AVUSTAJAKESKUS

www.avustajakeskus.fi

COURSE FOR PERSONAL ASSISTANTS OF DISABLED PEOPLE - WORKBOOK

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1 AVUSTAJAKESKUS

1.1 INTRODUCTION TO AVUSTAJAKESKUS

Avustajakeskus trains and acts as an agency for *assistants of physically disabled, visually impaired, intellectually disabled, clients with memory loss and employers of personal assistants of all ages* in Southwestern Finland and the Satakunta region.

For more than 25 years, Avustajakeskus has been a forerunner in voluntary activity and an agent for personal assistants. There is no similar activity elsewhere in Finland.

Avustajakeskus is an agent for:

- *Volunteer assistants* for spare time activities, for example, errands, hobbies, excursions, trips, group needs or individual assistance. The assistant enables many clients to move, participate and do things independently.
- *Paid assistants* including personal assistant work, school assistant work and temporary jobs etc.
- *Support persons*

Avustajakeskus trains:

- People interested in assistance work in *courses for personal assistants of disabled people*. The courses are open and free of charge for anyone interested in participating.
- *Additional trainings*, such as speech-supporting signs and ergonomics, are arranged for registered assistants. Registered assistants can also take part in *events* and they are well cared for.
- *Training and peer support for disabled employers* to strengthen and support them in their role as employers.

There are approximately 700 volunteer assistants and approximately 900 clients: around 14 000 volunteer assistant engagements are performed every year.

There are approximately 4 500 jobseekers each year, and approximately 2 300 employers are registered. There are more than 4 000 vacancies as assistants every year.

Avustajakeskus gives *advice, guidance and support* in assistance related matters.

The activities are *developed in cooperation* with the disability organisations and municipalities in the region, which make a valuable contribution to the development work, training and information activities.

Lounais-Suomen Lihastautiyhdistys ry (The association of muscle diseases in Southwestern Finland) is responsible for the activities of Avustajakeskus.

The activities are financed by *STEA (Funding Centre for Social Welfare and Health Organisations) and the wellbeing services counties*.

For more information, www.avustajakeskus.fi/in-english, www.lsly.fi (in Finnish)

1.2 VALUES OF AVUSTAJAKESKUS

These are the values to guide our activities at Avustajakeskus:

- we are a pathway to **inclusion**
- our services are professional and we respect **the joy of doing**
- our successful activities are based on continuity and **people-centricity**
- we know how and succeed **together**

For consideration:

What's important to me?

What kind of things do I appreciate?

For consideration:

What do I want to spend my time doing?

In which direction do I want to go in my life?

https://oivamieli.fi/viisaat_valinnat_intro.php - 'Omat arvosi' - video (2:48) ('Your own values') (in Finnish)

2 VOLUNTARY ACTIVITY

2.1 DEFINITION OF VOLUNTARY ACTIVITY

Volunteering is defined according to the European Parliament report (2008): *"An activity that is unpaid and open to all, undertaken of one's own free will and brings benefit to a third party outside the circle of family and friends."*

The different forms of volunteering are: mutual support between people sharing the same experiences (peer activities), helping other people (voluntary activities providing services), support for volunteers in need of special support (supported volunteering) and social inclusion (civic participation and association activities).

Voluntary activity and volunteering must be distinguished from salaried work. Voluntary activity is considered to be an activity while volunteering is considered to be performing a more concrete individual task. The concept of volunteering emphasises the importance of doing, and it is as valuable a job as salaried work. Volunteering is lifelong learning and a sense of community.

2.2 STATISTICS ON VOLUNTEERING

According to the market research company Taloustutkimus (2021), nearly half (47%) of Finns do voluntary work. On average, Finns volunteer 12.90 hours a month. Regarding volunteering, 76% occurs face-to-face and 5% online. Measured in monetary terms, the value of volunteering in Finland is approximately EUR 4.38 billion. S

ource and more information: https://kansalaisareena.fi/wp-content/uploads/2021/05/Vapaaehtoistyo_tutkimusraportti_2021.pdf ('Volunteering research report 2021') in Finnish

2.3 GENERAL PRINCIPLES OF VOLUNTARY ACTIVITY

Voluntary activity is guided and defined by joint and generally accepted principles. They serve as a guideline for volunteers and summarise what is important in volunteering:

- **Voluntariness**
  Everyone joins the activity voluntarily and by choice.

- **Equality**
  All parties in volunteering meet on an equal basis.

- **Reciprocity**
  Voluntary activity brings mutual joy and happiness to all parties involved.

- **Unpaid**
  Volunteering is work without salary and expenses. For travels and events, the client must reimburse the costs incurred, e.g. the costs for tickets and entrance tickets.

- **Non-professionalism**
  The volunteer works with the knowledge and skills of an ordinary person and does not replace a professional worker. The volunteer does not carry out housekeeping or medical tasks or act as a driver.

- **Cooperation**
  If necessary, the volunteer cooperates with the client, the client's relatives, professionals and other possible support networks of the client.

- **Reliability and commitment to the activities**
  The volunteer is reliable and carries out the agreed tasks. The volunteer decides independently how long they want to commit to the activities.

- **Confidentiality and secrecy**
  The volunteer is under the obligation of confidentiality. The volunteer is not allowed to tell outsiders about the client in such a way that the client can be identified. You can tell about volunteering at Avustajakeskus and how you like it, but not with whom and not about the client's personal affairs. The confidentiality obligation will continue even after the activities have ended.

- **Tolerance**
  In voluntary activity everyone involved is tolerated. The volunteer respects the differences among people.

- **Neutrality**
  The volunteer acts impartially and equally in everyone's interest. The volunteer doesn't spread ideologies or ideas.

- **Acting on the terms of the client**
  The client has the right to self-determination and is responsible for their own life. A good assistant is present in the situation, always ready and keen to assist in any situation. Take the client's wishes and needs into account and know your own limits! Do things together with the client, not on behalf of the client.

- **Community spirit**
  Important communities and friendships are formed through voluntary activity.

- **Right to support and guidance**
  The volunteer has the opportunity to get help and support from the organisation and peers, for example. The regional counsellor of Avustajakeskus is also there for you. You can tell the regional counsellor about client situations.

- **The joy of the activity and growing as a person**
  Volunteering is meant to be meaningful. It offers lifelong learning and the opportunity to develop oneself. We encourage and support you to try it. You never know beforehand what you're capable of, we can all discover new sides of ourselves.

For consideration:

Why are principles important?

For consideration:

What is important in volunteering?

Notes:

2.4 RIGHTS AND OBLIGATIONS OF A VOLUNTEER AT AVUSTAJAKESKUS

The volunteers also have rights and obligations in our activities. The principles of the voluntary activity and the rights and obligations of the volunteers together form the 'rules' of volunteering.

The rights of a volunteer at Avustajakeskus...

- you act as a volunteer - the knowledge and skills of an ordinary person are sufficient
- meaningful volunteering, diverse client base - you commit to a task that suits you and you do the voluntary activity you want to do for the time period you want
- the client pays you an expense allowance of 7€/time (swimming 9€/time)
- right to refuse voluntary work offered
- right to training and introduction
- right to guidance and support
- an insurance is valid during volunteering tasks assigned via Avustajakeskus
- right to participate in recreational events and peer meetings
- the activities should give you joy and make you happy

The obligations of a volunteer at Avustajakeskus...

- you act as a volunteer, not as a professional
- you agree to comply with the values of Avustajakeskus
- you do not volunteer under the influence of intoxicants
- you respect confidentiality and the client's right to self-determination
- you stand by your agreed assignments and inform in time, if you have a valid excuse not to carry out an already agreed event
- you comply with the principles of volunteering
- you contact Avustajakeskus, if something unusual happens during the time that you are carrying out a volunteering task
- you notify Avustajakeskus if you wish to stop volunteering
- as a volunteer you also take care of yourself and your own coping. Your work is immeasurably valuable, so your wellbeing is also important to us!

