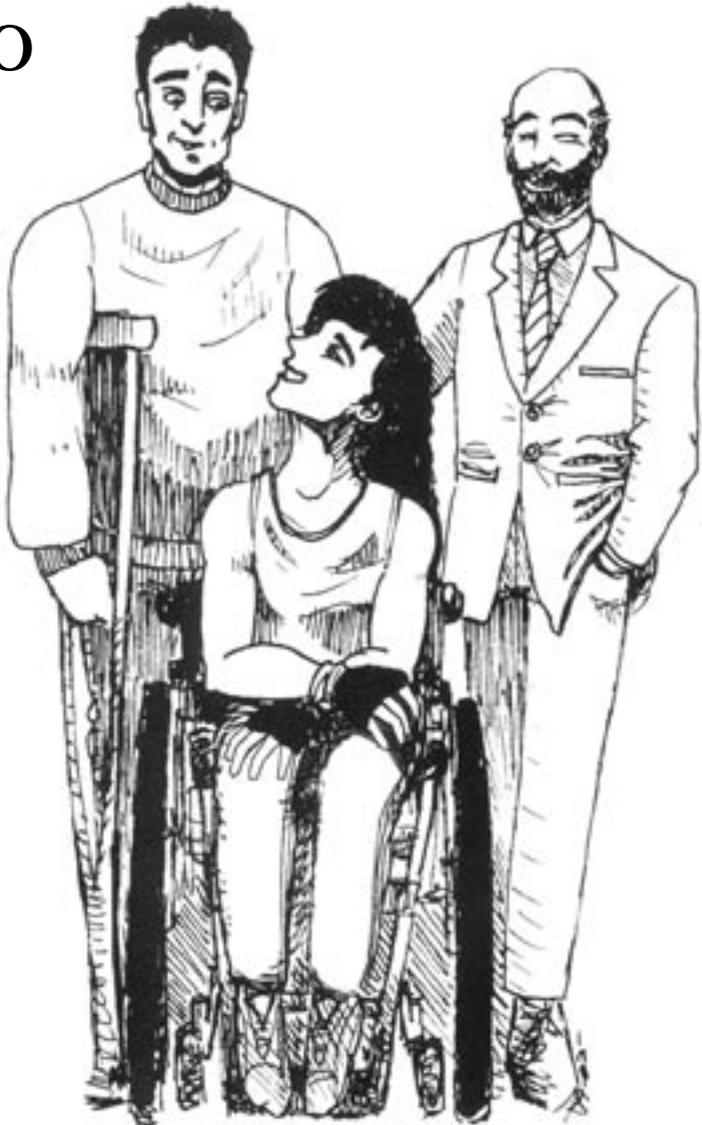


A practical guide for victims of polio

(Engelska)



A joint project
between SIOS and RTP

A practical guide for victims of polio

Thank you to the staff of the post polio clinic at Huddinge University Hospital, and all those who have provided valuable opinions and ideas.

— *SIOS in collaboration with RTP & RTP-S*

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▶ ▶ ▶ Introduction

This information brochure is aimed at those of you who suffer from polio, live in Sweden, but are born abroad. It deals with subjects which can help you understand your polio, and also presents ideas on how to make your day-to-day life easier. It also provides information on support facilities available in Sweden and finding these.

The majority of organisations and authorities mentioned in the pamphlet serve people living in Stockholm county (Stockholmslän). This information may vary if you live elsewhere. Provisions vary from council to council. State support is however the same throughout the country.

The brochure is also useful to those suffering disabilities other than polio since public support facilities are available to groups with a wide range of disabilities.

Handbok för Polioskadade (Polio Victim Manual) provides more information and can be bought from the National Swedish Association for Traffic and Polio Victims (RTP). An order form can be found at the rear of this brochure.

Medical background – what is polio?

Polio is a stomach and digestive system virus spread via water and air. The virus is of three types. In brief, it attacks the central nervous system, entering the body via the mouth, spreading into the blood system from the intestinal tract.

The illness can be divided into three phases. Phase one appears as a cold with stomach trouble, high temperature and tiredness. Phase two is characterised by e.g. stiff neck and phase three by paralysis. In some cases following infection period, paralysis may subside, in others nerve cells are destroyed, resulting in permanent handicap.

The task of nerve cells is to provide muscle fibres with signals so they can work. If these cells have died or been damaged then muscle fibres are affected and unable to function. The result is paralysis.

Post polio

Post polio (or later polio effects) can arise 15-40 years after the acute infection period. Symptoms include weak muscles and increased physical tiredness. Other highly common symptoms are muscular pain, aching joints, cold intolerance and in some cases breathing difficulties. Many polio victims are exposed to these symptoms to varying degrees.

