

SUPPORT
for brain injury patients'
FAMILY MEMBERS



Traumatic brain injury – a guide for family members

Information on hospital care and crisis
support



The Traumatic Brain
Injury Association of Finland



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For the reader

A person important to you has been hospitalised for a brain damage caused by an accident, i.e. traumatic brain injury (TBI). In addition to the shock caused by the accident, you and other family members suffer from uncertainty, and have many practical problems and questions. This manual contains general information on traumatic brain injuries and hospital care to support you in these difficult times. It is good to take time to go through the guide and keep it during the whole care process.

The guide is aimed at the initial phase of treatment in specialist medical care. Depending on the severity of the injury, the injured person will be treated in a hospital's intensive care unit or inpatient ward. This guide can also be useful if your loved one's TBI has been diagnosed as mild, because it does not require hospitalisation.

This guide describes how brain injury might show in different ways in appearance, behaviour and functional ability. You will also find instructions on what you can do as a family member, and how to be supportive.

The guide provides brief information on discharge and follow-up treatment and rehabilitation. In addition, there are tips for the time after discharge and information on possible long-term symptoms. These become clearer over time, and the effects of TBI are often only revealed after returning to home and everyday life.

The guide also provides information about the crisis process, which you might go through as a family member. There is also information on how to acknowledge children and young people in the crisis. You will also learn about peer support. Additional information sources are listed alongside the text.

This guide was developed with families of people with TBI, as well as healthcare professionals and specialists. We hope this guide will help you and provide answers to your questions.

Checklist for family members

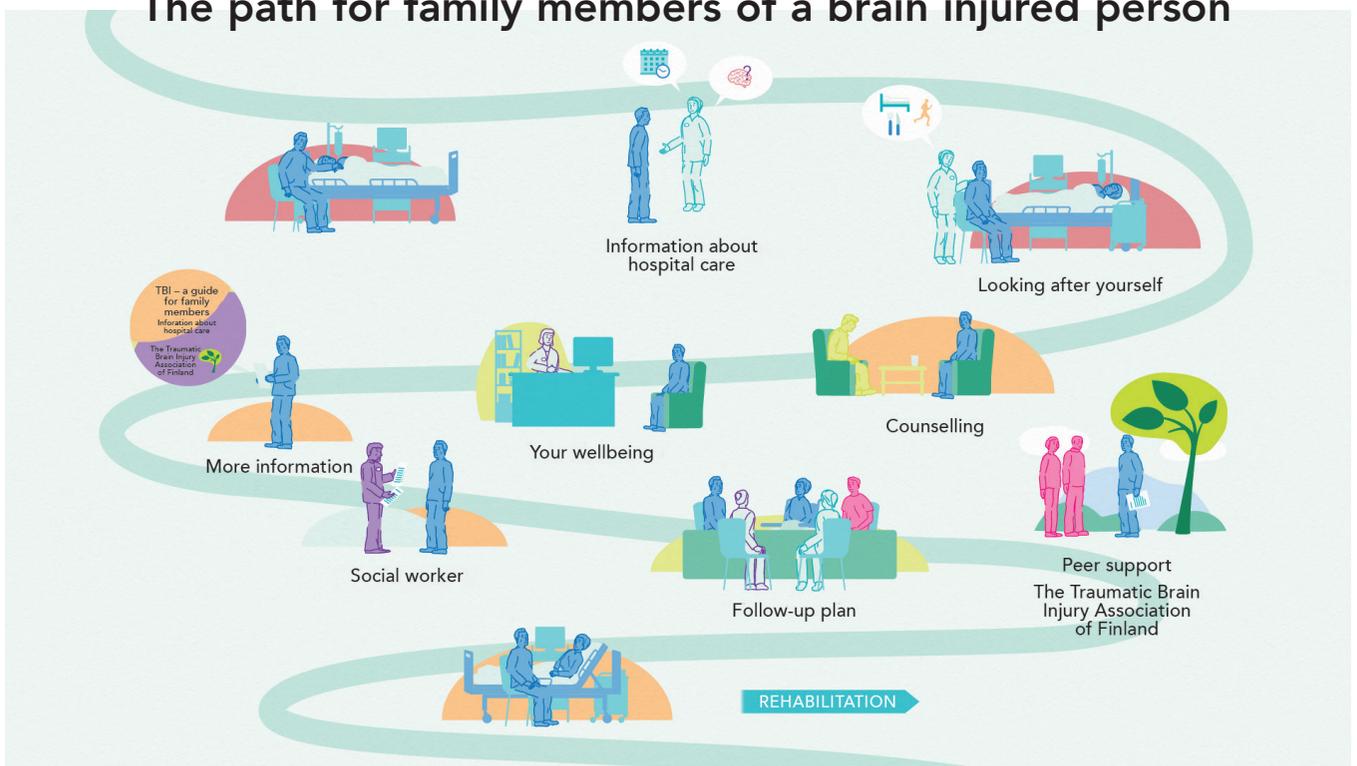
When someone close to you is suddenly hospitalised, and the duration of treatment is unknown, you can find yourself in a situation with much to think about and sort out.

Here is a checklist of things you might have to take care of. The severity of the injury and the duration of hospitalisation will determine which of the following applies to you and your loved one. You can mark the parts you have already been informed about. Ask the nursing staff for more information.

TAKE CARE OF YOUR WELL-BEING

- Think about your own ability to work, and if necessary, discuss the need for sick leave with your occupational health or health centre physician.
- Ask your nursing staff or crisis workers for **counselling** for yourself.
- Ask for **peer support** for yourself (p. 29).
- Remember to rest, eat and exercise.
- Ask the nursing staff how you can help the injured person recover (p. 12).

The path for family members of a brain injured person





PRACTICAL MATTERS DURING A HOSPITAL STAY

- Agree with other family members who the **contact person** is for when the hospital needs to contact you, or when you need to contact the hospital yourselves.
- Notify the necessary people and places about the accident (workplace, school, day-care centre).
- Tell the children what has happened, taking into account the child's age (p. 24).
- Tell the nursing staff if you know that the injured person has an **advance statement** for care, or if they have otherwise expressed their preferences for care and are unable to communicate themselves.
- Ask the physician for a **certificate of deputyship** or a **power of attorney** from your near relative being treated.
- Ask the doctor for a medical certificate for sick leave on behalf of your hospitalised loved one.
- Ensure that important payments are made (rent, maintenance charges and other important invoices).
- Talk to a **social worker** (p. 11) about any necessary social benefits, support services and income support, and find out the details of the injured person's insurance company, depending on the accident (occupational accident/traffic accident/leisure time accident).

Contact person: A family member of a patient who is primarily in contact with the hospital and who primarily handles a hospitalised patient's affairs. This contact person is the person who it is presumed can receive information about the patient's condition, even if the patient is unable to provide this information themselves.

