and peer events for families every year. In addition, events are held specifically for the siblings, mothers, and fathers of the child with illness, as well as others. Regional family events with children are also held annually. The events are planned based on feedback from families and often together with volunteers. You can get peer support, information, get to know new people, and meet old acquaintances at the events. The events offer a chance to spend nice time together.

Temporary assisted care

Often, one of the parents of a child on dialysis, with severe kidney or liver failure and, in special cases, a child with a transplant, acts as the carer for his or her child. Informal care support is an appropriated benefit granted by the municipality. Statutory days off for carers and, for example, caring for a child undergoing dialysis require special expertise. The Finnish Kidney and Liver Association coordinates a nationwide care ring service through which municipalities can buy informal care days for a carer. In this case, a specially trained nurse comes to the home to care for the affected child and, if necessary, his or her siblings.

STEA funding can also be used to provide short-term and mainly one-time care assistance to families where one parent is not a carer for a child. With the help of the service, parents have the opportunity to temporarily break away from burdensome care work and spend time together or with the other children.

Youth weekends

Youth weekends are intended for young people aged 12 to 17. At some of the meetings it is possible for the young people to bring a friend with them. During the weekend, it is possible to meet young people of the same age and participate in activities and hangout together. Over the weekend, experiences of one's life and illness can be shared during the activities.

The weekend programme is designed together with the young people and the aim is to try new, cool things. One of the best things to come out of the weekend are the new friendships, which have often continued even after the course. The weekend is also a good opportunity for the young people to show their parents that they are able to take responsibility for their own medical treatment and self-care. Employees of the association are there to support the young people over the weekends.

Youth Camp

Youth Camp (Nuorten Camp) is intended for adolescents who are transferring to adult treatment. Youth Camp provides information on social security, independence, sexuality,

and the practices at the adult care units, among other things. The annual meeting is also a chance to exchange experiences on studying and moving into working life. Youth Camp is organised in cooperation with the care units of the New Children's Hospital and other patient organisations. Youth Camp always has a relaxed leisure programme and the opportunity to get to know other young people.

The association also organises its own meetings annually for young people aged 18 to 25.

Support online and on social media

The association also organises regular events online. Participating in online events is easy from anywhere in Finland. Online events often include an introduction from a doctor or other expert. Online events offer peer support, information, and the opportunity to get to know new people. Adolescents, young adults, and parents are organised into their own online events.

There are several closed discussion groups on Facebook for parents of children with kidney and liver disease or with transplants. For example, our own group is for parents of children with biliary atresia, congenital nephrotic syndrome of Finnish type (CNF), and nephrotic syndrome.

A closed discussion group of parents of child patients of the Finnish Kidney and Liver Association includes a family-support worker from the association. This group, for example, provides information on future events and other issues affecting the lives of children with illnesses. Parents share peer support with each other, as well as many useful practical tips on how to care for a child.



Peer parenting activities

Peer support activities help people with kidney and liver disease, transplant recipients, and their families to cope with different stages of the disease. Peer support helps people understand that there are other people who have experienced the same thing. A peer parent is there to support when there is a child with kidney or liver disease or who has had a transplant.

"I want to keep in touch with my peers, because with peer support my child has also found many peers, and I hope that in the future, as they grow up, they will support each other in their own ways."

– Feedback from a parent who participated in the association's family activities

A peer parent has first-hand experience of the life of a family with children with kidney or liver disease or with a transplant. The peer parent has already made progress mentally in accepting and treating their child's illness. The association's peer parents have received training and guidance for their peer support work.

A peer parent is ready to listen, be present, and encourage. They are trustworthy and know their responsibility. A peer parent is ready to give their time and share their own experiences. Communication can take place face-to-face, on the phone, or on Facebook. Peer parents are provided by the association family-support worker.

New peer parents are constantly needed, and education is organised annually. If you are interested in being involved in the association's peer parenting activities, feel free to contact the association's family-support worker.

PEER PARENTS ARE

- parents of children with kidney or liver diseases.
- parents of children who have undergone dialysis.
- parents of children who have had kidney, liver, or heart transplants.
- parents of children with bladder exstrophy.
- living donors of the kidney.



Family and youth work group

For more than 30 years, parents of children with kidney and liver disease and transplant recipients have been raising funds through their own volunteering activities and developing the services of the association's families, as well as organising recreation and peer meetings.

The family and youth work group consists of parents of children representing families of children of different ages and illnesses throughout Finland. The permanent members of the work group are representatives from the Taika inpatient ward of the New Children's Hospital and a family-support worker, acting as the secretary, from the Finnish Kidney and Liver Association.

The activities focus on lobbying, information, fundraising, recreational activities, and cooperation with care units. The work group organises peer support activities for families and adolescents, raises funds for the activities, and promotes the professional skills of the nursing staff for children and adolescents.

JOIN

Becoming a member is the best way to support the goals and activities of the association and member associations. All members belong to the member associations.

Members receive the association's Elinehto magazine (mostly in Finnish language) four times a year delivered to their home, the association's electronic newsletters on current affairs and

events, the association's magazine or

membership letter, and national and local membership benefits, which can

be found on the association's website at www.muma.fi/jasenedut. In

addition, families with children receive family mail about three times a year, describing the association's family-activity events.

You can become a member online at the association's website at www.muma.fi/liity or by contacting your region's member association by phone, email, or letter. Contact information for the association can be found at www.muma.fi/yhteystiedot. The association's member associations can also be found online at www.muma.fi/jasenyhdistykset.

"I am pleased to have finally joined the association. I think you are going to do a lot of good things for our lives. Thank you very much for making us feel very welcome when attending your family event for the first time."

– Feedback from a parent who participated in the association's family activities





The association supports people with illnesses and their loved ones

The Finnish Kidney and Liver Association supports the well-being of people with illnesses and recipients of transplants, as well as their loved ones, and promotes their rights. The association shares information on kidney and liver diseases and their prevention, promotes organ donation, and acts as a social influencer. The association supports rehabilitation, organises adaptation training courses and professionally supervised group courses, and provides advice on social security.

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All contact information for the association can be found at
www.muma.fi/yhteystiedot.



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