2.5 VOLUNTARY ACTIVITY AT AVUSTAJAKESKUS

SINGLE ASSISTANCE	GROUP ASSISTANCE	SUPPORTED VOLUNTEERING
Single event for a single client accompanying a client on an errand at a time when the client needs it: to the shop, bank, doctor, movies, theatre, a hobby, fair, meeting, etc.	**General assistant at an event** times and tasks vary depending on the type of event Ruisrock, Pori Jazz, seminars, association events, etc.	**Volunteer for behind-the-scenes help** part of the supported volunteering, where an experienced volunteer supports a group or an individual volunteer
Regular assignments for the same client regular assistance to the same client 1-4 times a month, day and time to be agreed	**Assistant for physical activities in a group** adapted gym, water gym for adults, swimming for children with special needs, chair exercise, lavis (combining exercise and dancing on an open-air dance floor), boccia on one's own, etc., weekly recurring day and time.	**Supported volunteering, group** assisting as a group in such a way that the group has experienced behind-the-scenes volunteers to support the activities in accordance with the principles of increased support
MemoryMate for the same memory client (memory mate) regular assistance to the same memory client 1-4 times a month, day and time to be agreed upon	**Peer leader** 1-2 volunteers/group at assistants' peer meetings in different locations	**Supported volunteering, individual** the voluntary activities are carried out with increased support (strong support from the regional counsellor, behind-the-scenes volunteer). It is always agreed upon for a fixed period of time after which the volunteer continues with basic activities.

YOUR TIME IS PRECIOUS! HOW DO YOU WANT TO SPEND IT?

- **2-3 h occasionally**
  accompanying various clients with running errands (e.g. to the shop, bank, doctor, etc.)
- **2-6 h occasionally**
  various events e.g. association celebrations, meetings, seminars, public events
- **2 x 7.5 h once a year**
  Ruisrock!
- **2 h/2-4 times/month regularly, day and time to be agreed upon**
  outdoor activities and running errands with the same client
- **2 h/week regularly, same day and time** sports assistant in a group for adapted physical activity (only in Turku)

2.6 PEER SUPPORT FOR ASSISTANTS AT AVUSTAJAKESKUS

At Avustajakeskus, peer support activities are organized for assistants. You can participate in peer meetings both in traditional in-person gatherings and online. These activities include, for example, spring and autumn meetups for volunteers, “henkkari meetups” for personal assistants, as well as Christmas mulled wine events and springtime barbecues open to all assistants.

Peer meetings at Avustajakeskus are held as open groups, and you can participate whenever it suits you. Peer support is based on voluntary sharing of experiences. In peer support, it is important to both speak and listen. Shared experiences can sometimes be very meaningful and help increase mutual understanding.

A regional counsellor from Avustajakeskus is present at the peer meetings. The meetings may include a specific theme around which the discussion is centered. The meetings are confidential.

You are warmly welcome to join the peer activities, whether you are an experienced participant or new to the activities! The schedules for peer meetings are announced in Avustajakeskus newsletters, electronic bulletins, and on the website..

2.7 IDENTIFYING YOUR STRENGTHS

Strengths can be natural inclinations or skills being developed over the years. People like doing things that are meaningful for themselves, because doing meaningful things is the strongest motivational factor. Doing meaningful things already in itself brings joy and pleasure to the person doing it.

Identifying one's own strengths produces better results than focusing on weaknesses. Noticing strengths does not eliminate weaknesses and does not deny their existence. Nor does it mean that you should only do things that you already do well. Identifying your strengths provides energy and supports wellbeing.

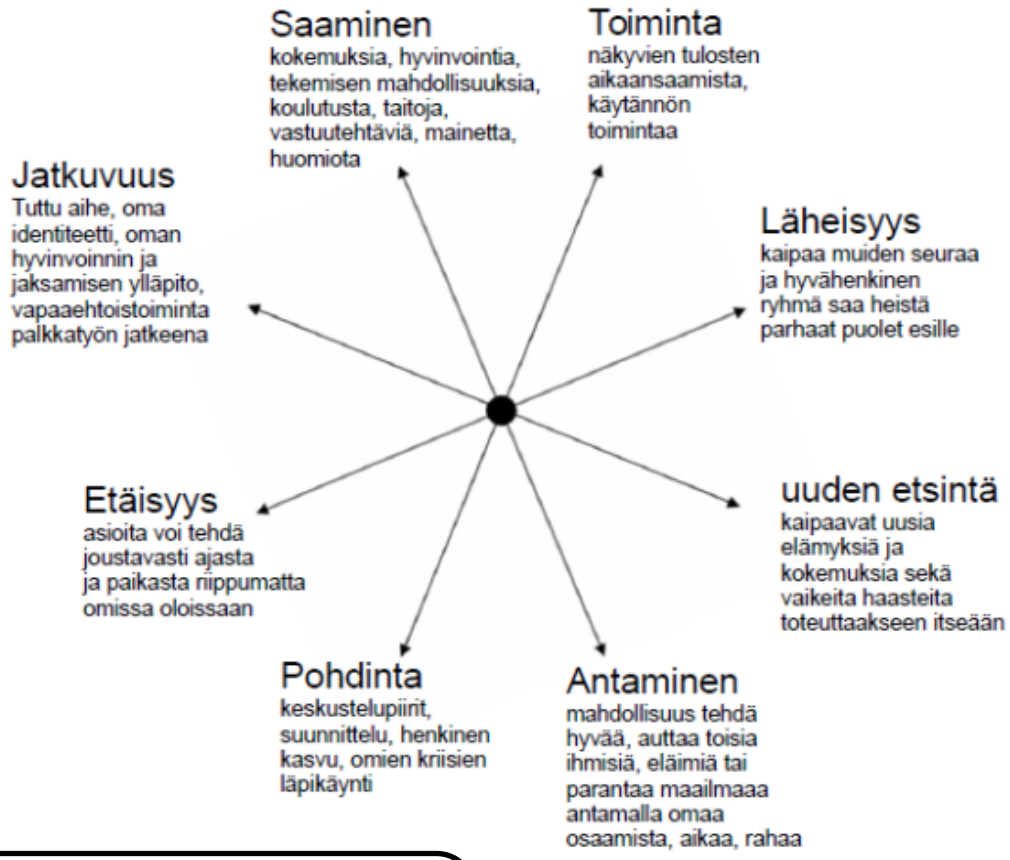
The following questions can help you reflect on your own strengths. Also, think about how the strengths are reflected in your everyday life and how you use them in your life?

- **What kind of activities inspire and attract you?**
- **What strengths have helped you move on from difficult phases in your own life?**
- **What kind of things come naturally for you?**

2.8 WHAT MOTIVATES YOU IN VOLUNTARY ACTIVITY?

There are many different reasons why people are inspired towards voluntary work. People's inner motives often lead them to take part in suitable volunteering. Voluntary work must be important to the volunteer and self-rewarding in itself, because volunteering is not guided by a salary or obligation.

Your inner motives for doing voluntary work can be considered with the help of the volunteering model (A. Yeung, the diamond model). The figure was made by Lari Karreinen and is based on Yeung's modelling.



For consideration:

What motivates you to start volunteering?

What's important to you?

For consideration:

What kind of volunteering are you interested in?

What strengths of yours could you use in volunteering?

Source and more information: https://vetovoimablog.wordpress.com/2015/05/28/tyo-vapaaehtoista-kiittaa/ (‘Work is rewarding for the volunteer’) in Finnish

3 MEETING AND ASSISTING THE CLIENT

3.1 MEETING AND INTERACTING WITH THE CLIENT

Assistance shall be based on confidential cooperation and compliance with agreements. Interaction is the interrelationship between two people. So good interaction is the responsibility of both. In the communication, you want to understand the other person, use comprehensible language and, if necessary, communication aids. The interaction also includes facial expressions, gestures, touching, eye contact and body language. Be present and listen, you may be the only non-treatment contact for the client in a whole week.

The client often knows best how they can be helped in the best way, so spend time talking to the client. Common sense and a calm attitude are important. Soothing speech and a peaceful environment make it easier for the client to succeed with their task. Always tell the client what you're doing. With anticipation, you ensure that the client is able to participate in the assistance situation and thus you respect their wishes.

At the first meeting...