Advance statement: A document made by the patient allowing them to express their preferences for treatment and care in advance.

Certificate of deputyship: A document drawn up and signed by a doctor testifying that the patient is incapable of managing their affairs due to an illness or injury, and their named family member/contact person can therefore manage affairs on behalf of the patient. Will be drawn up if the patient is unable to sign a power of attorney due to unconsciousness, for example.

Epicrisis: The epicrisis is a report of the illness and care prepared after the end of the patient's care. The epicrisis is a confidential patient document. The epicrisis can only be handed over to the patient themselves or to a person officially managing the patient's affairs. With the patient's or their deputy's permission, the epicrisis can be handed over to another necessary party such as the facility for continued care. The epicrisis can also be seen in My Kanta Pages.

Care meeting: A pre-arranged meeting at the hospital to discuss matters related to the patient's care and follow-up plans in a multi-professional manner, involving persons caring for the patient, as well as the patient's family members.

- Save all documents related to the care, such as medical reports, **patient documents** (epicrisis), and decisions issued by the Social Institution of Finland (Kela) and the insurance company. Check the accuracy of the documents immediately and request for rectifications or corrections if necessary.
- Discuss with the **rehabilitation counsellor** and inquire about the preparation of a **rehabilitation plan** (p.15).
- Ask the nursing staff to arrange a multi-professional **care meeting**.

PRACTICAL MATTERS AFTER THE HOSPITAL STAY

- Find out who is responsible for the care of the injured person, and how the follow-up treatment is carried out.
- Check who you can contact if you have any questions about the care or rehabilitation.
- If the injured person is prescribed medicine, check its purpose and dosage.
- Keep a record of the symptoms and observations you make about the patient's condition, behaviour and functional ability. Your observations may be needed when seeing a physician, social worker, or members of a multi-professional care or rehabilitation team.
- Your home municipality's department of social services will make a **service plan** and survey the required support services to provide support at your home. If necessary, check with the hospital's social worker or rehabilitation counsellor that the service needs of the injured person and the whole family are assessed at the time of discharge, and that the necessary plans will be made.
- Ask for **peer support** and information on the operation of the Traumatic Brain Injury Association of Finland and its local brain injury societies.
- Apply for **courses or adaptation training** (p.19) organised by the Traumatic Brain Injury Association of Finland or other organisations after approximately 1–2 years of disability. You may need a medical report to accompany your application.



Traumatic brain injuries and their treatment

Traumatic brain injury (TBI) is a brain disorder or structural damage caused by an external force. TBI can be caused by a direct blow to the head, a rapid change in movement that shakes the brain inside the skull, or an injury that punctures the skull.

There are different types of brain injury. An external force may cause brain contusion or haematoma in the brain tissue. The impact can also fracture skull bones. *Diffuse axonal injury* (DAI) refers to cellular damage in the brain, in which neurons stretch and twist in relation to each other and other brain structures, which can damage the connections between different areas of the brain.

The more serious the injury, the more likely it is to cause permanent symptoms. In the case of a **minor TBI**, consciousness is normal or only slightly reduced during care, and memory starts to function quite normally within 24 hours of the accident. The majority of those with a mild TBI recover to their normal state.

A **moderate TBI** is usually associated with an initial decline of consciousness or a brief state of unconsciousness, and a clear memory impairment can last from 24 hours to a week. Imaging examinations usually reveal an intracranial change caused by the injury. A large proportion of those with a moderate TBI will experience permanent symptoms.

In a **severe TBI**, the patient is unconscious in a hospital for more than 24 hours, or it takes more than a week for the memory to recover fully. Imaging examinations usually reveal an intracranial change caused by the injury. Severe TBI causes permanent symptoms in nearly all cases. A reliable estimation of the TBI's severity is often difficult at an early stage, as other injuries caused by the accident can complicate the assessment, for example.

A severe TBI can be tried to treat without surgery, with infusion therapy, ventilator care and sedatives, for example. Surgery should be considered if the head scans (CT or TT) reveal intracranial haemorrhage, resulting in compression of the brain. The primary goal of surgery is to get more space for the brain. The decision whether an operation is necessary is always made by the attending physician, who also considers all possible risks.

- More information on the surgical treatment of TBI: www.aivotalo.fi
- More information on the treatment path of a TBI patient: www.aivotalo.fi

The recovery process is always personal. It is impossible to fully predict the progress or speed of recovery from TBI.

There are several stages of recovery which do not always proceed straightforwardly or consistently.

Despite effective and long-term care, a patient may die due to an injury caused by an accident. There are no two identical people, and there are no two identical brain injuries. You may feel frustrated without certain information about the future, but false estimates do not make you feel any better either. You should ask the nursing staff about the situation even if they may be unable to provide an answer.

Aivotalo: a website developed by healthcare professionals that provides support and information on brain health and adult brain diseases. The site contains information and guidance on the symptoms, care and rehabilitation of brain injuries in adults, and life after a brain injury. Aivotalo is part of the Terveyskylä.fi

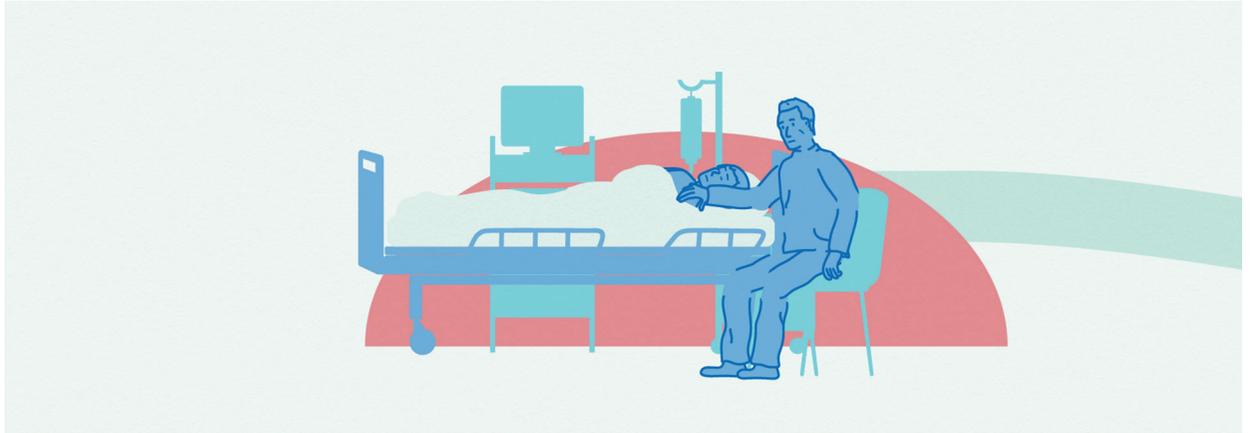
Accidents and hospitalisation of someone close to you can be a crisis. Read more about traumatic crises and how to cope on page 20.

