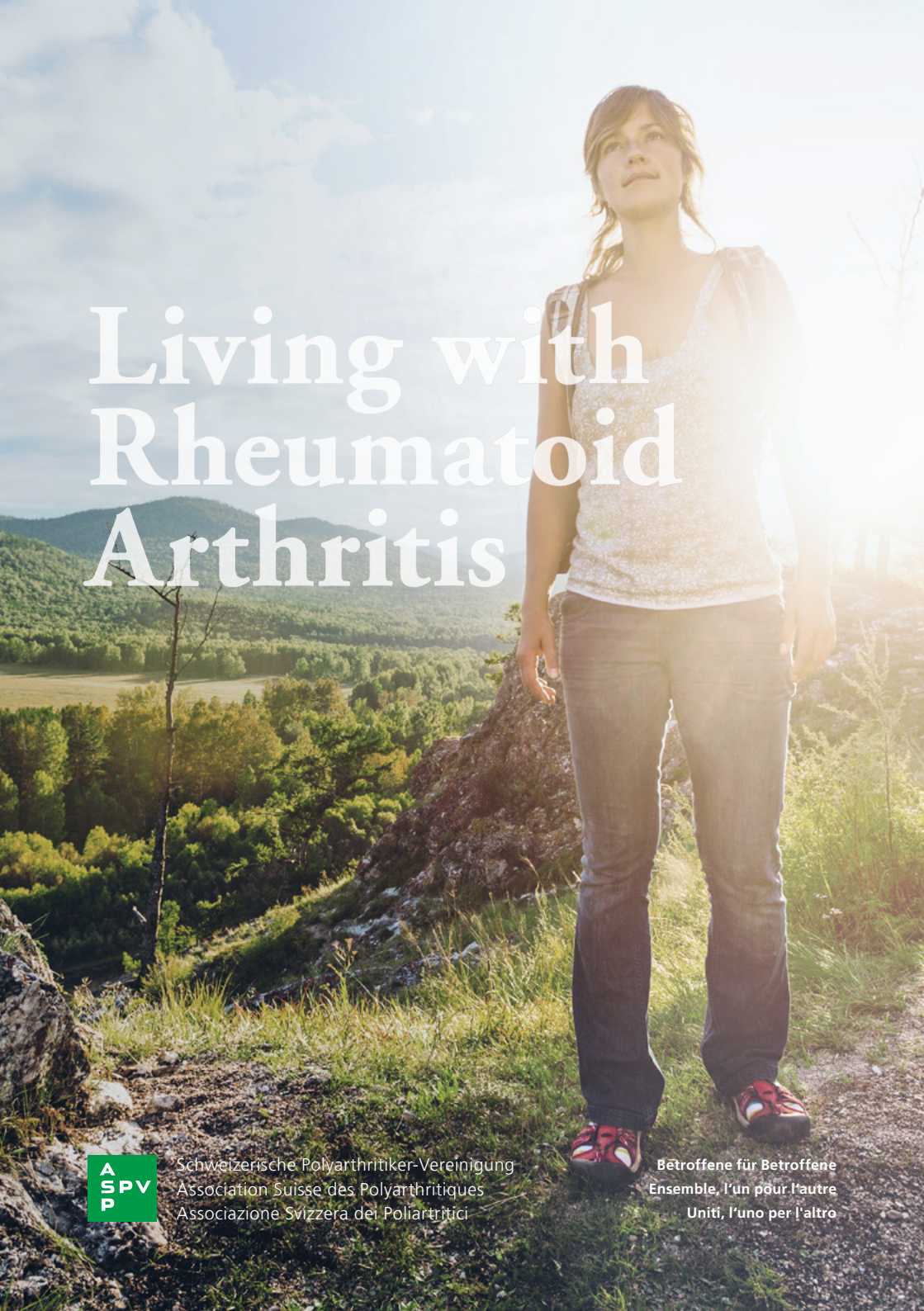


Living with Rheumatoid Arthritis

ASPV

Schweizerische Polyarthritiker-Vereinigung
Association Suisse des Polyarthritiques
Associazione Svizzera dei Poliartritici

Betroffene für Betroffene
Ensemble, l'un pour l'autre
Uniti, l'uno per l'altro

SPV office

Swiss Polyarthritis Association
Josefstrasse 92
8005 Zurich
Telephone: 044 422 35 00
spv@arthritis.ch
www.arthritis.ch

Postbank account 80-37316-1
IBAN CH69 0900 0000 8003 7316 1
Bank details
Raiffeisenbank, 9001 St. Gall
IBAN CH92 8000 5000 0113 1989 2

Impressum SPV/ASP

Living with Rheumatoid Arthritis 03/2019 **Published by** SPV/ASP, Zurich
Translation UGZ, Zurich **cover photo** istockphoto
Designed by agentur-mehrwert.ch **Printing** gdz AG, Zurich **Print run** 200 Ex.