- **Presentation** - Tell who you are and why you are there. If you have the Voluntary Assistant card with you, you can show it to the client. First impressions are always important!
- **Expectations** - What does the client want? What are you prepared to do? How much time do you have available?
- **Joint agreement (for regular visits**) - How often do we meet? How long do the meetings last? Please agree on how you notify each other of any cancellation of an agreed visit, e.g. due to illness.
- **Operational principles** - Remember the principles of voluntary activity!
- **Introduction** - Tell about yourself and ask the client to tell about themselves too. Getting to know a new person requires time and patience. Openness and kindness bring security and create a successful relationship with the client. If necessary, take some time to, together with the client, familiarise yourself with any assistive equipment the client uses.

Interaction is influenced by personal chemistry, roles, time, environment and life experiences.

In a good interaction you respect the other person and accept differences.

It's a good idea to share your feelings and wishes to avoid misunderstandings.

Excerpt from the Lupa palvella (Permission to Serve) blog: how do we treat a disabled client?

"A friend of mine gave an impulse for a discussion on Facebook today about what it is like to be a healthcare client sitting in a wheelchair. It was a new experience to my friend, as he only used the wheelchair temporarily. Yet, he felt that he himself was ignored, that things happened over and past him. The conversation was not directed at him, but at the assistant.

The discussion thread accumulated other similar experiences. On top of everything, it was stated that ultimately you don't even have to be disabled. It is enough to be a short person, even then you are easily ignored. That's something I have first-hand experience of, too. But despite being only 156 centimetres tall, luckily, I have a strong voice. And I am quite good at standing high jump...

That discussion made me reflect on how difficult it is for most of us to meet a disabled client and it does not seem to come naturally. However, I do not want to believe that this is a case of deliberate rudeness or indifference. More like a lack of understanding. We do not know any disabled people and do not realise that, for example, a physical disability does not mean that the person also has a problem with comprehension. Or if the speech is slow, it doesn't mean that the person is slow. Nor that he can't hear.

Probably the most difficult thing for us, is how to interact with an intellectually disabled person. At least that's what I think. It is difficult to know how much the other person understands and how to make oneself understood. That's why it's easier to behave like you don't notice the person at all. And if you don't notice, you can't help, can you?"

Translated excerpt from Merja Heinonen's blog: https://lupapalvella.blogspot.com/ (in Finnish)

To consider:

Do I have prejudices?

To consider:

What can I, as an assistant, do to improve the meeting with a client?

To consider:

What thoughts does the blog raise?

3.2 DEALING WITH DIVERSITY

Is diversity exaggerated - after all, are we not all the same?
And is similarity a virtue - or should we rather emphasise the acceptance of diversity?

When dealing with diversity, **prejudices and stereotypes** become of primary importance.

- **Prejudices =** ***presupposing, often unfounded***
- **Stereotypes =** ***schematic and simplified generalisation***

In order to be able to meet a person, we must give up the automatic categorisation of people we do through prejudices and stereotypes. Especially in situations where we don't see people as individuals but as representatives of a group – these categorisations become harmful.

DEALING WITH A CLIENT

- **The client is always the expert of their own life**: don't be ashamed or shy if there is something you don't know. Ask the client for instructions on how to assist.
- **Listen, make no hurry**: rushing and impatience won't help you move forward, even if you are in a hurry. By calming yourself down in new situations, you are able to look at them objectively.
- **Don't over-help, making the client helpless**: let the client do as much as possible themselves, it can be important for their rehabilitation. However, do not become a therapist who demands things of them, citing their rehabilitation, that is not your role as a volunteer.
- **Assist, do not patronise**: it is not the job of an assistant to think for the client and to guide/patronise them during the task. Remember to respect self-determination in all situations!
- **Confidentiality:** the things that happen during the assignment stay between you and the client.
- **Body language:** we can communicate a lot with our gestures. Let's keep a positive body language!
- **Smile, touch, eye contact:** important, small elements that create a positive connection.
- **Using the name**: the clients are not our patients, they are personalities with a name.

OUR CLIENTS FACE MANY CHALLENGES, make sure you are not one of them

- An elderly person is seen only as the object of help, not as someone who can give something, despite their extensive life experience.
- At the service counters people talk to the assistant, past the disabled person, even though the client is right in front of them.
- People with intellectual disabilities are often described as “easy-going, open, cheerful, straightforward” etc. But is that diminishing when the description is raised as the prevailing trait?
- "Will I be seen beyond my diagnosis?" Meet the client as a person, not as a diagnosis. It is not always in the client's interest that you satisfy your thirst for information with a question.
- As a human gets older, some people automatically see them as deaf, blind, forgetful, intellectually slow, and this elderly person’s needs are no longer a priority. We all get older – treat elderly people in the same way as you want to be treated!

To consider:

How do stereotypes and prejudices appear in everyday life?

3.3 ASSISTING THE CLIENT

- **The client often knows best how to be helped in the best way**
  So take time to talk to the client (how is the person able to help themself, etc.)

- **Important to use common sense and a calm attitude**
  Consider the purpose of the move, know your own resources and skills.

- **Use assistive equipment**
  Learn how to use and familiarise yourself with the client's assistive equipment. It will take some time to learn, but over time they speed up the tasks and give both of you a sense of safety.

- **Fix the environment, remove the hazards**
  Remove loose items, the floor must be dry and non-slip, be aware of your own hanging scarves, blouse edges, etc. Make sure that you are positioned close enough to where the client shall be moved and that they are in the correct position, e.g. with a wheelchair. Remember the brakes!

- **Ask for help if possible or if you need it**
  However, always consult first with the client.

- **Tell the client what you're doing at any given time**

- **Don't grab hold of clothes when lifting**
  They might stretch, tear and get out of position > correcting them can be difficult. Lifting by the clothes is also uncomfortable for the client.

- **Take care of your client also after the move!**
  Do not let go of your client until you are sure that the client can keep the balance and will remain in place. Make sure that the limbs and head are in a good position and correct the clothes if they have twisted badly. Make sure that the position of the person is good, especially for clients who are unable to correct their position themselves.

- **Experience makes you a pro!**
  It is always exciting the first few times, and you may feel clumsy, but the more often you do it, the better you get and the lifting gets easier.

3.4 MOBILITY AIDS

Mobility aids are intended for persons whose functional capacity is limited due to disability, illness, ageing or developmental disorders. Mobility aids help a person to manage independently both at home and outside, as well as prevent functional capacity from becoming impaired.

Manual wheelchair

- So-called ordinary wheelchair
- can be pushed from the rear by the assistant or self-propelled
- can be disassembled, assembled
- weight about 8 kg
- can be lifted
- can pass over obstacles and on stairs
- brakes to be locked (not 100% grip)
- beware of obstacles, potholes, bumps, etc. If you are pushing a wheelchair, you must be observant about where and how you go!
- use the safety-belt, if the client has one!

Electric wheelchair

- rechargeable batteries, self-controlled
- cannot be pushed (can be put into “neutral” and pushed a small distance)
- cannot be disassembled
- weight about 50 kg
- cannot be lifted/height adjusted
- can only handle obstacles smaller than its ground clearance, cannot be driven on stairs (requires a ramp)
- no separate brakes (power off > brakes "on")
- observe the use of the seat belt if the client has one!

Wheel walker

- popular support for walking
- usually four wheels, brakes (not 100% grip), a built-in seat and often also a basket for small items
- agile and easy to move around, almost all models can be disassembled/assembled
- big wheels that make it easy to pass obstacles

Note!

Take some time, together with the client, to familiarise yourself with any assistive equipment the client uses!