Development of post polio is due to several factors:

- More serious degree of polio during acute infection.
- Longer period of acute illness.
- Greater functional recovery following polio.
- Polio infection as an adult.
- Individual has permanent disability from polio.
- Recently increased weight.
- Muscular pain in connection with training.

(from Handbok för Polioskadade, pub. RTP 2001)

► ► ► Distribution of Polio

Worldwide

It is not known how long polio has existed on earth, but the first documented case is an Egyptian male who lived 4,000 years ago. The World Health Organisation (WHO) puts the global level of polio victims at 10-20 million. It is estimated that 40% of these may develop post polio. Polio is found in 30 different countries, in particular in Africa and the Middle East. WHO's objective is wiping out the disease by year 2005. The number of cases has fallen greatly in recent years.

Vaccination

All newborn babies and migrants into a country must be consistently vaccinated if full protection against polio is to be maintained.

All children in Sweden are given four polio vaccinations. Non-vaccinated adults should thus get vaccinated. If you are unsure how many jabs you have had, get an extra one. Overdose risk is non-existent. Polio victims should also be vaccinated.

Sweden

The number of polio victims in Sweden is not fully known. RTP puts the figure at 15-20 thousand. This includes those people originating in countries other than Sweden.

Sweden had the world's highest number of paralysis cases in proportion to its population. A major epidemic in 1953 resulted in 3,500 cases of paralysis. Polio vaccine became available in 1957, with children and youths at first prioritised. Polio in Sweden was almost entirely wiped out by 1963, seven years after introduction of vaccination.

▶ ▶ ▶ A Practical Guide for Polio Victims

Diet

- Keep in mind the importance of avoiding overweight. Increased weight increases strain on joints and muscles.
- Avoid alcohol, particularly in the evening. Alcohol makes swallowing more difficult and affects nutritional processes.
- Eat plenty of dietary fibre, e.g. vegetables, coarse-grain flour, grain and bran.
- Adequate fluids intake is important. Two litres per day prevents dehydration.

Medicine

- Avoid narcotic medications at all time. Magnecyl or similar (aspirin) containing acetylsalicylic acid (ASA) is to be preferred for muscle and joint aches.

Training

- Every polio victim is unique, thus training capability varies. Individual training programmes are therefore essential.
- Everyone can train something. Some people, for example, are helped by relaxation, musculo-skeletal training designed to counteract brittle bones, others by stretching aimed at maintaining joint articulation.
- Water training is excellent for polio victims. The strain on muscles is lower in water than in other training environments.

Resources and aids

- In order to forestall the secondary effects of muscular weakness, aids such as orthotic devices (support bandages), crutches, walking sticks or wheelchairs are available. Particularly if you fall quite often.
- Rest sometimes works as an adequate treatment against aching muscles. Heat treatment (e.g. steam pack), acupuncture, TENS and anti-inflammatory drugs can also help.
- It may be necessary to change method of walking, e.g. through use of crutches, to avoid backache.
- Consider how changes in your daily life can lead to improvement. Changes in leisure activities or ways of moving can make life easier.

Listen to your body

- Become aware of changes in your body. Listen to the signs coming from your body.
- Everyone should know the limitations of their own strength and staying power to avoid overstrain. Rest when you feel you should.

▶ ▶ ▶ A Brief Guide to What is Available

A series of laws and public authorities have been developed in Sweden to strengthen the rights of disabled people in society. One example is the Disability Ombudsman who monitors the rights and interests of the disabled. Two important laws are the Social Services Act (SOL) and legislation on support and service for those with specific disabilities (LSS). These state the support and service facilities which society must offer to people with disabilities.

Monetary allowances can also be applied for via social insurance (Försäkringskassan) and council offices.

When applying for an allowance, filling in relevant forms is important if a negative decision is to be appealed against. These are available at your social insurance office, or at www.fk.se. Should you need help in filling in a form or have questions to ask, then contact the welfare officer of the post polio clinic at Huddinge Hospital, BOSSE, or ask your supervisor to help you. You always have a right to apply for allowances. If a supervisor tells you on the phone you do not qualify for a specific payment, then still ask that person to send you an application form.

Careful preparation before applying for the various support and service facilities is also important. Instead of concentrating on the diagnosis describe the problems/limitations caused by your polio.

You are entitled to be present when your case is dealt with. Here you get the opportunity to answer questions and explain your situation before a decision is made. Inform your social insurance office supervisor that you wish to take part. Remember: you are always entitled to an interpreter.