Foreword

Dear readers

The Swiss Polyarthritis Association (Schweizerische Polyarthritiker-Vereinigung) SPV was set up in 1981 as a patient organisation for people affected by RA (rheumatoid arthritis) or a related disease. The Association supports affected people by providing information about the disease.

Actions that are difficult for sufferers, such as opening a plastic bottle, getting dressed or unlocking a door, can impair the quality of life of a person suffering from RA.

The SPV understands these problems. Our work strives to broaden the experience of people with arthritis and their environment (carers, relatives) and to bring about change for the better.

This brochure provides comprehensive information on rheumatoid arthritis (RA): symptoms, diagnosis, treatment options and how best to live with the disease. As well as suggestions on how to maintain a good quality of life despite RA, it also gives you useful advice on exercise, diet and self-management. You will also find tips on how best to prepare for positive and sustained cooperation with medical staff involved in your treatment.

We hope the tips and suggestions will make your day-to-day life easier, and will motivate you to take control of your life with RA – and enjoy it.

Best wishes

Swiss Polyarthritis Association

Contents

What is RA?

Rheumatoid arthritis (RA) is characterised by chronic inflammation of the joints and the tendon sheaths, with possible destruction of the joints. It is the most common inflammatory rheumatic disease.

Unfortunately, it is still considered incurable, but in recent years new drugs have been developed to treat it which have considerably improved the quality of life of those affected.

Studies have repeatedly confirmed that the earlier the disease is treated, the more likely the sufferer will be able to continue leading a normal life. Many people affected by RA are able, with appropriate medication, to live a virtually normal everyday life, albeit with some adjustments. So it's all the more important that you see a doctor (rheumatologist) if you are experiencing persistent symptoms such as morning stiffness and joint pain.

Some statistics:

- 70,000 adults are affected by RA in Switzerland
- approx. 75 per cent of those affected are women
- RA can occur at any age, most often between 30 and 50 years of age
- the treatment options have improved greatly, and allow many sufferers to live a virtually normal life

If you are experiencing persistent morning stiffness and joint pain, make sure you see a doctor.

Pathogenesis of RA

RA is an autoimmune disease. Aberrant immune system cells attack the body's own structures (such as articular cartilage). The joint becomes inflamed, stiff and starts to hurt. The cause of this immune system disorder has still not been established.

From research, it is known that certain genes which have an influence on the immune system may be associated with RA. But this doesn't mean that everyone who has these genes also has RA; however, these people have a greater likelihood of developing RA.

Factors such as stress, infections, viruses, smoking or hormonal changes in the body may also have an impact on the development of RA.

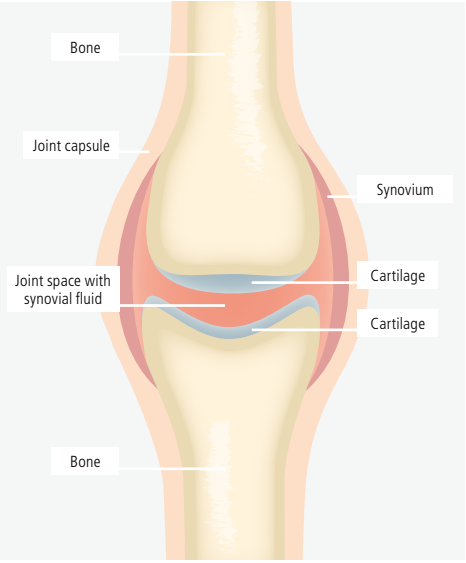
Joints affected

RA manifests differently from person to person. In the classic form of the disease, the joints are affected symmetrically – that is, the same on both sides of the body. At disease onset or in mild cases, however, individual joint regions may exhibit asymmetrical symptoms. Finger, hand, foot and toe joints are most commonly affected. Less often, the disease affects knee, shoulder, elbow and ankle joints.

What exactly happens to the joint?

To understand what happens with RA, it's important to know how a normal joint works.

The joints in our body perform different tasks, but all have essentially the same structure. Anatomically, they are the junction between two or more bones, and it's thanks to them that we are able to move at all.