More information about mobility aids: www.invalidiliitto.fi (in Finnish)

Assisting a user of a manual wheelchair https://www.youtube.com/watch?v=Q2gNfCOsuaU (00:02.04) in Finnish

Getting around in an electric wheelchair https://www.youtube.com/watch?v=ZZudxE_EqTs a car (00:02:08) in Finnish

Using a wheel walker https://www.youtube.com/watch?v=BL0Ez2fNd3A (00:02:34) in Finnish

Assembling a manual wheelchair and its parts https://www.youtube.com/watch?v=MSfIctX-7FY (00:02:19) in Finnish

Mobility scooters https://www.youtube.com/watch?v=dLf7t8RH_3o (00:01:31) in Finnish

3.5 GUIDING

- the client often knows best how to to be guided, so ask!
- usually the assistant offers the arm, which the client can hold on to. Let's not drag or "carry" the client
- the speed depends on the client, does not necessarily mean you have to slow down, but keep a normal walking pace
- make sure your balance is good all the time and look where you step so you don’t lose your balance

3.6 ASSISTING WITH DINING

- we do it together!
- eating habits
- good eating position
- no hurry

Self feeding client:

- the necessary aids and food in the right places
- assist the client if necessary
- tell a visually impaired person where the different dishes are located on the plate (clock face)

Client that must be fed:

- eating at everyone's own pace
- mouthfuls of suitable size
- cleanliness
- allowing enough time
- talk as little as possible to prevent food from getting cold
- agree on the order in which food is eaten
- do not mix the dish ingredients

The ASSISTANT eats either at the same time as the client or only after the client is ready.

Notes:

3.7 MEANS OF COMMUNICATION

The functional limitation of the speech impaired is set by the environment!

- We are used to words conveying information and non-verbal communication attitudes. How does a person communicate for whom one or both abilities are disturbed!?
- The time from thought to audible speech is quite long and complicated and therefore easily vulnerable.
- There are many causes of speech impairment
- Speech is only part of linguistic activity
- As our language develops, we adopt knowledge of the language character system and its system of rules
- With our own example, we can shape the environment

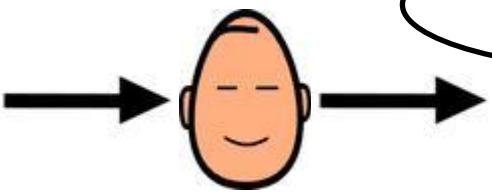
Blissymbolics

Sheep

Pictogram, pictures

Good morning!

Sig symbols



"in one ear and out the other"

WLS Image Library

Spider

Sing language image

Family

NILBILD Image Bank

Cinnamon roll

SUPPORT FOR COMMUNICATION:

- listen
- repeat and ensure
- ask
- calm the situation (yourself, the other person and the environment)
- simplify and concretise

Direct communication systems:

- showing
- gestures and expressions
- sign language
- signed speech
- simplified sign systems

Systems that require an aid:

- drawing and writing
- pictures
- speech interpreter
- objects
- plain language
- image symbols
- alphabetic and word boards
- Blissymbolics

Technical communication tools:

- printers
- devices with prerecorded messages
- computer programs and systems
- switches, head pointers, headlights, etc.

Notes:

More information: www.papunet.net (in Finnish)

Tips for interacting with a person with a speech impairment on the Paputuubi YouTube channel:

https://www.youtube.com/user/paputuubi (in Finnish)

4 GROUPS OF INJURIES AND DISABILITIES

4.1 BRAIN INJURY

Brain injury is caused by an external impact, kinetic energy on the head or an object penetrating the brain. The majority of brain injuries are caused by falling down and tripping over, traffic accidents or assaults. About 36,000 people suffer from brain injuries every year. Brain injuries are divided into three categories: mild, medium and severe brain injuries.

A brain injury causes both physical and psychological harm. The consequences of the injury depend on the injury mechanism, the severity of the injury and the location and extent of the affected area.

Brain injury can e.g. cause

- memory difficulties
- concentration and attention deficit disorders
- speech disorders
- slow detection and processing of data
- lack of initiative
- fatigue
- difficulties in planning
- various behavioural disorders
- changes related to moods, emotional reactions and personality
- various physical symptoms: headache, epilepsy, field of vision disorders
- symptoms of paralysis

Because the numerous changes caused by a brain injury may occur together or separately at various degrees, they can have long-term effects preventing an independent life.

A person with a brain injury can recover well from their physical injuries, but other inconveniences can constantly complicate everyday life. The injured cannot cope as before with work, hobbies and social relationships. The whole life situation of a person with a brain injury and their family will change.

Source and more information: www.aivovammaliitto.fi/ (in Finnish)

www.terveyskyla.fi/aivotalo/aivosairaudet/aivovammat (in Finnish)

4.2 CEREBROVASCULAR DISORDER

Cerebrovascular disease or stroke is a common name for blood-vessel conditions in the brain.

cerebrovascular disorder causes brain dysfunction

brain dysfunction can also be caused by a brain injury, brain tumour or encephalitis

An important cause of cerebrovascular embolism is hardening and blocking of arterial veins. Blockage in a cramped vein prevents blood circulation, leaving a certain area of tissue without oxygen. The neurons in the brain need a continual supply of oxygen, otherwise they are permanently damaged in a short time. We talk about *cerebral infarction.*

In a *cerebral haemorrhage*, the arterial vein ruptures, causing either blood to leak into the brain matter (ICH) or a subarachnoid hemorrhage (SAH). SAH most often causes a rupture of the congenital aneurysm of an artery on the surface of the brain. The leaked blood is gradually absorbed out of the brain, but the bleeding, however, causes tissue damage.

The brain controls human activity. Therefore, the tissue damage caused by cerebrovascular disorder in many ways affects the physical, mental and social function of the patient. The consequences are always individual depending on the location and extent of the damaged area. Cerebrovascular disorder can cause permanent or transient paralysis symptoms of the body, disturbances in linguistic functions and other mental performance.

A person who has had a stroke often has difficulties in everyday life with:

- mobility
- eating
- dressing and taking care of hygiene
- creating and maintaining social relationships

There are approximately *100,000 people in Finland* suffering from cerebrovascular disorders. Approximately 15,000 Finns get a cerebral infarction each year and about 4,000 Finns a cerebral haemorrhage. Cerebrovascular disorder is also the third leading cause of death.

Notes:

4.3 APHASIA

Aphasia refers to a linguistic impairment that can occur in different ways. A person suffering from aphasia can have difficulties to create and understand speech, as well as to read and write. Despite the linguistic impairment, the person's intelligence and thinking are often normal.

Aphasia is caused by a damaged or dysfunctional brain tissue, which is usually located in the left hemisphere of the brain. The most common cause of brain damage is a cerebrovascular disorder; cerebral infarction or cerebral haemorrhage. Brain injuries and brain tumours can also cause aphasia.

Source and more information: https://www.aivoliitto.fi/english/, www.aivoliitto.fi/afasia in Finnish

Still being Matias https://www.youtube.com/watch?v=IiriB02Eq4Q&list=PLVEIb6gzvbak-thFX30t2gTOuyAtOvSAbu&index=5 – video of aphasia (00:03:03) in Finnish

Notes:

4.4 CEREBRAL PALSY

Cerebral palsy or CP injury is caused *by permanent damage to the brain of the foetus or small child*. The damage is in the area of the brain that regulates movement and that makes it difficult to take and maintain a position, as well as perform voluntary movements. The injury is permanent, but its symptoms range from minor dysfunction to severe physical disability. In Finland , approximately *100–120 children are diagnosed with a CP injury every year*.

The causes of CP injury are divided into:

- pregnancy related causes
- neonatal causes
- early infancy

Functional defects related to cerebral palsy:

- one-sided muscle tone (hemiplegia)
- difficulty using the feet (diplegia)
- functional defects in hands and feet (tetraplegia)
- low muscle tone (athetosis)
- motor skills disturbance (ataxia)

There may also be secondary symptoms related to a CP injury (e.g. neurological problems):

- sensation problems (affecting vision and hearing)
- rendering disorders (perception difficulties)
- sensory impairments (sensation disturbances, sensory defensiveness or hypersensitiveness handled by the central nervous system)
- hyperacusis or sound sensitivity (central nervous system caused hypersensitivity to sounds)
- tactile hypersensitivity (tactile hypersensitivity, does not like contact)
- posture, senses of motion and balance (difficult to correct and maintain posture)
- speech ambiguity and numb speech communication (dysfunction in the muscles involved in speech production)
- epilepsy

Although the brain damage causing a CP injury is not progressive by nature, the symptoms of a CP injury change as a person grows, develops and gets older. To maintain functional capacity, people with CP disabilities need multi-professional rehabilitation throughout life.