Assistance benefit (applied for via social insurance or council office)

Assistance Benefit is for those people with disabilities who have difficulty in coping with their basic needs. Help can be in the form of a personal assistant. Basic needs include personal hygiene or dressing/undressing. If you consider you need the help of a personal assistant more than 20 hours per week, then apply for assistance benefit at your social insurance office. Under 20 hours per week, you apply through your council. Such support is regulated by LSS and the LASS law governing assistance benefit.

Car support (applied for via social insurance office)

Do you have a long-term disability and have real difficulties in travelling or using public transport? Then you can gain a car allowance if you belong to one of the following categories:

1. Disabled person under 65 years, dependent on car for work or studies.
2. Disabled person under 50 years, not working or studying.
3. Disabled parent with child at home under 18 years.
4. Parent with disabled child. Parent and child must live together.

Written application is made to social insurance office. Individual assessment is then the basis for a decision made by the social insurance board. Medical certificate is required, and cases 2-4 also require a driver's licence. Decisions can be appealed against.

Adaptation of accommodation (applied for via council)

If you have mobility problems at home you can apply to have your accommodation adapted to suit you. You are visited by an occupational therapist who discusses with you your needs and what aids are available. Payments are not means-tested and there is no maximum amount. Decisions can be appealed against.

Transport for disabled (applied for via council)

Special transport (färdtjänst) is available to those finding difficulty using public transport. You, and occasionally your helper, may use taxi or disabled mini-bus at reduced cost. Application is made to färdtjänst at the social services within your council area. Information on prices and regulations is also available here. These may vary from council to council. Applicants must have a medical certificate.

From July 1 2000, disabled in the Stockholm region are entitled to a maximum of 208 journeys per calendar year. Special rules apply for journeys to work or education. Special tickets are also available to those temporarily in another district (utomlänsbiljetter). These must be applied for well in advance through färdtjänst customer service.

Entitlement to färdtjänst is regulated by the Färdtjänst act. Decisions can be appealed against. Regulations vary throughout Sweden.

National transport for disabled (applied for via council)

Those travelling long distances in Sweden can apply for national transport for disabled (riksfärdtjänst). In this case, journey payment is no greater than the cost of a second-class train ticket. You are also entitled to assistance, such as help in changing trains, during the journey. If required, a helper may accompany you.

Disability allowance (applied for via social insurance office)

If your costs are high due to your disability and/or you have considerable need of support and service, then you can apply for disability allowance. Make a written application. Medical certificate is required. Assessment is made from case to case and decisions can be appealed against. Further information and guidance is available from BOSSE and the RTP-S county branch.

Home help service (applied for via council)

Home help is available to those who due to their disability need practical support and/or personal service at home. Individual assessment is made. The cost is means-based and varies from council to council. The service is regulated by the SOL act. Decisions can be appealed against.

Early retirement pension (applied for via social insurance office)

Early retirement pension is available to those between 16 and 65 unable to work due to long-term disability. It is assessed in relation to your ability to work and may be paid as half, two-thirds, three-quarters or full early retirement pension. Applicants must be resident in Sweden at least three years from date of applying for residence permit. Pension payable from year following pension application.

Healthcare travel allowance

A county council healthcare travel card is available to those travelling to hospital or medical clinic and unable to use public transport. A certificate from the hospital is required. Such journeys should primarily be made using public transport but may be made using färdtjänst or own car.

Job centre

The task of the job centre is to ensure that job vacancies are filled and that job-searchers find suitable work. An appointment with a staff member can be made, or you can use job centre computers and see what jobs are available in the platsbanken. Staff are there to help. Job vacancies are also advertised in newspapers at the job centre. Advice to those wishing to change jobs or start studying is also available here.

Stockholm county has a series of job centres. More information is available on the Arbetsförmedlingen website – www.ams.se.

A number of supportive measures are available to make finding a job easier:

Wage subsidy

Wage subsidy is financial support to employers who take on disabled people. Information to employers is available through AF Rehab.

Employment training

Unemployed are entitled to a maximum of six months employment training at a job with benefit payments (dagpenning). The training gives work experience and takes place with guidance. You can find a suitable workplace yourself and then contact the job centre so as to train at that particular workplace.

Special training courses (Arbetsmarknadsutbildning)

Activity support payments are available to those wishing to train in a specific profession or attend upper secondary school (Komvux), folk high school or third level education. Activity support aims at increasing the chances of job-searchers finding a job. A list of special training courses available can be found at the job centre.

Workplace aids/workplace adaptation

You can apply for funding from your social insurance office if you require special aids at your workplace. Your employer is entitled to funding if your workplace needs adapting to suit your disability. This funding is also available to those who have been self-employed for at least six months.