- Read more about recovering from a brain injury p. 12
- More information www.aivotalo.fi

INFORMATION ON INTENSIVE HOSPITAL CARE

Intensive care is used to treat serious and life-threatening injuries by monitoring and supporting the patient's vital functions. Intensive treatment of a TBI patient aims to prevent the worsening of brain injury and the expansion of brain damage. In intensive care, a patient's condition and care needs constantly determine which treatment and examinations are used on the patient. Diagnostic imaging can help with directing care and evaluating the patient's condition. The patient's level of consciousness is assessed regularly.

During intensive care, the patient's vital functions (blood pressure, pulse, respiration and temperature) are monitored continuously. Intracranial pressure is also often monitored. If necessary, oxygen supply and respiration are secured by intubating the patient, i.e. by inserting a breathing tube into the trachea and connecting the patient to a ventilator. In intensive care, the patient is usually given intravenous medication, fluid and nutrition.



The injured person's intensive care is overseen by **physicians**, with **nurses** and other healthcare professionals. Physicians make medical decisions about the progress of care. In the intensive care unit, nurses work around the clock, observing the injured person's condition at all times. The intensive care unit also employs a number of other healthcare professional such as a **physiotherapist, occupational therapist, speech therapist, hospital chaplain and social worker**, depending on the patient's needs.

You can visit the intensive care unit according to hospital policy. You can also call to inquire about the health of the injured person. It is advisable to select one contact person who will be in touch with the hospital by phone and pass the information on to the rest of the family and friends.

- More information on intensive care for a TBI patient: www.aivotalo.fi

INFORMATION ON INPATIENT CARE IN HOSPITALS

If the condition of the injured person does not require constant supervision or support in vital functions, and they are not in immediate danger of death, they will be admitted to an inpatient ward for care. Transferring to an inpatient ward can suggest that the patient is recovering.

The patient's condition and effects of treatment are monitored in the ward. The rehabilitation that already started in the intensive care unit is also continued. Maintaining and increasing functional ability are important goals at the inpatient ward, and the reintroduction of mobility is begun carefully with the help of the staff or under their supervision. Self-sufficiency is encouraged in daily activities, and the aim is to return to as normal a daily rhythm as possible. For example, if the injury has caused weakness in the limbs of one side, it is important to learn how to use assistive devices correctly. The planning of continued treatment, rehabilitation and the return home will begin in the inpatient ward.

In the inpatient ward, physicians make medical decisions about the progress of care daily. Nurses work around the clock to support the injured person's recovery. In relation to the number of patients, fewer nurses work in the ward than in the intensive care unit. In addition to physicians and nurses, other healthcare professionals such as a physiotherapist, occupational therapist, speech therapist, hospital chaplain, rehabilitation counsellor, neuropsychologist and social worker can participate in the ward care.

OLKA: Many hospitals have OLKA® through which you can get peer support and information on the forms of support of patient organisations and healthcare. Ask the nursing staff whether the hospital in question has OLKA.

- Read more about peer support

You can visit the ward according to visiting hours and department policies. Family support is important for a patient after a TBI. Visits improve the patient's sense of time, create a sense of security and activate the brain. If you would like to be more involved in the care, you should talk to the staff about how it can be arranged.

- More information on inpatient care of a TBI patient: www.aivotalo.fi

HOSPITAL HEALTHCARE PROFESSIONALS

In hospitals, various professionals cooperate in a multi-professional manner. Representatives of a wide range of professions are working for the good of patients in the hospital and to promote recovery.



Physician:

The physician decides on the examination, diagnosis and related care of the patient. In general, a neurosurgeon or neurologist oversees the start of a TBI patient's specialist medical care. If necessary, they may consult other medical specialists. Intensive care always involves an intensive care physician, who is responsible for anaesthesia, vital functions and pain relief.

Nurse:

A hospital nurse is usually a registered nurse or a practical nurse who is responsible for the patient's care. Nurses take care of the patient in accordance with the agreed care policies and consult other professional groups when necessary.

Social worker:

The hospital often employs a social worker who evaluates the need for social services and helps patients apply for social security and services. A social worker can help with matters such as work, insurance and applications. A social worker also supports patients and their family members in a changed life situation.

Rehabilitation counsellor:

A rehabilitation counsellor guides and advises the patient and their family members on issues related to the rehabilitation and service system. Rehabilitation guidance evaluates and analyses the need for rehabilitation and services individually, and aims to ensure a functional and appropriate rehabilitation and service package for the rehabilitee.

Physiotherapist:

A physiotherapist evaluates, promotes and instructs the patient's mobility right from the start of care. A physiotherapist takes care of learning to walk in rehabilitation in the hospital, for example.

Occupational therapist:

An occupational therapist can be involved in the treatment of a TBI patient at an early stage. An occupational therapist evaluates the patient's functional ability and need for various assistive devices.

Hospital chaplain:

A hospital chaplain offers mental and spiritual support for patients and their families and friends, regardless of their conviction and philosophy of life. In crisis situations, you can contact a hospital chaplain when you need a listener and want to talk to someone.

Speech therapist:

A speech therapist evaluates and rehabilitates issues with speech, language, voice and communication, the motor skills of the face and mouth, and swallowing. Speech therapy aims to influence the brain so that the development or restoration of communication skills and normal nutrition are possible.

Recovering from a traumatic brain injury and instructions for family members

After TBI, the brain begins to repair itself. Recovery is strongest in the first six months, but often continues for a long time after that. In addition to the severity and nature of the injury, age and possible other illnesses can influence recovery.

The following is a description of the different levels of consciousness and their changes in the recovery process, as well as instructions for how to support the injured person.

UNCONSCIOUSNESS

Your family member may have lost consciousness due to an accident, or they may have been medically induced into a state of unconsciousness, i.e. anaesthetised, to promote recovery. The unconscious patient does not wake up even if you talk to them. Respiration and vital functions are supported mechanically and are monitored. Even unconscious patients may sweat, cough, yawn, grin or have reflexes, i.e. involuntary movement of the limbs. They may recognise pain by resisting the cause of pain and open their eyes. They may be able to hear speech, but they cannot respond to requests or react to speech systematically. An unconscious person usually needs intensive care (especially in the early stages).

What can you do when the injured person is unconscious?

You can talk to the injured person about things they know and touch them. Even though they cannot speak, they may hear you. Talk to them in a normal and calm voice.

- Listening to music with headphones, for example, activates the brain.
- You can keep a patient diary and write about the treatment daily. This stage is unlikely to leave any proper memories. You can use the patient diary later to go over what happened.

CONFUSION AND AMNESIA

As the brain begins to recover, or the need for sedative medication decreases, the injured person begins to wake up and regain consciousness, which means they can respond to speech more systematically. However, they may have various difficulties in managing the way they respond to the surrounding stimuli. They may not understand their own feelings, or what is happening around them. They may be anxious, forgetful, incoherent and confused.