If the inflammatory processes cannot be halted, they lead to the destruction of cartilage and bone

The ends of the bones are called articular surfaces. Each of these is covered with a layer of cartilage, the articular cartilage.

Externally, the joint is encased in the joint capsule, the inner surface of which is lined by the joint membrane (synovial membrane). The capsule is filled with joint fluid, also known as synovial fluid or synovia. This fluid lubricates the entire surface of the cartilage, enabling the cartilage surfaces to glide smoothly across each other when we move.

Inflammatory process

In RA, there is an overreaction by the immune system, which incorrectly identifies the synovium as a foreign body and triggers an immune reaction, an inflammation. In contrast to normal inflammation, this inflammation cannot be brought down, because the overreacting immune system is continuously producing new T- and B-cells which maintain the inflammation in the joint.

B-lymphocytes, or B-cells for short, are among the leukocytes (white blood cells). They are the only cells able to produce antibodies, and together with the T-lymphocytes they make up the essential component of the adaptive immune system.

The inflammation causes the joints to be sensitive to pressure, painful and swollen. If this inflammation is not treated, it continues to progress. The inflamed synovium may proliferate beyond the articular cartilage into the bones. This process leads to bone defects (erosions) and cartilage damage.

According to the current state of research, the destruction of the joints occurs as early as the first few months or years after onset of the disease. To prevent any permanent damage, early diagnosis of RA is crucial.

Early signs and symptoms

Despite individual symptomatology, the onset of RA is often characterised by the following complaints:

General symptoms mask the onset of the disease

- General malaise – flu-like symptoms
- Tiredness and exhaustion
- Listlessness
- Loss of appetite and weight loss
- Reduction in performance
- Elevated temperature, mild fever (around 38 degrees Celsius)

These symptoms may also occur during an acute flare-up.

Pain and weakness are a first alarm signal

- Pain in various joints (such as fingers and toes)
- Persistent pain (at rest and during movement)
- Weakness (objects can no longer be held properly, fall from your hands)
- Possible tenosynovitis

Symmetrically occurring symptoms

- Joint swelling with signs of excessive warmth and pain
- Morning stiffness (lasting min. 30 minutes)
- Symmetrically occurring symptoms (right and left simultaneously), even if the affected joints may alternate

Course and diagnosis

RA may progress slowly or take a relapsing-remitting course. It can rarely be brought completely under control after the first flare-up. RA subsides spontaneously only in approx. 10 % of sufferers. If the disease cannot be controlled with appropriate therapy, over the years there is a gradual destruction of the articular cartilage and bone, as well as the surrounding tendons and ligaments. This causes the formerly characteristic deformity of the affected joint regions.

In addition to the joints, the tendon sheaths, especially in feet and hands, and the bursae are also inflamed in RA. Moreover – but typically only after years and in severe cases – other organs such as the skin, eyes, lungs, heart, veins and the peripheral nervous system may also be affected.

Diagnosis is difficult in the early stages of the disease. Diagnosis is made on the basis of various, fairly typical findings. These include joint swelling: painful swelling of the finger base and middle joints and the toe base joints, which are not reddened.

Often at disease onset, no changes to bones and joints are seen on x-ray images. Only as the disease progresses (after months or years) do the typical changes occur, with destruction of the joint bones.

Basically, the earlier the disease is diagnosed and treatment started, the better the prognosis!

Blood tests

Blood tests often show increased inflammatory activity, i.e. the so-called erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP) levels are elevated.

CRP is used as a non-specific inflammatory marker to assess the severity of inflammatory diseases.

The ESR is a non-specific search technique for suspected inflammatory diseases or a laboratory test to evaluate their progress.

If the rheumatoid factors and/or the CCP antibodies (cyclic citrullinated peptide) in the blood are positive, this may indicate RA. But these blood tests are positive only in 50 % of cases at onset. Rheumatoid factors also occur in other diseases. The CCP antibodies, however, are very specific to RA.

How does the future look?

Being diagnosed with RA is a shock. You are deluged with information. It's perfectly normal for this to trigger emotional ups and down.

Few of those affected are aware that RA is one of the most common autoimmune diseases. The greatest anxiety relates to the destruction of the joint bones and the associated permanent deform-

ity of the joints. But today there are a multitude of new treatments and drugs available, which can be very effective particularly where the disease is diagnosed early on. Once an appropriate drug treatment has been adjusted to the individual, most sufferers can virtually carry on with their normal lives.