A CP injury should not be confused with intellectual developmental disability. Sometimes a CP injury can be associated with learning difficulties or intellectual developmental disorders, but more common secondary symptoms of a CP injury include visual and auditory damage and sensory hypersensitivity.

Source and more information: www.cp.liitto.fi (in Finnish)

Disability does not prevent you from dreaming http://yle.fi/elavaarkisto/artikkelit/vammaisuus_ei_esta_unelmia_36628.html#media=36633– video (00:28:00) (in Finnish)

4.5 INTELLECTUAL DISABILITIES

It is estimated that there are approximately 50,000 people with intellectual disabilities in Finland. The injury can be caused either by prenatal causes, damage during childbirth or childhood illnesses and accidents. An intellectual disability occurs before the age of 18.

Intellectual disability means having difficulty to learn and understand new things. However, people with intellectual disabilities learn many things in the same way as others. The impact of intellectual disability on an individual's life varies greatly. The intellectual disability can be mild, in which case the person can manage quite independently and only need support in some areas of life. A person with severe intellectual disabilities needs constant support.

Intelligence is only part of the human personality. Upbringing, life experiences, learning and environment affect development and consequently the kind of people we grow into. People with intellectual disabilities can live as equal members of society, but they need support, guidance and services. Individual, necessary support helps people with intellectual disabilities to live a good independent life that is natural to them.

Necessary support, guidance and service may be related to:

- communication
- self-motivation
- housekeeping
- social skills
- moving around in the environment
- health
- security
- literary skills
- leisure time
- work

The degree of intellectual disability ranges from severe disability to mild learning difficulties. Many people with intellectual disabilities have additional disabilities that may make it difficult to move, talk or interact with other people.

Regardless of the degree of intellectual disability, people have the right to make their own choices and live self-motivated lives, as well as partake in the availability of accessible services. Regardless of the disability, everyone also has the right to act in various social roles – as employees, citizens and local residents, members of an association or hobby group, users and developers of services, customers and voters.

Source and more information: www.kehitysvammaliitto.fi/in-english/, https://www.tukiliitto.fi/etusivu/english/

Meeting people with intellectual disabilities http://www.youtube.com/watch?v=ntA8qtO2Gl0 – video (00:03:05), in Finnish

4.6 MUSCLE DISEASES

Muscle diseases are rare neurological disorders characterized *by a progressive deterioration of the voluntary muscles*. A muscle disease can occur already in a newborn or only later in childhood, adolescence or as an adult. Even the same diagnosis can be different in severity, even for members of the same family, varying from slight functional defects to severe disability.

According to current estimates, *there are approximately 20,000 people* in Finland with some kind of muscle disease. One diagnosis group usually consists of a few to ten to a few hundred people. No cure has yet been found for muscle diseases.

In muscle-related diseases, the cause of the disease is in the muscle cell itself and its function. The cause may also be malfunctioning motor or peripheral nerve cells or neuromuscular junction. In this case, it is a functional or cooperation disorder between the nervous system and muscles, in which case the disease is called a neuromuscular disorder. Most muscle diseases are hereditary and often progressive.

Muscle diseases affect mobility. The treatment is exercise and physiotherapy, sometimes also medication. Mobility aids make life easier for people with muscle diseases.

Source and more information: www.lihastautiliitto.fi/the-finnish-neuromuscular-disorders-association-2/

Meeting a person with muscle disease http://www.youtube.com/watch?v=IQLnsUv_QX0 – video (00:03:05) in Finnish

4.7 MYASTHENIA GRAVIS (MG)

Myasthenia gravis is a disease in which antibodies destroy the communication between nerves and muscle, with the most common symptom being weakness of the skeletal muscles worsened as muscles are used and eased when resting. The cause of the disease is unknown.

The disease affects the muscles of the eye area (drooping eyelids), weakness of the mouth and throat area (trouble pronouncing words and swallowing) and later possibly the muscles of the limbs and body.

Most people with the disease can lead normal lives with little or no symptoms. *There are approximately 1,700 people with myasthenia gravis* (i.e. MG patients) in Finland.

Source and more information: www.lihastautiliitto.fi, www.suomenmg-yhdistys.fi (in Finnish)

4.8 MULTIPLE SCLEROSIS (MS)

Multiple sclerosis is a disease of the central nervous system, i.e. the brain and spinal cord. The immune defence of a person with MS functions incorrectly and causes damage primarily to the myelin of the central nervous system. Myelin is a substance that surrounds the nerve cell axons and allows electrical impulses to transmit more quickly and efficiently along the nerve cells. MS symptoms are caused by a damaged myelin sheath, which slows down or stops the nerve impulse from the brain and spinal cord to the rest of the body.

The progress of MS differs from one person to another. At first, MS progresses in waves. The disease involves both worse periods and sometimes it can be symptomless for a long time. Multiple sclerosis is not inherited.

Symptoms of multiple sclerosis:

- visual and eye symptoms
- changes in the sense of touch
- fatigue
- difficulties in moving
- difficulties with memory and concentration
- affective problems
- problems with bladder and bowel movement
- pain

MS and many rare diseases are diverse in both their symptoms and progression. *Approximately 12,000 people are suffering from MS in Finland.*

Source and more information: www.neuroliitto.fi/neuroliitto/briefly-in-english/

Pala palalta-eväitä elämään http://www.youtube.com/watch?v=1gjYvF533mw life – video,

A joint video about the lives of the neurological disability organisations (00:35:00) in Finnish

Notes:

4.9 MEMORY DISORDERS

Progressive *memory disorders degenerate the brain and widely weaken the ability to function.* Memory disorders are mainly diseases affecting older people. In Finland, approximately 150,000 people have some form of memory disorder, of whom 2,700 are of working age. Each year there are 23,000 new cases of memory disorders.

Memory is affected by many factors, both short-term and long-term. For example, stress or fatigue can impair memory and concentration, but when stress eases off and after a good night's sleep, memory works normally again.

Progressive memory disorders include: *Alzheimer's disease, memory disorder associated with cerebrovascular disease, Lewy Body disease and other causes.* Most progressive memory disorders are caused by non-hereditary factors. The risk factors are related to the environment and lifestyle, and many of them are still unknown.

The individual progression and symptoms of a memory disorder are affected by, among other things:

- The personality of the person who suffers from a memory disorder and the life lived with all its experiences, emotions and habits
- The diagnosis and severity of a memory disorder (each affects the brain at different points and in different ways)
- Pain, low blood pressure, fatigue or other discomfort
- The (negative) attitude of another person towards the sick person
- Challenges in adapting to the disease
- Sense of security, number of stimuli and calmness/restlessness of the environment, and
- Treatment and rehabilitation matching the individual needs.

There are a number of symptoms associated with memory disorders. Some of the symptoms are typical of almost all memory disorders. The most well-known symptom is a decline in memory and other cognitive functions (i.e. information processing).

The symptoms of the disease are related, for example, *to the ability to understand the information that the senses provide as well as to cognitive functions, such as remembering, communicating and logical thinking.* The disease can also bring *difficulties in identifying places or remembering where you are going. To concentrate and perceive places, time and objects can become more difficult.*

Interaction with a person with a memory disorder:

- Speak normally and calmly, pay attention by e.g. touching the hand
- Use familiar words
- Ask or pass one thing at a time
- Give the person time to answer you.
- Pay attention to the person’s strengths, not problems
- Avoid DO NOT expressions, give positive instructions.
- Avoid unnecessary questions (no "memory testing")
- Use the first name, it supports self-image preservation
- Illustrate your speech by showing what you mean
- Remember the importance of body language and eye contact
- Try to minimise unnecessary distractions

Source and more information: www.muistiliitto.fi/en/homepage/ https://www.muistiturku.fi/fi/muisti-luotsi/ (in Finnish)

Meeting a person with a memory disorder https://www.youtube.com/watch?v=1SkC34OuiN0 – video (00:06:13) in Finnish

4.10 VISUAL IMPAIRMENT

There are approximately 80,000 visually impaired people in Finland, but only 10,000 of them are blind. Not all visually impaired people use a white cane or guide dog, so visual impairment may not be visible on the outside. Some visually impaired people wear the visually impaired sign.