The injured person may have to be restricted as part of the care so that they do not hurt or injure themselves, or remove the care equipment attached to them. They may be angry, anxious and weepy. They may scream, kick, flail their arms or try to get out of the bed. They may be unable to concentrate for long periods or understand the purpose of their treatment. Incoherence may vary greatly at different times, and the daily rhythm of the injured person may be abnormal.

If your family member is able to speak, they may say the wrong words, or the order of words may be wrong. They may have issues with short-term memory. They may be *disoriented*, which means they may not remember where they are and why.

What can you do when the injured person is incoherent and forgetful?

You can talk to and touch them. Speak in a normal and calm voice. You can talk about things they know and calm them down. You may have to remind them of things. If treatment allows it, you can assist the injured person in simple daily activities with the help of nursing staff (such as teeth brushing, eating and dressing). The presence of a familiar person often soothes and creates a sense of security.

Do not force the injured person to keep up or do things if they cannot or are too tired. If they cannot remember where they are, you can tell them:

- What day it is.
- Where they are.
- What happened to them (briefly).

Keep the room and surroundings calm. You may need to limit the number of visitors and visits, because the injured person needs peace to recover. Ask the nursing staff for instructions on mobility and eating.

DISORIENTATION

Although the injured person's level of consciousness is good, and their memory works better at times, their concentration may still be short-term and easily lost. They may experience difficulties with taking the initiative and get stuck in functions. Their orientation, i.e. understanding of time and place, or even of themselves, may also vary. Their behaviour may be unpredictable and sometimes inappropriate or uninhibited, and they may be prone to irritation. They may have difficulty understanding changes in the environment, be sensitive to sounds and find guests stressful, for example. They may not understand the consequences and symptoms of the disability, or the inappropriateness of their behaviour.

What can you do when an injured person has symptoms of TBI?

- Be brief and simple.
- Repeat, do not assume that they remember everything they have heard before.
- Try to make the environment calmer if necessary.
- Help them get started with things and guide them to continue when necessary.
- If the injured person behaves inappropriately, try to direct their attention and interest to other things.
- Encourage self-sufficiency and create routines that make it easier to remember and structure.
- Give them a chance to rest, because it is important for the recovery.
- Rehabilitation activities (such as memory exercises) can be practised together, if the injured person has enough energy.
- Practise everyday things together (such as using a phone) if necessary.



Brain injury clinic: Conducts diagnostics of suspected TBI, and performs work and functional ability assessments, rehabilitation assessments and rehabilitation plans related to brain injuries.



Rehabilitation plan:

Includes goals drawn up with the rehabilitee and the means by which the goals are achieved.

The rehabilitation plan contains the number of services, the duration of individual therapy and the method of implementation. In addition, the duration of the plan and the person responsible for monitoring are included. A named healthcare contact person oversees the rehabilitation. The contact person may be a physician, but also a social worker or a rehabilitation counsellor, for example.

REHABILITATION AFTER HOSPITAL CARE

Rehabilitation usually starts at the hospital, and the injured person may already have a **rehabilitation plan**. When the patient no longer needs continuous hospital care, the injured person can be transferred to rehabilitation outside the hospital.

Rehabilitation can take place at a follow-up treatment facility, rehabilitation facility or by going to rehabilitation from home. The aim of rehabilitation is to help the injured person survive as independently as possible in everyday life and in their own living environment. Brain injury rehabilitation is a long-term process that can last the rest of your life. Often, at least for people of working age, follow-up after TBI and assessment of the need for rehabilitation are carried out by a **brain injury clinic** if one exists in your hospital district.

Neuropsychologist:

A neuropsychologist is an expert on human information processing, assessment of behavioural and emotional changes and rehabilitation, working in a hospital, polyclinic or rehabilitation centre. A neuropsychologist examines problems of memory, attention, problem-solving, perception or psyche caused by TBI, and implements the rehabilitation.

MEDICAL REHABILITATION

Medical rehabilitation is organised by public healthcare, Kela and accident insurance companies. The most important form of medical rehabilitation in TBI rehabilitation is **neuropsychological rehabilitation**. The aim of rehabilitation is to reduce the issues of information processing, behavioural changes and emotional regulation caused by TBI, and to find ways to cope in everyday life despite the problems caused by the injury. Neuropsychological rehabilitation has been shown to have positive effects on functional ability. In addition, multi-professional rehabilitation can be implemented, including physical, functional and speech therapy, rehabilitative nursing and social work.

VOCATIONAL REHABILITATION

Vocational rehabilitation is organised by Kela, insurance and employment pension institutions, TE services and occupational healthcare services. Some organisations also provide rehabilitation services. Vocational rehabilitation examines the needs related to the ability to work, choose a profession or change a profession. Vocational rehabilitation may include education and coaching, work trials, and various support measures for coping at work.

The sponsor of rehabilitation is determined individually depending on the circumstances of the accident that caused the TBI (such as an occupational accident, leisure-time accident or traffic accident). The injured person may need more than one form of rehabilitation to help them recover. Rehabilitation is planned and organised individually according to the needs of the rehabilitee. Rehabilitation may involve a wide range of services and rehabilitation professionals. All rehabilitative actions in everyday situations are also important. Participation in the activities of brain injury societies and the courses organised by the Traumatic Brain Injury Association of Finland are also rehabilitative

What can you do when the injured person is in rehabilitation?

Their close circle is an important part of the everyday life of a rehabilitee. Your support of the rehabilitee may be encouraging, assisting in everyday situations, and walking alongside them. The most important thing is to be present in their life as before. A family member should come along when the rehabilitee visits various professionals, report their own observations on the rehabilitee's ability to function, as well as share their perspective on the rehabilitation needs in terms of everyday life and ask for advice on how to support the rehabilitation. As a family member, you too can receive information and guidance on the symptoms of TBI and rehabilitation, as well as support from rehabilitation professionals. However, remember your own well-being and do not let your relationship with the injured person become a nursing relationship.

- Read more about the Traumatic Brain Injury Association of Finland and the local brain injury societies activities p. 30
- More information: www.kuntoutumistalo.fi

Sequelae of traumatic brain injury

During a hospital stay, the primary focus is on treating the TBI and its symptoms, and starting the rehabilitation process. The impact TBI has on the skills needed in everyday life and the need of necessary support measures will be considered later. The perception of the need for help and guidance will only become clearer once everyday life begins.

Symptoms that emerge and become permanent as the recovery progresses are called the sequelae of TBI. Here are some of the most typical residual symptoms, as well as examples of coping with them. The rehabilitation physician and the members of the multi-professional rehabilitation team can provide individual advice and guidance on coping with the sequelae. A neuropsychologist can help understand the symptoms and cope with them in everyday life.