Job centre – Rehabilitation (former AMI)

A special job centre is available for those with reduced working ability. The rehab job centre provides profession-oriented rehabilitation and guidance to the unemployed. Stockholm has several such centres. The centre for you depends on where you live. Contact the job centre (Arbetsförmedlingen) for more information.

Polio project

The polio project is run by SIOS (Cooperative Body for Ethnic Organisations in Sweden) together with RTP (National Swedish Association for Traffic and Polio Victims) and the Stockholm branch of this association – RTP-S.

It is a three-year project which started in May 2000. It is aimed at those polio victims who live in Stockholm county but are born abroad. The objective is to inform you of your rights and lend support in your contacts with the authorities, as well as provide study and work guidance. The project also addresses ethnic organisations in order to shed light on the situation of polio victims.

The project also works with various methods to get people in the project target group into contact with RTP and its activities.

Cooperative Body for Ethnic Organisations in Sweden, SIOS

The SIOS works with issues common to people from foreign countries. This may concern right to own culture, mother tongue and discrimination issues. The SIOS works for a fairer, more equal and more democratic society.

The following national associations are SIOS members: Assyrian RF; Chilean RF; Eritrean RF; Finno-Swedish RF; Greek RF; Iranian RF; Italian RF; Kurdish RF; Portuguese RF; RF Polish Association; Serb RF in Sweden; Spanish RF; Sweden-Finland RF; Syrian RF; Turkish RF. Observer status: Roma International. More information on these member associations is available on the SIOS website.

SIOS

Address: Bellmansgatan 15, 1tr, 118 47 STOCKHOLM.

Phone: 08-556 933 60 • Fax: 08-643 90 68

Phone: 08-556 933 61 (Project Manager)

Email: kansli@sios.org • Website: www.sios.org

National Swedish Association for Traffic and Polio Victims, RTP

The RTP represents traffic, accident and polio victims in Sweden. Total membership is 23,000. National level RTP activities include political lobbying, producing information material, providing advice and support on road traffic insurance, social insurance and social services issues, and supporting and following research favourable to its members.

Address: RTP, Vintergatan 2, Box 2031, 169 02 SOLNA

Phone: 08-629 27 80 • Fax: 08-28 15 60

Email: info@rtp.se • Website: www.rtp.se

RTP – Stockholm

RTP-S is the RTP branch covering Stockholm county. This branch organises seminars, conferences, courses and other types of activity, such as experience group meetings for exchange of experiences. RTP-S organises trips abroad and into the Swedish countryside each year, museum visits and fishing outings. It has leisure time aids available. Its swimming club provides flexibility training under physiotherapist guidance. RTP-S also has a free advice service where qualified people provided support in various issues relating to contacts with the authorities, polio and disability. Members receive a quarterly magazine with articles, information on various activities and news of the latest developments in functional aids.

Address: RTP-S, Strandbergsgatan 61, 112 89 STOCKHOLM

Phone: 08-545 622 60 • Fax: 08-545 622 75

Email: rtp-s@telia.com • Website: www.rtp.se

Post polio clinic – Huddinge Hospital

The post polio clinic team at Huddinge Hospital offers clinic patients various kinds of help. The doctor conducts examinations, pain analysis, medical investigations, provides information, gives advice and treatment, writes out certificates and referrals. The occupational therapist gives advice designed to make your day-to-day life easier. The therapist may suggest home aids, home adaptation and workplace adaptation. The physiotherapist makes assessments and gives treatment, as well as instructing individual and group training. The welfare officer can inform you on the support facilities available and help you in applying for these, as well as following up your applications through e.g. contacting relevant authorities if required.

Huddinge Universitetssjukhus

Address: Postpoliomottagningen, Rehabmedicinska kliniken R43, 141 86 STOCKHOLM

Phone: 08-585 800 00

Disability Ombudsman

The HO (Handikappombudsmannen) is a state authority which monitors the rights and interests of people with disabilities.

One task of this authority is to ensure that UN standard measures for people with disabilities are realised. These UN rules are translated into all languages and are available from SIOS central office.

The authority also has the task of ensuring that law against discrimination of disabled people in working life is followed.

Handikappombudsmannen

Postal address: Box 49132, 100 29 STOCKHOLM

Visiting address: S:t Eriksgatan 44, 3tr, STOCKHOLM

Phone: 08-20 17 70 • Fax: 08-20 43 53

Email: info@ho.se • Website: www.ho.se

Young Disabled

Job centre rehab (Arbetsförmedlingen Rehabilitering) has a special section for young disabled people under 30.