Visual impairment is defined as a person with a visual acuity of the better eye of less than 0.3 corrected with glasses and blind if the visual acuity of the better eye is less than 0.05 corrected with glasses or the vision field diameter has decreased below 20 degrees, or if the functional vision has deteriorated for any other reason in the same way.

A visually impaired person can have poor eyesight or be blind. A person whose vision can be corrected to normal with glasses or if one eye has normal sight is not classified as visually impaired.

Visually impaired people can see in different ways: one person cannot read, but is able to move around without a white cane, another is able to read with the help of the remaining accurate vision, but cannot see their surroundings. Poor eyesight is also often associated with night blindness and extreme light sensitivity.

Total blindness is not very common. Blind people can see light and even shapes. Functionally blind is defined as a person who has lost, among other things, locomotor vision in a foreign environment and reading vision in the normal sense, but may be able to read using special aids such as TV magnifier reading aid.

The most common eye diseases are:

- macular degeneration (damaged sharp and central vision)
- diabetes (decreased visual acuity, vision field changes, reduced contrast and colour vision)
- retinitis diseases (narrowing the vision field, night blindness)
- glaucoma (functional sight disturbance)
- optic nerve and visual pathway defects (low visual acuity, reduced vision fields, anomalous colour vision)

Visual impairments are also caused by e.g.:

- occupational accidents and infections (decreased)
- congenital developmental disorders and optic nerve system defects in children

The most common practical problems caused by visual impairment are problems related to mobility, doing errands and conceptualising the environment:

- orientation
- estimating distances
- detecting level differences
- defective colour vision
- night blindness
- light sensitivity
- defective vision field
- inability to adapt to changes in the lighting level
- tripping, falling or colliding
- inability to identify people by appearance
- difficulty in detecting expressions and gestures
- noticing and responding to eye contact is often impossible

When meeting a visually impaired...

- ask "Can I help you?" or "Do you need help?"
- if you are in a crowd, touch the visually impaired lightly on the arm so that the person knows you are talking to them.
- speak to the visually impaired person, not the guide dog
- use precise expressions such as to the right, to the left, etc. when advising
- while guiding, offer the visually impaired person your forearm and take the lead
- say hello in words don't just nod or wave your hand
- tell the visually impaired person your name even if you know them
- use the visually impaired person’s name when addressing
- before you leave, tell the visually impaired person that you are leaving so your companion knows that you've left
- explain what food is on the plate. The watch face illustrates the directions, for example, potatoes at six o'clock, salad at three o'clock, etc.
- when you put money in the person’s hand, start with the coins and then give the notes

Source and more information: www.nakovammaistenliitto.fi/en

Meeting the client with respect

http://www.youtube.com/watch?v=aFaRfMQBpLw – video, sokeat (00:04:00), in Finnish

Half a step ahead - guiding

https://www.youtube.com/watch?v=Yggeg1FWs9U – video (00:04:01), in Finnish

How can I help? Meeting a visually impaired person https://www.youtube.com/watch?v=a1zUR-gkkU38 – video (00:03:51), in Finnish

Notes:

4.11 PARKINSON'S DISEASE

There is currently no cure for Parkinson's disease, which is a *normally slowly progressive neurological condition*. Parkinson's develops when cells in the brain stop working properly and are lost over time. These cells control movement. The symptoms are caused by loss of cells in the black nucleus of the brain and resulting in a reduced production of dopamine. The loss of nerve cells is progressive and, for the time being, cannot be stopped by any treatment. Symptoms are treated with medication and rehabilitation.

In Finland, there are approximately 16,000 people living with Parkinson's disease. Most people with Parkinson's start to develop symptoms at the age of both sides of 60 on average. Developing the disease under the age of 30 is rare, although possible. There is no clear gender difference.

Symptoms of Parkinson's disease include:

- resting tremor, muscle stiffness
- slowness of movement
- balance problems
- various autonomic nervous system disorders (e.g. skin fatty degeneration, excessive sweating, constipation and problems with peeing)
- problems with intellectual functions and emotional disorders (e.g. increased emotional sensitivity, tendency to depression, impaired initiative and slowing down of thoughts)

Exercise is very important to maintaining functional capacity. It is especially important for people with Parkinson's disease.

Source and more information: www.liikehairio.fi/en

What is Parkinson's disease? https://www.youtube.com/watch?v=SkrTypWOvf8 – video (00:03:13), in Finnish

Notes:

4.12 Polio

Poliovirus is an enterovirus belonging to the picornaviruses. In the past, a poliovirus infection could be transmitted by inhalation or orally, from where the virus travelled to the digestive system and thrived there for several weeks. Infected people experienced flu-like symptoms such as a fever, a sore throat, nausea, aching muscles and fatigue. If the virus attacked the central nervous system, it caused encephalitis, damaged the muscle nerve cells and caused damage to the spinal bulb.

It took weeks to recover from the illness and years of rehabilitation. Eventually, the human organism adapted and the remaining muscle nerve cells partially took on the load of the lost cells. The muscle nerve cell fibres began to swell so that they could handle the tasks of nerve cells lost to the disease. Some of those with polio recovered fully at that time, others were left with significant damage. *In Finland, the number of people infected with polio is estimated between 4,000 and 6,000. Nowadays, polio has almost completely disappeared from Finland thanks to vaccinations.*

Post-polio syndrome

Decades later, the large size and strain of the muscle nerve cells, as well as damage to the spinal bulb, cause symptoms to return. Someone who has had polio in the past, but did not suffer from paralysis, might develop symptoms again. This is known as *post-polio syndrome or the sequelae of polio, which implies how important it is to pay attention to exercise and rest within the limits of one's own coping.*

Symptoms of post-polio syndrome include:

- fatigue
- muscle weakness
- muscle cramps
- the stiffness of muscle function
- breathing difficulties
- sleep apnoea
- swelling of the lower limbs, blueness
- pain
- swallowing problems and problems with voice and speech
- difficulty urinating
- balance problems
- sensory disturbances (hypersensitivity)
- temperature control problems
- declined feeling of thirst
- weakening of the regulation of the cardiovascular system

In addition, becoming disabled by polio infection may in due time cause other problems such as:

- osteoarthritis due to uneven load
- osteoporosis caused by muscle weakness
- damage caused by tendon and muscle overload

There is no medicine for post-polio/polio sequelae. The most important treatments are adapting exercise and rest to your own muscular strength, as well as healthy lifestyles (e.g. physiotherapy, occupational therapy and painkillers).

Source and more information: www.polioliitto.fi (in Finnish)

Simo Lampinen - Getting polio https://www.youtube.com/watch?v=JbUtaYQvkvM – video interview (00:04:33), in Finnish

Simo Lampinen – Rally champion https://www.youtube.com/watch?v=BwgXxj9jy6I&feature=youtu.be – video interview (00:06:04), in Finnish

Notes:

4.13 RHEUMATISM

Rheumatic diseases include *musculoskeletal disorders* and conditions that are very different in terms of symptoms and effects. They can be mild and quickly transient, but sometimes also have severe symptoms.

Rheumatic diseases can be divided into inflammatory and non-inflammatory diseases. The inflammatory type includes rheumatoid arthritis (approximately *45,000 adults in Finland* suffer from rheumatoid arthritis), juvenile idiopathic arthritis, ankylosing spondylitis, arthritis and psoriatic arthritis and gout, arthritis caused by virus, bacteria or other microbes, systemic connective tissue diseases and vasculitis. The non-inflammatory type include degenerative diseases, rheumatic symptoms associated with hormonal or metabolic diseases, and soft tissue diseases.

Most rheumatic diseases are autoimmune diseases, which means that something triggers a long-term activation of the immunological system in a person prone to genetic diseases. The resulting inflammatory reaction is that your immune system attacks the cells that line your joints by mistake, mostly causing various symptoms of musculoskeletal disorders.