For a positive approach to RA, experience shows that three things are needed:

- Confidence in the doctor treating you
- A sympathetic personal environment (partner, family, friends)
- Personal ability and strength to accept the changed life situation and shape it positively

Professional support in coping with RA

Relationship between doctor and patient
The relationship between doctor and patient can be very demanding for both sides. As a patient, I must be able to trust that my rheumatologist is proposing the appropriate therapies for my clinical picture, even if to begin with they seem to have no effect – only unpleasant side effects. The doctor should also have time to discuss my doubts and questions, and understand if I decline a treatment he suggests. Often, an assessment by an independent consultant, perhaps as part of a clinical consultation at a university rheumatology clinic, can help reinforce confidence in the therapy.

Mutual trust is the prerequisite for successful therapy.

It may help you in the beginning to take a friend or family member with you to the consultations. Write down your questions for the doctor, and your symptoms. Your doctor's appointment could fall on a day when you are doing comparatively well, so there is a risk that you have forgotten what was affecting or bothering you on the days prior to that. Make notes during the consultation as well. If you don't understand what the doctor is saying, then say so and ask for clarification. Ask him for a detailed explanation.

Your treatment team
In addition to the drug treatment, function-related measures are also very important. Physiotherapy, occupational therapy, physical activity and rehabilitation and sports are aimed primarily at enabling you to perform as well as you possibly can, and achieve independence in everyday life, job, leisure time and family life. By reducing pain and limitations, these measures help improve general physical and mental well-being und thus quality of life.

Physiotherapy: Physiotherapy treatments are generally geared towards the sufferer's current problems, particularly their pain, functional limitations and the inflammatory activity. It is necessary to distinguish between treatments during active joint inflammation, and treatments when the inflammation has been brought under control on the drug therapy.

Treatment goals in physiotherapy

- Improve the mobility, blood flow and metabolic performance of the joints
- Relax and strengthen the muscles
- Prevention and correction of defective positioning
- Relieve pain
- Functional improvement of strength, flexibility and coordination

Occupational therapy: Occupational therapy aims to enable sufferers to carry out activities within their personal environment that are important to them as individuals, in the areas of self-sufficiency, productivity and leisure time. With specific activities, environmental adaptations and advice, people are given the capacity for action in their day-to-day lives, and afforded the means for social participation and improvement in their quality of life. Mod

ern occupational therapy focuses on individually meaningful activities relevant to the RA sufferer's areas of life (job, family, hobbies and leisure time, social activities). In the treatment of RA sufferers, physiotherapy and occupational therapy often work hand in hand. For instance, functions such as flexibility or strength regained in physiotherapy are integrated into everyday tasks and sequences of actions during the occupational therapy.

Occupational therapy tasks

- Joint protection and energy management
- Adjustment of splints
- Provision of aids and ergonomic equipment
- Structuring of day-to-day routine
- Structuring of solutions to problems

In occupational therapy sessions, sufferers are also counselled on accepting their illness and given advice on coping strategies and problem-solving, to boost their resources.

Catalogue of everyday living aids available at:
www.rheumaliga-shop.ch
Available in german, french and italian

Orthopaedic technology: In RA, the inflammation process affects the ankle joints and tendons, causing significant changes to the foot. The abnormal biomechanical stress on the joints often causes foot problems. The aim of providing orthopaedic footwear is to enable the joints to be supported in such a way as to relieve the pain. These footwear aids may include shoe insoles or shoe technology systems which help immobilise the joints, thus preventing extreme or abrupt movements.

Dietary advice: A balanced diet containing all nutrients in sufficient quantity is the basis of healthy nutrition.

Objective of dietary advice: normal weight. Overweight and underweight cause additional joint problems.