TYPICAL SEQUELAE OF TRAUMATIC BRAIN INJURY

Fatigue caused by TBI: The injured person becomes tired more quickly and is more sensitive to stress than usual. The tiredness feels different to being tired from a lack of sleep. Brainwork that requires remembering and concentration is often felt to be more tiring than physical exertion. Fatigue can make otherwise controlled symptoms more apparent, such as disruptions in memory, difficulty concentrating, irritability or headaches. Sleep, adequate rest and meaningful action are important for brain recovery.

Regular naps, rest periods and taking pauses can support daily coping.

Reduced attention and concentration: Difficulty in doing more than one thing at the same time. Maintaining attention and concentration may be difficult. In the short term, concentration may work well, but lapses in concentration happen more quickly than before. Doing things in small parts and according to a plan can help. Disturbances and interruptions from outside make it difficult to do things when you feel distracted, and external stimuli cannot be ignored in the same way as before. It is also important that family members remember this and allow the person peace to do things.

Memory impairment: In particular, short-term memory impairment may occur as memory difficulties, which is most often associated with remembering new things. The memory may not be as reliable as before. Items get lost, things get forgotten, and your family members

may have to tell you the same things many times. The injured person may not remember even the most important things. Short-term memory weakness may be connected with a difficulty to learn new things. Routines and memory rules, as well as storing items in specific locations, can help.

Impaired capacity for initiative, planning and evaluation: The initiative for action may be impaired even if the injured person used to be very active in the past. Multi-stage matters should be planned and implemented one stage at a time, because they are then more likely to get done. The difficulties of taking initiative can be alleviated by external encouragement and instructions. You can help get things started or set reminders on the phone that tell the injured person when to get started. Maintaining activity may require support and guidance.

Deceleration of action and thinking: It does not necessarily show, but the injured person may feel that their thinking and acting have slowed down. Family members often notice this symptom. It may take more time to do things, and thinking is not the same as before. There may also be difficulties in finding words. This requires patience from both the family members and the disabled person themselves, and it is worth reserving a lot of time to do things.

Unawareness of symptoms: Disturbances and changes in the ability to function caused by TBI may be difficult to identify yourself. Unawareness of symptoms can apply to all typical sequelae of TBI. As a family member, you may notice these changes better. You should mention them in healthcare, as the disabled person may be unable to do so themselves. The injured person may have unrealistic thoughts about their well-being, and their chances of coping and being able to function. It often becomes easier with time, and rehabilitation can also help with noticing changes in oneself. Awareness of changes in functional capacity is the basis for managing symptoms and reducing the impediment. The most difficult thing for a disabled person is often to be aware of changes in their behaviour.

The sequelae of TBI often include difficulties in controlling emotions and behaviour, especially impaired tolerance and irritation, changes in character, depressive symptoms, anxiety and exaggerated or faded personality traits. Understanding non-verbal communication, gestures and expressions may also be more difficult. The sequelae may also include a variety of physical symptoms such as strokes, balance disorders, headaches, epilepsy, sleep disturbances, visual field defects or difficulties in linguistic functions such as speech production and understanding. These symptoms are always individual and may not be immediately measurable at the start of care.

SUPPORT FOR EVERYDAY LIFE WITH A BRAIN INJURY

In addition to everyday routines, you may have a wide range of new things to deal with: filling in applications, assisting at home and out of home, maintaining assistive devices, meetings, phone calls and clearing things up, etc. You may have to manage your family member's affairs on their behalf (such as paying bills). Depending on the sequelae of TBI, the injured person may need instruction and care in everyday activities. This may be either verbal instruction or reminding. If the symptoms are physical, your family member may need help with daily self-care activities.

*Being a **family caregiver** means taking care of a family member or close friend who, due to a disability or other special care needs, cannot cope with everyday life on their own.*

*A **family caregiver contract** is made individually with your municipality, after which you can receive **support for family care**.*

The municipal social service will check the support needs of the disabled person and their family and if necessary, make an individual service or customer plan. The plan will include the kind of support or services the disabled person and their family need. Support and services in accordance with disability services include housing modifications, transportation services and a personal assistant. Other forms of support offered by the municipality include home care, family care support and family work. However, the need for these will always be assessed individually. After returning home, you may act as a family caregiver for your family member and thus be the official caregiver of the injured person.

Even if the injured person needs your care and help, it is also important to take care of yourself. It is therefore advisable to find out how to use and apply for various support services with the help of a social worker or social counsellor. It is important to have time for your own hobbies and things that support your well-being.

If necessary, contact the municipal social services to identify the need for assistance. A social worker or social adviser can be of great help and support in clarifying and managing matters.

- More information: www.sosiaaliturvaopas.fi

COURSE ACTIVITIES AND ADAPTATION TRAINING

Participation in the course activities and adaptation training organised by of the Traumatic Brain Injury Association of Finland and other organisations is relevant when the rehabilitation is no longer progressing with great strides. Usually, the appropriate time is about 1–2 years after the accident, but this is also individual.

The courses include group activities led by professionals. Their aim is to provide information on brain injuries and the ability to deal with the changed life situation as a result of the disability. The courses provide resources and means to cope with everyday life, and you can meet others who have experienced the same things, and their families.

Exchanging experiences in various discussions is peer support. There are different courses with different themes, some of which are aimed at the whole family. Family courses organise their own programme for children, and brain injuries are handled according to their age level.

The courses are free of charge for the participants. Some courses require a doctor's recommendation and justification for participation on application. The Traumatic Brain Injury Association of Finland organises several courses on various topics each year. You can find information on current courses from the Traumatic Brain Injury Association of Finland.

An injury is also a crisis for family members

A sudden crisis, such as a family member becoming disabled after an accident, causes a psychological situation called a traumatic crisis. People react differently to these kinds of situations, and you cannot prepare yourself for the emotions caused by a sudden event. An injured person may also be going through a similar crisis, but it may show in a different way and at a different time than the family member's crisis.

A family member's disability following an accident can cause a wide range of emotional reactions. You may experience insecurity, fear, anger or guilt. You may also feel confused, frustrated or miserable. These are normal and appropriate reactions of the mind to the changed life situation.



The crisis is associated with typical and varied emotional reactions, and getting to know them can help understand your own feelings and behaviour in the situation. The severity of the crisis is influenced by the severity of the injured patient's condition and individual differences in experiencing emotional reactions, for example. Some may deal with the crisis more quickly than others, and the process is not always straightforward. Coping with the crisis takes a lot of strength, but there are also various ways to make things easier. It is important to remember that a crisis does not last forever – even a difficult situation will stabilise, and you will find a balance.

Initial shock

When you are informed of an accident involving someone close to you, you may suddenly be in **shock**. You may not be able to understand what has happened yet. Shock can paralyse you completely, which may cause you to act mechanically and rule out feelings.