The most common symptoms of rheumatic diseases are:

- pain in the musculoskeletal system caused by the inflammatory reaction
- stiffness, inflammation, swelling or degenerated functionality
- warmth, redness and swelling in the lining of joints
- joints can also feel stiff and sore, as well as tender to move and touch

Source and more information: https://reumaliitto.fi/en/

Notes:

4.14 SPINAL CORD INJURY

A spinal cord injury after an accident often changes the life of the person and his loved ones in the blink of an eye. In addition to physical injuries, the situation is also tough for the patient's psyche. Concentrating treatment and rehabilitation in competent hands benefits the patient.

A spinal cord injury patient is usually quite young: the average age is 39 years. Nearly 80 per cent of those disabled are men. *Approximately 200-300 Finns* suffer a spinal cord injury each year as a result of an accident. Spinal cord injuries may be caused by, for example, traffic accidents, falling, the result of several illnesses or diving accidents. Almost half of damage to the spinal cord is in the neck area. In this case, both arms and legs are paralysed. We talk about tetraplegia. In an accident, the patient often suffers injuries other than those to the spinal cord.

The ability to get into a wheelchair or an upright position depends not only on the patient's general condition, but also on their other injuries and the way in which the fracture has been repaired. A person with a spinal cord injury must practice turning in bed, getting up to sit and moving into a wheelchair. In such cases it is important to train strength and endurance.

Approximately one in ten patients will later be able to walk without aids, and a quarter will move with the help of various lower limb supports and forearm crutches or walking sticks. Half of the injured use a manual wheelchair as their main exercise tool, and one in ten use an electric wheelchair. Most people with spinal cord injuries are able to drive a car with special equipment. Eating, freshening up, reading and writing, using media and electronics, housekeeping and cooking may require assistive devices.

A person with a spinal cord injury needs follow-up and rehabilitation throughout life. Everyone is encouraged to move around and exercise also at home. Years of wheelchair use can cause occasional really difficult strain problems in the hands and upper arms. Finding the right sitting position and adjusting the wheelchair to fit the patient are an important part of the patient's care. A person sitting in a wheelchair can do a variety of work.

Source and more information: www.aksonry.fi/in-english/

Notes:

4.15 MUSCULOSKELETAL DISORDERS

The human musculoskeletal system comprises bones, joints, ligaments, muscles and tendons. Bones support our body, which is moved by muscles and tendons. *More than one million Finns have a long-term musculoskeletal disease*, that limits their ability to function.

The most common musculoskeletal disorders are:

- joint diseases
    - rheumatoid arthritis
    - osteoarthritis
- osteoporosis
- spinal diseases
- troubles with the neck and shoulder
- fractures and accidents
- other musculoskeletal disorders

Maintaining musculoskeletal health can best be influenced by lifestyles that not only support musculoskeletal health, but also prevent the emergence or progression of problems and diseases that arise from them.

Source and more information: www.suomentule.fi (in Finnish), www.reumaliitto.fi/en/

Notes:

5 ADAPTED PHYSICAL ACTIVITY (EXERCISE FOR GROUPS WITH SPECIAL NEEDS)

The Act on the Promotion of Sports and Physical Activity requires that basic services and conditions for physical activity are created equally for all residents of a municipality.

Target groups for adapted physical activity:

- disabled, children with chronic diseases and adults
- elderly people with poor physical ability who are unable to participate in the physical activities of fit pensioners

Adapted physical activity refers to:

- the physical activities of persons who, due to a *disability, illness or other decreased ability to function or social situation, find it difficult to participate in commonly available exercise forms*. In these situations, physical activity requires adaptation and special expertise. (definition of the Committee report 1996).

Operational Objectives:

- improving and maintaining health and ability to function
- maintaining and improving physical condition
- learning basic skills of physical activity and knowing your own capacity and possibilities to physical activity
- exercising regularly

Social Objectives:

- taking other people into account and being able to work together
- adding peer contacts
- accepting support and encouragement from other people

Emotional objectives:

- experiencing success
- self-confidence
- joy and recreation
- motivation, i.e. feeling that physical activity is important

Informational Objectives:

- learning to know the structure and function of the body
- knowing your own disability or illness
- the effect of physical activity
- being aware of suitable forms of physical activity and possibilities for leisure time activities

More information: www.sportscience.fi/adapted-physical-activity/what-is-apa.html

6 DISABILITY SERVICES AND PAID ACTIVITIES

6.1 DISABILITY SERVICES ACT AND DISABILITY SERVICES

- **Key legislation related to disability services includes:**
  - Social Welfare Act (1301/2014)
  - Disability Services Act (675/2023)
  - Act on Special Care for People with Intellectual Disabilities (519/1977) (during the transitional period until needs are met under the new Act)

- **Disability Services Act (675/2023):**
  - The purpose of the Act is to ensure that persons with disabilities have equal opportunities to participate in society and to live on an equal basis with others, to promote inclusion and self-determination, and to prevent and remove barriers and disadvantages caused by disability.

- **Definition of a person with a disability (675/2023, Section 2):**
  - A person who has long-term functional limitations due to a disability or illness and who repeatedly or continuously needs assistance or support to manage everyday activities, and who does not receive sufficient support under other legislation.
  - The new Act no longer classifies individuals as “disabled” or “severely disabled”; instead, the need for services and support measures is assessed individually and in relation to the person's need for assistance, support, or service

- **Assessment is carried out on a multidisciplinary basis:**
  - Functional capacity assessment may include statements from a physician and other experts
  - Service needs assessment is carried out in cooperation with the individual

- **Key services under the Disability Services Act (subjective rights or based on assessed need):**
  - Personal assistance
  - Transport services
  - Support for housing (including supported living)
  - Daytime activities
  - Home modifications and equipment provided for the home
  - Interpretation services for sign language, speech recognition methods, or other communication
  - Coaching and support during life changes and in managing everyday life
  - Support for children’s development and participation
  - The right to a personal service plan, the preparation of which is the responsibility of the wellbeing services county

- **Principles guiding the provision of services and support measures:**
  - Individuality and consideration of personal needs
  - Inclusion and independent living
  - Self-determination and freedom of choice
  - Equality and non-discrimination

The wellbeing services county is responsible for organizing disability services. Each person with a disability is provided with an individual service plan that guides the implementation of services.

More information: www.finlex.fi/en, www.stm.fi/en/frontpage

6.2 PERSONAL ASSISTANCE AND EMPLOYER MODEL

Personal assistance is:

- *necessary assistance* provided by another person in matters (in ordinary life), which the person cannot do in part or in whole due to disability or illness
- *a service that enables a person with a disability to live independently, participate in society*, and carry out their own choices
- a service that must be granted to a *person with a disability* who meets the criteria set out in the Disability Services Act

Personal assistance is granted for daily activities, work and studies, hobbies, participation in society, and maintaining social interaction.
The provision of assistance is always based on individual needs, and the person must be able to express what kind of help they need (communication methods may vary).

The employer model is a way of organizing personal assistance in which a person with a disability hires their assistant themselves, and the wellbeing services county reimburses the costs of employing the assistant, as well as other costs resulting from the employer's legal obligations.

There has been a wish to create the employer model in such a way that a disabled person's self-determination, inclusion and own choices are put into practice. Employer obligations are primarily handled by the disabled person, so they also have the rights and obligations of an employer. The employer model provides a great deal of freedom, for example allowing the person to decide more flexibly on the tasks assigned and to choose their own assistant.

More information: www.thl.fi/en/web/handbook-on-disability-services

6.3 PAID ACTIVITIES AT AVUSTAJAKESKUS

Persons who, under the Act on Disability Services and Assistance, have received a decision from the social welfare administration about personal assistance for the care of a close relative during holidays (according to the employer model regarding a support person or substitution), can recruit a suitable personal assistant, support person or holiday stand-in to care for a close relative through, for example, Avustajakeskus.

Avustajakeskus maintains a register of jobseekers and informs them of vacancies and tasks on its website www.avustajakeskus.fi (in Finnish). Avustajakeskus provides guidance, counselling and also additional training and peer support for persons in its register.

In addition to its basic activities, Avustajakeskus provides special services, which require a decision by the municipal social services before being taken into use. These special services are intended for

persons with disabilities who have received a decision on personal assistance according to the employer model.