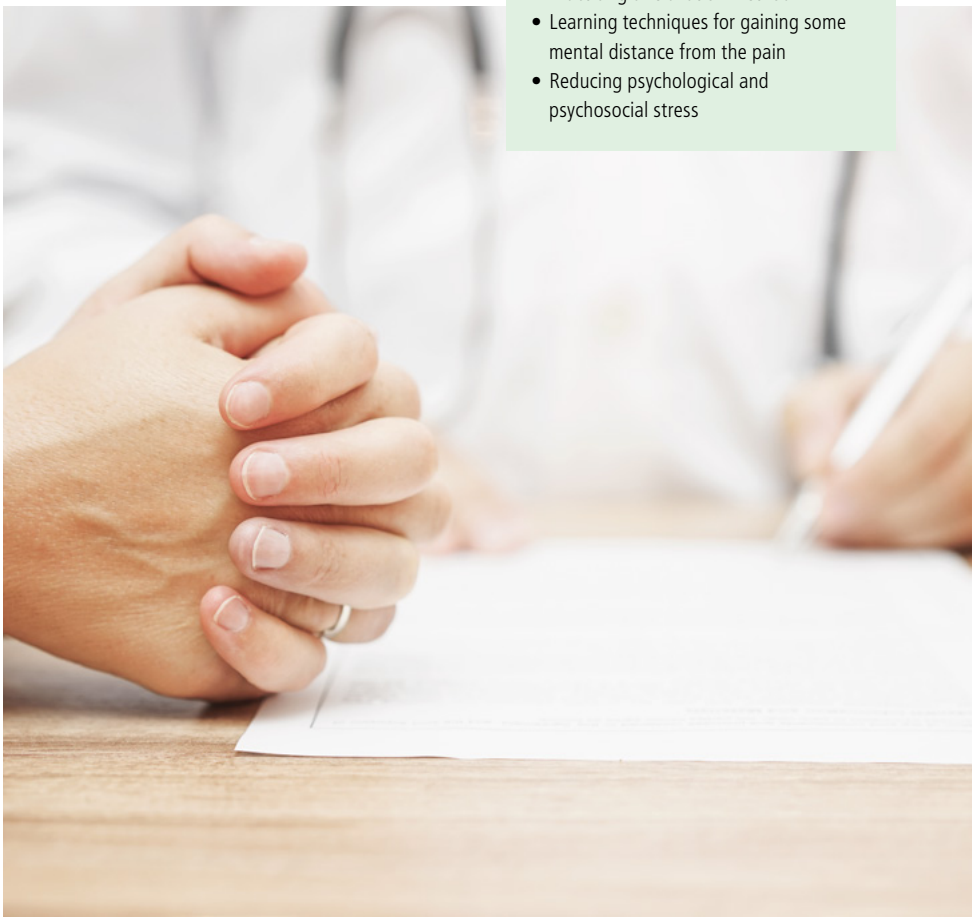
The main objective of nutritional therapy is to achieve (and maintain) a good state of general health. This includes a good nutritional status (normal weight) based on adequate energy and protein intake, and enough vitamins and minerals.

Psychological pain therapy: RA is a disease with far-reaching consequences for those affected. In addition to the pain, the limitations in day-to-day life are a challenge for mental health. The uncertain course of the disease also tends to increase fears and worry.

Staying active, taking time to relax, not letting the pain get you down and coping with life despite movement-dependent pain is no easy task. The support of a specialist can be helpful and can improve your quality of life.

Psychological pain therapy focuses on the following objectives:

- Providing information on the interplay of biological, psychological and social factors
- Practicing a relaxation method
- Learning techniques for gaining some mental distance from the pain
- Reducing psychological and psychosocial stress



How is RA treated?

If a diagnosis is confirmed, there are many treatment options that can help to relieve pain and maintain mobility. Function-related therapies such as physiotherapy, occupational therapy, physical activity and sports, as well as relaxation techniques, can be helpful in the treatment of RA. But drug therapy is the core in keeping the disease at bay.

It is recommended that you keep a diary in which you record symptoms, questions for your next consultation, medication and the progress of your blood tests. It is also worth keeping a list of all current medications, including those you buy yourself.

There are many drug therapies for the treatment of RA. They are individually tailored to the patient and sometimes prescribed in combination.

IMPORTANT: your body needs time to adjust to a new treatment or a change to existing treatment.

Drug therapy
The drug therapy for RA consists of non-steroidal anti-inflammatory drugs, painkillers (analgesics), cortisone and disease-modifying antirheumatic drugs (DMARDs).

Non-steroidal inflammatory drugs and analgesics relieve pain. While analgesics have no effect on the inflammation, non-steroidal anti-inflammatory drugs are more effective, as they ease pain and inflammation (with joint swelling and excessive warmth).

Cortisone drugs are very similar in their chemical structure and effect to the body's own hormone, cortisol. Cortisol modulates inflammatory processes of the body's own defence system. In RA, cortisone drugs work by positively influencing first of all the inflammatory processes, and secondarily the pain as well. As cortisone drugs also slow down the joint destruction, they can be counted among the disease-modifying antirheumatic drugs.

DMARDs are anti-inflammatory drugs that are used in the treatment of immunologically-mediated inflammatory reactions, such as in RA. By curbing joint inflammation and disease activity, DMARDs alleviate the symptoms (pain), and inflammation-related organ damage can be minimised, or may not develop at all. With DMARDs, the occurrence of inflammation-related joint destruction in RA can be delayed or prevented altogether. DMARDs take several months to take effect, and must be taken/injected long-term.