Unga Handikappade

Address: Arenavägen 47, plan 5, 121 18 JOHANNESHOV

Phone: 08 600 71 59 • Fax: 08 600 71 51

Disability Information, HU

HU (Handikapp Upplysningen) is a service with disability information in Stockholm county. It has information on support, rights, leisuretime activities, current events etc.

Phone: 08-690 60 10

Website: www.hu.se

Coordination Committee for the National Associations for Disabled Persons, HSO

The HSO (Handikappförbundens Samarbetsorgan) is an umbrella group for 37 different disabled organisations in Sweden. It has information on various questions affecting people with disability.

HSO

Postal address: Box 1386, 172 27 SUNDBYBERG

Visiting address: Sturegatan 4, 2tr, SUNDBYBERG

Phone: 08-546 40 450 • Fax: 08-546 40 444

Email: hso@hso.se • Website: www.hso.se

BOSSE – Advice, Support and Knowledge Centre

BOSSE is for people under 65 with disabilities and who need help in contact with the authorities. It informs you of your rights and helps with authority contacts such as applications and appeals. If you have difficulties within the healthcare system, then BOSSE can help you contact the right people. BOSSE also organises courses and education. The service is free, and if required an interpreter can be arranged.

BOSSE

Address: Döbelnsgatan 59, 113 52 STOCKHOLM

Phone: 08-544 88 660 • Fax: 08-544 88 661

Email: bosse@bosse-kunskapscenter.se • Website: www.bosse-kunskapscenter.se

▶ ▶ ▶ National Disability Policy – Objectives

On May 31 2000 the Swedish Parliament proposed the following bill:
“From patient to citizen – a national disability policy plan of action.”

The plan of action lays down the following national disability policy objectives:

- A society based on diversity
- Formation of society so that people of all ages with disabilities take full part in society.
- Equality of life for girls and boys, women and men with disabilities.

Most Important Features in the New Plan:

- Identifying and removing obstacles preventing full participation in society of people with disabilities.
- Preventing and fighting against discrimination of people with disabilities.
- Giving children, young people and adults with disabilities the basis for independence and participation in decision-making.

Handbok för Polioskadade (Polio Victim Manual)

There are between 15,000 and 20,000 polio victims in Sweden at present. Nine-tenths of these suffer from post polio syndrome (PPS).

Post polio syndrome represents new polio damage in polio victims who have had a stable pattern of illness for many years since acute infection. Most frequent symptoms are increased and more severe muscle ache, muscle fatigue and wearing out of joints.

Many of those hit suffering polio syndrome experience great sorrow at once again finding themselves back in the situation which existed during acute infection. The new symptoms can be seen as unexplainable and dangerous among those unaware they once suffered from polio.

The manual explains what post polio syndrome is and the steps which need to be taken. It also deals with the importance of polio victims themselves gaining the right attitude towards their illness in order to maintain their strength and avoid negative changes.

The book in Swedish is primarily aimed at polio victims, but also at relatives and healthcare personnel at county and local authority level.

Price/Pris: 125 kr

Memb. price/Medlemspris: 75 kr

Order no. 246

Box 2031, 169 02 Solna. Phone: 08-629 27 80. Fax: 08-28 15 60

Email: info@rtp.se. Website: www.rtp.se

I wish to order.....copies of "*Handbok för polioskadade*"
Jag beställer exemplar

Customer/Kund.....

Invoice to/Faktura till Phone/Tel.

Invoice address/Faktureringsadress

Postcode/Postnummer..... Postal district/Ort.....

Delivery address/Leveransadress.....

Postcode..... Postal district/Ort.....

Date/Datum Signature/Underskrift

Member

Non-member

Plus postage!

Order is sent cash on delivery.

The logo for RTP (National Swedish Association for Traffic and Polio Victims) consists of the letters R, T, and P in a bold, serif font. The letters are arranged horizontally and are slightly overlapping, with the 'R' on the left, 'T' in the middle, and 'P' on the right. The background behind the letters is a light, textured grey.

National Swedish Association for Traffic and Polio Victims

R T P

Riksförbundet för Trafik-och Polioskadade
National Swedish Association for Traffic and Polio Victims



The following national associations are SIOS members:
Assyrian RF; Chilean RF; Eritrean RF; Finno-Swedish RF; Greek RF;
Iranian RF; Italian RF; Kurdish RF; Portuguese RF; RF Polish Association;
Serb RF in Sweden; Somali RF; Spanish RF; Sweden-Finland RF;
Syrian RF; Turkish RF. *Observer status:* Roma International.