Supported Employment service:

- Avustajakeskus handles the salary payment to the personal assistant and some of the employer's legal obligations.
- Avustajakeskus's own regional counsellor is there to support and assist in matters related to the employment and problem situations.
- Home visits by the area coordinator at the start of the employment relationship (e.g. work scheduling, employment contract) and whenever needed
- Handling statutory employer obligations with a power of attorney (e.g. payroll). The employer status remains with the person who has received the decision
- Advice and guidance on employment-related matters
- The area coordinator can support the well-being of the employment relationship when needed
- Training is provided and peer support opportunities are offered

7 THE PROCESSES OF THE CENTRE OF ASSISTANCE

7.1 PROCESS FOR VOLUNTARY WORK

You are interested in starting as a volunteer...

- you can participate in the basic training of Avustajakeskus; the course for personal assistants of disabled people or assistant start - the short course in assistance (taking a course is not a prerequisite for starting as a volunteer)
- we agree on a time for a discussion with your own regional counsellor
- together with the regional counsellor we identify which form of volunteering that you are interested in
- we look for a volunteer task that suits you and the time you have available
- we identify the possible need for additional support

You volunteer at Avustajakeskus...

- you can participate in additional training organised by Avustajakeskus and strengthen your skills
- you can get support from your own regional counsellor or from the peer support group in your region
- you get information from your regional counsellor about new volunteering opportunities
- you get login details to the website, where you can see open volunteering vacancies
- you can participate in events of thanks and recreational activities for volunteers
- your regional counsellor will call you once a year
- if you do voluntary work by visiting a client regularly, we always gather information about the visits (the number) at the turn of each year

You want to take a break or stop doing voluntary work...

- tell Avustajakeskus about your intention to quit as soon as possible:
  to our service number or your own regional counsellor

  https://www.youtube.com/watch?v=RHDGVJ7bCt4 Avustajakeskus, Vapaaehtoisavustajaksi -video **(**00:02:51) (in Finnish)

7.2 PROCESS FOR SUPPORTED VOLUNTARY ACTIVITY

If you are not yet sure whether volunteering at Avustajakeskus or volunteering in general is an activity that you want to participate in, we will be happy to help you with your decision. Avustajakeskus supports you in your decision **through the "My Path" service.**

You can take part in the service at any time, you only need to inform Avustajakeskus that you are interested.

The "My Path" service supports you

- support in making the decision on whether or not to engage in volunteering
- assessment interview
- we review rights, obligations and opportunities
- plain language
- guidance into volunteering through the service

Supported voluntary activities, individual support

- fixed-term – the volunteer moves on to basic activities when the time limit expires
- the regional counsellor's accentuated support to the volunteer: guidance of the activity, putting in effort, detailed instructions and reminders etc.
- finding an experienced volunteer for background support to a new volunteer (mentor)

Supported voluntary activity, group support

- voluntary activities in a group assisted by persons supporting in the background, e.g. in events or service accommodation
- tripartite cooperation: Avustajakeskus – background organisation of the supported – background organisation of the receiving client
- groups in Turku and Mynämäki

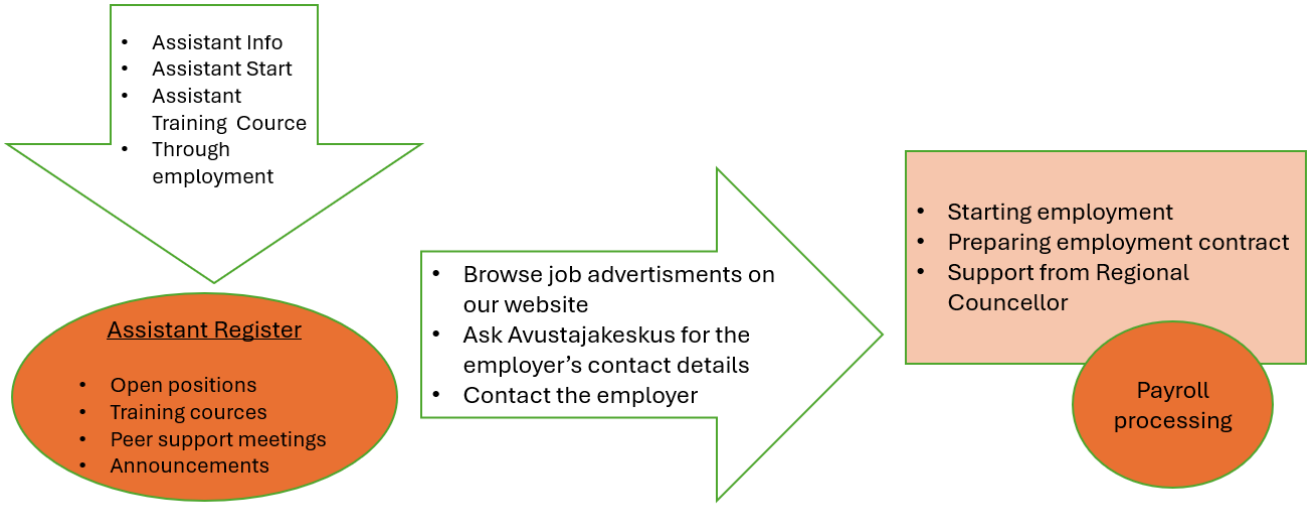
As a volunteer providing background support, it is possible to help a volunteer in need of special support, either in group activities or through individual support. Behind the activities there is the idea of a mentoring model, in which an experienced volunteer from Avustajakeskus shares their knowledge and skills to guide and support a person requiring special support in the assisting tasks.

7.3 PROCESS FOR PAID ACTIVITIES

You are registered at Avustajakeskus...

- via Avustajakeskus you can see the open vacancies for personal assistants (as well as vacancies for stand-ins for caring for close relatives and support persons) and apply for the jobs you want.
- you can participate in additional training organised by Avustajakeskus and strengthen your skills.
- you can get support from you own regional counsellor or from the peer support group in your region.

Your path to employment



https://www.youtube.com/watch?v=fpbFAfwfWQ4 Avustajakeskus, Henkilökohtaiset avustajat (00:02:43) (in Finnish)

http://www.youtube.com/watch?v=e12TyAdFOTk – video avustajan työstä (00:10:00) (in Finnish)

Notes:

7.4 ROUTES TO THE ACTIVITY

Support person

Informal care substitution for holidays

Paid activities

Personal assistant

Do you need support in choosing your own route? Ask us, we will help you choose and guide you forward!

Occasional assignments

Voluntary activity

Group assistance

Regular volunteers

Volunteer background support

Supported voluntary activity

Volunteer requiring additional support

"My Path" service

For consideration:

What kind of route suits you?

8 SPOON THEORY

The Spoon Theory (a theory by Christine Miserandino) describes what life with chronic illness or disability is really like. The theory is most often used in connection with diseases where the symptoms are "invisible", because often people without visible symptoms are described as lazy, inconsistent or as people with poor time management.

The spoons describe the units of energy you can spend during one day. The spoon theory allows you to plan your day so that you have enough spoons for the whole day.

Various everyday activities carried out during the day (e.g. go shopping and working, run errands, hobbies) take up a certain amount of energy per day. The spoons describe this energy. So every day you need to make choices so that you don't run out of spoons. You simply do not have enough energy for everything. The spoon theory helps you understand everyday life and helps you understand what it is like to live with a disability or illness.

Notes:

Source and more information: https://hdsunflower.com/au/insights/post/spoon-theory

9 CONTACT INFORMATION

Telephone: 02 251 8549

avustajakeskus@avustajakeskus.fi

Assistant agency, guidance and counselling, registrations, inquiries about vacancies

MON-THU at 9 am. – 12 am. and at 1 pm. – 3 pm.

Website

www.avustajakeskus.fi

Facebook

www.facebook.com
general homepage: Lounais-Suomen Avustajakeskus
closed group: Lounais-Suomen Avustajakeskus Avustajat

Instagram

www.instagram.com
Lounais-Suomen Avustajakeskus

YouTube

www.youtube.com
Lounais-Suomen Avustajakeskus

WA-communities

for coordinating volunteer activities and job opportunities.
For further information contact your regional councellor

COOPERATION OVER THE BORDERS