We make a distinction between traditional DMARDs and modern bioengineered DMARDs, known as biologics. The latter have changed the treatment dramatically over the past few years.

Bioengineered DMARDs (biologics) have resulted in a higher response rate. That means that in some RA sufferers the inflammatory processes are completely suppressed. But the positive effect only lasts as long as the drugs are taken.

RA sufferers are usually looked after by a therapeutic team. In close consultation with the rheumatologist and therapeutic services – occupational therapy, physiotherapy, psychological service, social services if need be – the family doctor is responsible for long-term care. Depending on the situation, either orthopaedic surgeons or other specialists will take over portions of the therapy.

Non-steroidal anti-inflammatory drugs (NSAIDs)
Non-steroidal anti-inflammatory drugs (NSAIDs) are drugs that inhibit pain and inflammation (with joint swelling and excessive warmth, including fever).

Some examples (with respective brand names):

- Ibuprofen (Brufen®)
- Mefenamic acid (Ponstan®)
- Etoricoxib (Arcoxia®)
- Diclofenac (Voltaren®)
- Naproxen (Napranax®)

Like all medicines, NSAIDs can have side effects. It is very important that the doctor is notified of any side effects immediately and can take the necessary precautions.

Possible side effects:

- Gastrointestinal ulcers (for this reason NSAIDs are often prescribed in combination with a drug to protect the stomach)
- Increased tendency to bleed (NSAIDs should therefore be stopped prior to any surgery)
- Deterioration in renal function
- Liver side effects (rare)
- Increased blood pressure
- Fluid retention in the body, especially in the legs
- Allergic reactions
- Dizziness and concentration problems (rare)

Cox-2 inhibitors are among the newer generation of non-steroidal anti-inflammatories. They also have an anti-inflammatory, pain-relieving effect, but fewer side effects on the gastrointestinal tract and the tendency to bleed. Unfortunately these drugs have an increased risk for cardiovascular events (heart attacks, strokes). Of these NSAIDs, only two drugs are still available in Switzerland; all others had to be taken off the market due to undesirable side effects.

The following drugs are available in Switzerland (with respective brand names):

- Celecoxib (Celebrex®)
- Etoricoxib (Arcoxia®)

NSAIDs can also be used as cream, gel, ointment, transdermal therapeutic system (plaster) or as eyedrops.

Brochure 'Medications' available at:
www.rheumaliga-shop.ch
Available in german, french and italian

Cortisone drugs
Everyone produces cortisol in the adrenocortical gland. Cortisol is a vital hormone; it is essential for the functioning of the human body and has a regulating role in the circulation and the body as a whole.

Corticosteroids act on inflammatory mechanisms by inhibiting substances that trigger inflammatory reactions. In addition, corticosteroids have an immunomodulating effect on white blood cells (leukocytes). These effects are used in RA. This results in a reduction of the inflammation processes, and as a consequence reduces pain as well.

Cortisone drugs are available in the following forms:

Tablets: Cortisone drugs can be taken daily, usually in the morning and in tablet form. There are now a large number of preparations/generic drugs in the corticosteroids group.

Some examples (with respective brand names):

- Prednisone (Decortin®)
- Prednisolone (Spiricort®)
- Deflazacort (Calcort®)

Infusion: In severe RA flare-ups or in patients who have a long-term need for corticosteroid treatment and are under a specific stress (such as surgery), cortisone drugs can be given as an infusion over 24 hours.

Injection: Corticosteroids are used to treat local inflammatory diseases, and for this purpose are injected locally into the affected arthritic joint. This local form of cortisone administration has the most favourable effect/side effect ratio. The most commonly injected products (with brand names) are:

- Bethamethasone (Diprophos®)
- Triamcinolone (Kenacort®)

When taking cortisone drugs, note the following:

If they have been taken daily for several weeks, corticosteroids cannot be stopped abruptly from one day to the next. Any dose reduction or discontinuation of such drugs must first be discussed with the doctor treating you. The dose of the corticosteroids also should not be increased independently by the patient without discussion with the doctor, nor should the time of taking the drugs (usually mornings at around 8:00) be changed.

Side effects of corticosteroids:

After injections or infusions of corticosteroids there are side effects, which fortunately disappear again a few days after cessation of the therapy. These side effects include facial rash and sensation of warmth in the face, increase in blood pressure, blood sugar and/or eye pressure, and sleep disturbances. With a long-term (several months) daily dose of less than 7.5 mg Prednisone the side effects are minor, but cannot be prevented completely.