The initial stage can involve a denial of the event, and feeling unreal and outside. Yelling, crying and panic may also be part of the initial stage.

In the early stages, it is important to feel safe and to have clear instructions. You should not be alone. Instead, seek out others and unravel your feelings. Shock can affect how well you can receive information. You may not remember what you have been told. You may not remember what you were told at the hospital, or what instructions you were given. If you are unsure if you have been instructed, you can ask your healthcare professional to repeat what they have told you.

When the reality of the situation strikes

Gradually, you can start to face the situation and form an idea of what has happened. Strong reactions and feelings can arise. You may feel a need to blame yourself or others for what happened. Feelings can be painful, and your mood can swing from one extreme to another. You may be furious and angry, weepy, and the next thing you know, relieved. The crisis can manifest itself as insomnia and loss of appetite. Your body may react in nausea and other physical symptoms.

The mind may still try to deny what has happened, and often the whole body responds to shock. A feeling of fear and anxiety may arise then. You may question your personal coping and sometimes feel hopeless. At this stage, people's feelings are often similar. They often use expressions like "I can't stand it" or "will I ever get past this?".

Usually, speaking makes you feel better at this stage and helps you structure what has happened. You should contact your healthcare professional and ask for conversation therapy. Peer support can also help.

From an emotional turmoil to processing the situation

Gradually, when emotional reactions begin to subside, you start to process what has happened. You start to understand the event and begin to be ready to face the changed situation. You may have a strong urge to put your feelings into words. An accurate description and reflection of what has happened may help the processing.

This often involves remembering the past, comparing the present and the past, and mourning what has been lost. Your injured family member may have changed permanently, or things that used to be part of your life and leisure time are no longer possible. You can go through what happened in the best possible way for yourself. It may be reminiscing, talking, writing or listening to music. From time to time, your feelings may be intense. It is normal to feel irritated and want to withdraw from social relations.

Processing takes a lot of strength, your ability to concentrate may be lacking, your memory may be impaired, and the future may be difficult to think about. As the processing moves forward, people usually begin to want more information about TBI, and their care and rehabilitation options. You may notice that you do not remember anything they told you at the hospital, or that you feel unsure of the instructions you have received. You can ask the care provider for information and a recap of the given instructions – in writing as well.

Talking to friends or family, professionals and peers may ease your grief and anxiety. You can ask your own care unit for help, through occupational healthcare or a health centre, for example.

Towards adaptation

Once the situation has been dealt with, and sufficient time has passed, you can restart orientation and adaptation. What happened is slowly becoming part of life. You can already live with what happened, and it is not on your mind all the time. The grief and pain may still arise at times, but they are no longer dominant, and there is also joy in life. It is possible to restore confidence in life.

Adaptation is affected by the condition of the injured person and the change to everyday life. Others may need more support in everyday life, and the rehabilitation of the disabled person may proceed varyingly. If there are difficulties in rehabilitation and everyday life, family members may also find it difficult to adapt to the situation. Taking care of your own resources is highlighted at this stage. At this stage at the latest, it is good to have peer support and contact other people in the same situation. The need for information about TBI is also increasing.

The course activities and adaptation training of organisations will start being relevant for both the disabled person and their family members about one to two years after the event, when adjustment has already begun. The courses allow you to deal with the emotions caused by the new life situation and get important information about everyday life with TBI. The courses also allow you to meet other people in the same situation and receive peer support.

Crisis emergency services:
Provides emergency assistance in acute crises, as well as support in handling the situation and guidance for the future.
Ask the nursing staff for the contact information of your municipality's emergency services.

- Read more about course activities
p. 19
- More information on the stages of a crisis: www.aivotalo.fi



WHERE CAN I GET HELP TO COPE WITH THE CRISIS?

When someone close to you is in the hospital, your coping is also tested. It is natural to experience guilt, frustration, depression or uncertainty about the future. By recognising feelings of loneliness or exhaustion, you can influence your personal coping. Having relationships and hobbies increases your well-being, and you get understanding and support in what may be a frightening situation.

Your well-being also affects the rehabilitation and well-being of the disabled person. You can cope better yourself by giving yourself time to relax, rest and do things you enjoy. It is comforting to visit the injured person in the hospital, but you should not spend all your free time in the care or rehabilitation unit.

You should seek help in handling a crisis at a regional crisis centre, occupational healthcare, a health centre or your municipality's social and crisis emergency services. For example, you can ask to be referred to a psychologist or psychiatric nurse for conversation therapy. You may need support to deal with the crisis even after a longer period. Persistent symptoms of TBI can also bring a variety of adaptation challenges to you as a family member

How can you improve your coping?

- Make sure you get adequate rest, eating and exercise.
- Ask for and accept help.
- Talk to peers.
- Save time for yourself and your hobbies.
- Spend time with people you care about.

- Read more about peer support *p. 29*
- More information on the stages of a crisis: www.aivotalo.fi
www.kuntoutumistalo.fi

Acknowledging children and young people in a crisis

When a family member or someone close to you is suddenly hospitalised, you may wonder how to tell the children what has happened. It is important to talk to children calmly, honestly and according to their age. You should not make promises you cannot keep – for example, that the injured person will recover, even if it feels comforting at the time. It is important for the child to know that they can trust the things they have been told.

Children of different ages may react to the situation by looking after you. When you go somewhere, they may want to know exactly when you are coming back. They may also be concerned about your health and well-being. They may fear that you will be hospitalised too. It is important for them to know where you are at any time. The child may also be inclined to blame themselves for what happened or think that they caused the accident by acting up. Convince the child that it was not their fault.

A child does not necessarily express grief and shock in the same way as adults, and it may therefore be difficult to know how a child will experience a crisis. There is no

need to be afraid to show your feelings, because it can also encourage the child to express their feelings and concerns. After a shocking event, the child has the same feelings of emptiness, confusion, sadness, anger and disbelief as adults. You can ask the child how they feel about what happened and explain that if adults seem to behave strangely, it is because of grief. A child may try to protect an adult by concealing their own feelings. It is therefore good to encourage them to express their feelings and tell them that all feelings are allowed. They are allowed to be happy and laugh even if their family member is in the hospital.

If possible, have the more detailed discussions about the care of the injured person, the situation and your own fears without the presence of children. If children hear these conversations, they may draw their own conclusions and be afraid.

How can you tell a child that someone close to you is in hospital?

- Tell them what happened peacefully and in a safe environment.
- Be honest about the seriousness of the situation and tell them that you do not know what will happen.
- Assure them that physicians and nurses are doing their best, and that the injured person is being well cared for.
- You should not make false promises about the family member getting better.
- Talk to the children in an age-appropriate way.