With a long-term daily intake of cortisone drugs in a dose of more than 7.5 mg Prednisone, the following adverse side effects have been observed:

- Increased appetite and corresponding weight gain, especially in the face and torso
- Fluid retention in the tissues, especially in the legs
- Increased tendency to infectious diseases
- Acne
- Increase in blood sugar, blood pressure and/or eye pressure
- Eye lens opacity (cataract)
- Thin skin, often with minor skin bleeding
- Slight muscle weakness
- Bone thinning (osteoporosis)
- Menstrual disorders
- Cholesterol increase
- Change in mood

The side effects can be prevented in some cases. The risk factors for cardiovascular circulation and cerebral perfusion in particular must be minimised by:

- Stopping nicotine
- Losing weight
- Lowering cholesterol and blood pressure
- And optimal treatment of any existing diabetes.

The development of osteoporosis can be delayed or prevented by taking adequate calcium and Vitamin D3.

Traditional, synthetically manufactured DMARDs

DMARDs are anti-inflammatory drugs that are used in RA to treat immunologically mediated inflammatory reactions. By curbing joint inflammation and disease activity, DMARDs alleviate the symptoms (pain) and inflammation-related organ damage can be minimised, or prevented from developing at all. With DMARDs, inflammation-related joint destruction can be delayed or prevented entirely, thus avoiding disability.

The concomitant use of several different DMARDs is a proven treatment strategy.

For adequate suppression of joint inflammation, disease-modifying antirheumatic drugs (DMARDs) are indispensable. In expert hands, they have far fewer side effects than cortisone drugs, and also fewer than anti-inflammatory painkillers (non-steroidal anti-inflammatory drugs (NSAIDs). Conventional DMARDs begin to take effect only after several weeks or months, and they must be taken/injected long-term.

For many DMARDs, regular monitoring of the therapy is necessary, with blood tests in particular. Fine-tuning the DMARD therapy to the individual needs of the sufferer is difficult and requires a lot of experience. Treatment should therefore always be carried out in collaboration with a rheumatologist.

The most commonly used DMARDs (with respective brand names) and side effects:

Methotrexate®

Gastrointestinal problems, skin and mucosal changes, slight hair loss, infrequently liver and lung inflammation, suppression of blood formation – slightly increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Methotrexate®. Intake should be stopped at least three months before any planned pregnancy/conception. Methotrexate® should not be used during pregnancy or breastfeeding.

Arava® (leflunomide)

Diarrhoea, slight hair loss, infrequently liver and lung inflammation, suppression of blood formation, high blood pressure – slightly increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Arava®. Intake should be stopped at least six months before any planned pregnancy/conception; a special washout procedure is also necessary, due to the long half-life of this drug. Arava® should not be used during pregnancy or breastfeeding.

Salazopyrin® EN (sulfasalazine)

Gastrointestinal problems, skin allergy, blood formation disorder, nausea, headache, sore throat, fever – no susceptibility to infection.

Salazopyrin® can also be taken during pregnancy and breastfeeding.

Plaquenil® (hydroxychloroquine)

Photosensitivity of skin and eyes, very rarely retinal damage to the eye – no susceptibility to infection.

Plaquenil® can also be taken during pregnancy and breastfeeding.

Sandimmun Neoral® (cyclosporin A)

Gastrointestinal problems, increased hirsuteness, swelling of the gums, high blood pressure, renal dysfunction – slightly increased susceptibility to infection.

Sandimmun Neoral® can also be taken during pregnancy and breastfeeding.

Imurek® (azathioprine)

Slight nausea, gastrointestinal problems, suppression of blood formation, liver inflammation – slightly increased susceptibility to infection.

Imurek® can also be taken during pregnancy and breastfeeding.

CellCept® (mycophenolate mofetil) and Myfortic® (mycophenolate)

Gastrointestinal problems – slightly increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with CellCept® and Myfortic®. CellCept® and Myfortic® should not be used during pregnancy or breastfeeding.

Endoxan® (cyclophosphamide)

Gastrointestinal problems, suppression of blood formation, hair loss, bladder infection, frequent infections, sterility.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Endoxan®. Intake should be stopped at least six months before any planned pregnancy/conception; a special washout procedure is also necessary, due to the long half-life of this drug. Endoxan® should not be used during pregnancy or breastfeeding.