ACKNOWLEDGING CHILDREN OF DIFFERENT AGES

Babies and toddlers do not yet understand what has happened, but they do understand that their normal daily rhythm has suddenly changed. For example, the child may react to one parent being in the hospital and not being around in everyday life. This may show itself in increased crying, trouble sleeping, eating problems or restlessness

- It is important that familiar adults spend time with the child, offering a lot of comfort and intimacy.
- Maintaining routines with as little changes as possible helps adapt to the situation.

Pre-schoolers show their concern by asking concrete questions about the situation. Children of this age may react by regressing to the behaviour of a smaller child, such as sucking their thumb and wetting their bed. They may require more attention, behave badly or withdraw. Children deal with things by playing and drawing, and it is possible to learn about the child's feelings through them.

- Answer the child's questions briefly and give an answer only to what the child asked. Do not go into too much detail about what happened. 

- Give comfort and intimacy and put your feelings into words.
- If your child's play or drawings concern you, you should contact a professional.

School-age children usually want to know more about what happened. You can tell them a little more about what happened. Children of this age may ask if the injured person is going to die. Responding to this can be difficult, especially if the situation is unstable, and the nursing staff cannot say what is going to happen. At this age, children may benefit from writing. Speaking emotions out loud can be difficult, and writing may help.

- If the child asks, you can tell them a little more about what happened.
- Ask the child if they would like to show you their writing or drawings, and discuss them.
- Give time and space for the child's questions.
- Ask the child how they feel and tell them how you feel.

Teenagers are better able to understand a serious accident. You may want to protect your child from the details, but they may draw their own conclusions if they feel that something has been left unsaid. People of this age already understand other people's feelings well, and may prefer to talk to another adult to spare you the most serious thoughts and questions. Adolescence is a challenging time for young people, and it is therefore important that they spend time alone and with friends. However, it is also important to spend time together as a family, even if it is only for a short period at a time.

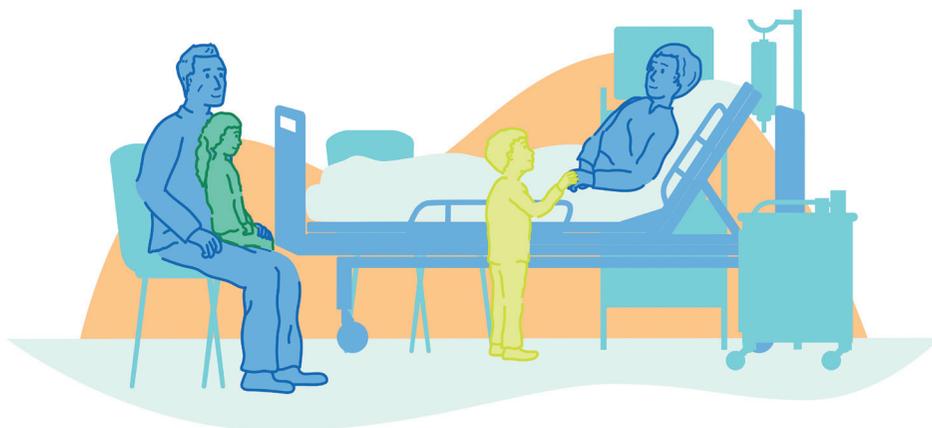
- Let the child ask questions and assure them that you will tell what you know.
- Tell them that they can ask questions at any time and give them time.
- Young people need time away from home and with friends.
- Older children can be given some responsibility for running everyday life, but it is important to make sure that they are not too responsible for other family members

VISITING THE HOSPITAL WITH CHILDREN

Hospitals have different policies and guidelines for visiting with children and young people. The situation also affects whether it is worth bringing children to the hospital. Talk to the nursing staff before taking children to the hospital.

You should think about whether the child has spoken of a wish to visit the hospital. If the child does not want to visit, they should not be pressured into it. The child's fear of visiting may be eased by preparing them for the visit. You should discuss the situation several times before the visit to make sure that the child understands it.

Talk to the child in advance about the hospital and ward, as well as the various devices used in the treatment. You can describe the sounds that the devices make



and what they mean. You should mention if the injured person has visible injuries, or if they have a breathing tube or cannulas so that the child knows to expect them. You could show a picture of the injured person in the hospital so that the child knows what they look like. Before taking a photo, check the hospital's policy for taking pictures. Agree with the child that they will say as soon as they want to leave the room. If the child changes their mind and does not want to visit the hospital, support them in that decision.

The child can be instructed to make a card, drawing or write a letter to the injured person, which can be delivered to the hospital at the time of the visit or later. This helps the child feel useful and connected to the injured person in the hospital.

Make sure you know of the latest treatment and condition before your visit. Even on arriving at the hospital, it is still worth checking that it is okay to visit. It is important to remain calm and safely support the child in the situation. If possible, invite another close adult to attend the visit. They can take care of the child if you need time to talk to the nursing staff, for example.

During the visit, you can instruct the child to speak to the injured person and touch them in accordance with the instructions given to you. The child can be encouraged to ask questions. It is advisable to limit the duration of the visit to a short period. A visit can be a lot for a child to take in, and the injured person also needs a lot of rest. Give the child time to reflect on the visit and ask questions afterwards. Emphasise that they can ask questions that come to mind at any time.

WHEN THE TIME TO RETURN HOME IS NEAR

Returning home can cause many kinds of feelings and reactions in children. It can be difficult to get used to a new situation if the injured person has been treated for a long time and the new everyday life has started to run smoothly. This can show as distant behaviour, especially if the TBI has caused changes in the behaviour of the injured person.

Children can look forward to the injured person's return to home and expect that everyday life will return to how it was before they were hospitalised. The injured person may not be the same person they were before becoming disabled, and this may cause confusion and anger. It is therefore important to prepare the child for the fact that the behaviour of the injured person may be different from before even if there are no visible injuries.

Even you may not yet know what kind of symptoms of TBI have remained, which is why you should learn about the typical sequelae. You should stress that the injured person returning home needs a lot of rest and sleep, because their brain is still recovering.

- Read more about the sequelae of TBI p. 17

WHERE CAN I GET SUPPORT FOR A CHILD OR YOUNG PERSON?

The accident may cause the child to misbehave, for example, at their day-care centre or school, and it is therefore important that teachers and carers know about the family member's situation. Ask them about the child's behaviour in the day-care centre or school, as well as to look for any changes or behavioural symptoms.

Sometimes, the child does not start showing symptoms until the situation has otherwise calmed down and stabilised. It is therefore advisable to follow the child's or young person's behaviour and signs of symptoms for longer, even if it seems that the accident has not affected the child at first.

If you are concerned about the child's symptoms, you can ask a maternity clinic, early childhood education staff, class teacher, school curator, school nurse or school psychologist for help. Professionals involved in the child's everyday life can help provide the necessary support services. Discussion with a professional can help preventively, even if there are no noticeable symptoms yet.

Overall, it is important to ensure that the everyday lives and hobbies of children and young people continue as normally as possible. This may require support from other family members and friends, and you should ask for help. You can also talk to a social worker if you need help with everyday life.

Children will certainly continue to need support, and with age, the child's need to address the issue will also change. It is worth participating in the course activities of the Traumatic Brain Injury Association of Finland as a family, which also gives children the opportunity to meet others whose family members are disabled and deal with the matter with professional help.

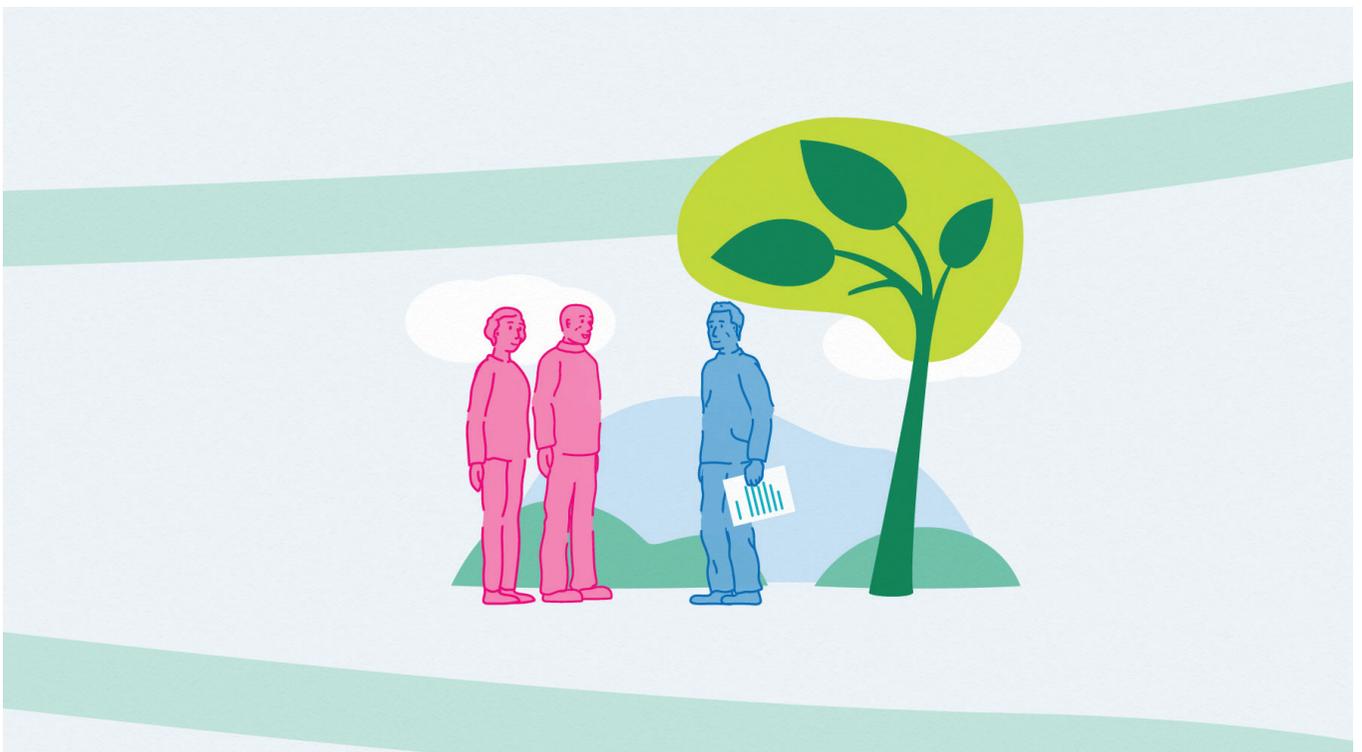
- Read more about the Traumatic Brain Injury Association's course activities p. 19
- More information on current courses: www.aivovammaliitto.fi

Peer support

When someone close to you is hospitalised, you may have a great thirst for information. In addition to the care provider and literature, information can be obtained from peers with the same experience. They can share their own experiences of living with TBI. It is important to hear what TBI means in practice, and how it affects everyday life.

A newly injured person and their family members may be relieved to talk about what they have experienced. Peer supporters are volunteers, trained and under an obligation of confidentiality.

Peer support can provide information on the disability, its effects on life, forms of treatment and recovery. People with the same experience can give practical tips on how to cope with the disability and hear how other family members have dealt with their situation. Peers also provide answers to questions that you may not even think to ask. Peer support makes you feel you are not the only one in a situation like this. You can get encouragement and understanding from peers who share your life situation. Hope awakens, and it is encouraging to see and hear how others have survived.



WHERE CAN I FIND PEER SUPPORT?

Relatives, as well as disabled people, have their own peer support. There are different kinds of peer support, and you can find the right one for yourself at the right time. Peer support is available in some hospitals. The Traumatic Brain Injury Association of Finland organises peer support nationwide, and brain injury societies operate in different locations.

The Traumatic Brain Injury Association of Finland

The Traumatic Brain Injury Association of Finland is an interest group for brain-damaged people and their family members that aims to promote the performance of brain-damaged people in society independently and on an equal footing. The activities also aim at improving research, care and prevention of brain injuries. The Traumatic Brain Injury Association of Finland organises course activities and peer events. The Traumatic Brain Injury Association of Finland is made up of local **brain injury societies**. The societies operate on a voluntary basis and produce various events for their members. Many also have activities aimed at families and close friends.

Services provided by the Traumatic Brain Injury Association of Finland:

- Advice and guidance
- Peer support for family members and the disabled person themselves
- Course activities and adaptation training
- Experience activities
- Youth activities
- Information on local societies
- Aivoitus magazine

Find the brain injury society closest to you and get acquainted with the Traumatic Brain Injury Association of Finland! Follow us on social media @aivovammaliitto



OLKA®

OLKA is coordinated organisational and volunteer activity at a hospital. OLKA provides patients and their families with information about the support offered by patient associations and hospital units, peer support and other volunteer support. You should ask the ward's nursing staff about your hospital's OLKA activities and their cooperation with patient associations.

- More information: www.olkatoiminta.fi
- More information: www.vertaistalo.fi

SUPPORT for brain injury patients' FAMILY MEMBERS



THANK YOU

This guide was produced by the Traumatic Brain Injury Association of Finland **Support for brain injury patients' families** project in 2019–2021. The guide has been designed and compiled on the basis of research data in cooperation with Metropolia University of Applied Sciences, healthcare professionals, experts and family members of people with TBI. Members of the Traumatic Brain Injury Association of Finland and experts have also participated in the compilation of the guide.

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**The Traumatic Brain
Injury Association of Finland**

The Traumatic Brain Injury Association of Finland is an interest group for brain-damaged people and their family members. Societies under the Traumatic Brain Injury Association of Finland organise activities in different parts of Finland.

Read more about brain injuries and join us!

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