Xeljanz® (tofacitinib)

Headache, diarrhoea, liver inflammation, suppression of blood formation, frequent infections – increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Xeljanz®. Xeljanz® should not be used during pregnancy or breastfeeding.

Sometimes it is necessary to change a DMARD several times until an effective and well-tolerated therapy is found. This may call for a great deal of patience.

But with all the drugs currently available, we are getting closer and closer to the ultimate goal of one day achieving complete and sustained suppression of the inflammatory process in all sufferers.

Bioengineered DMARDs (biologics)

Biologics are drugs that are produced using biotechnology and genetically modified organisms. These are artificially produced protein substances which exert their effect by specifically interfering with the biological inflammatory process. For instance, they may neutralise soluble or cell-associated proteins which mediate inflammatory signals, or they may target certain inflammatory cells. Their development has only been made possible by modern molecular biology. The pharmaceutical industry uses genetically modified cells or microorganisms as 'living factories', to produce the desired active substances.

The development and production costs of biologics are immense. The drugs are therefore very expensive. For this reason, a commitment to cover costs must be obtained from your health insurance company before they are used.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with biologics. With the exception of certain TNF inhibitors, biologics must not be used during pregnancy.

TNF inhibitors

There are five TNF inhibitors available: infliximab, etanercept, adalimumab, certolizumab and golimumab. Both in the joints and in the rest of the body, they selectively block tumour necrosis factor-alpha (TNF-alpha), one of the key inflammatory mediators. This enables them to suppress the inflammatory process. In many sufferers, the inflammation of the joints can be significantly reduced with TNF inhibitors.

The TNF inhibitors are well tolerated, but also entail certain risks. Infections frequently occur. These may have an atypical and more severe course than usual.

The TNF inhibitors are injected under the skin at intervals of one, two or four weeks; infliximab is given as an infusion.

All TNF inhibitors can be used in conjunction with Methotrexat® or other conventional DMARDs. Such a combination can achieve an even better effect.

The five available TNF inhibitors are listed below (with respective brand name); their side effects are also given:

Enbrel® (etanercept)

Skin reactions at the injection site – increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Enbrel®. Enbrel® should not be used during pregnancy or breastfeeding.

Remicade® (infliximab)

In rare cases, infusion reactions similar to allergic reactions (reddened skin, chest tightness and difficulty breathing) – increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Remicade®. Remicade® should not be used during pregnancy or breastfeeding.

Humira® (adalimumab)

Skin reactions at the injection site – increased susceptibility to infection .

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Humira®. Humira® should not be used during pregnancy or breastfeeding.

Cimzia® (certolizumab)

Skin reactions at the injection site – increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Cimzia®. Cimzia® should not be used during pregnancy or breastfeeding.

Simponi® (golimumab)

Skin reactions at the injection site – increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Simponi®. Simponi® should not be used during pregnancy or breastfeeding.

Other active agents of the biologics are:

Rituximab

This protein substance specifically targets the B-lymphocytes (also called B-cells), which as specialised white blood cells produce rheumatoid factor and anti-CCP antibodies, among others. Rituximab is given as an infusion. It takes some time to take effect, but it can last 6 to 12 months and sometimes even longer. It is recommended that rituximab be combined with Methotrexate® or other synthetic DMARDs.

Abatacept

By accumulating on the surface of certain immune cells, this protein substance inhibits the activation of the T-cells, which play an important role in the inflammatory process. It is injected under the skin on a weekly basis; alternatively, it can be given at monthly intervals as a half-hour infusion. The effect can be expected within one to two months. Abatacept can also be used in combination with conventional synthetic DMARDs.

Tocilizumab

The protein substance tocilizumab targets the interleukin-6 receptor. It produces a decrease in the activity of interleukin-6, one of the immune system's key inflammatory mediators. This can alleviate the inflammation of the joints and the systemic effects such as fatigue. It is injected under the skin on a weekly basis, or can be given as

a one-hour infusion every four weeks. The effect on the systemic inflammation and its symptoms occurs very rapidly, and the effect on the joints within about two months.

Other active agents of the biologics (with their respective brand names) and side effects:

MabThera® (rituximab)
In rare cases, infusion reactions similar to allergic reactions (reddened skin, chest tightness and difficulty breathing) – increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with MabThera®. MabThera® must not be used during pregnancy or breastfeeding.

Orencia® (abatacept)
In rare cases, infusion reactions similar to allergic reactions (reddened skin, chest tightness and difficulty breathing) – increased susceptibility to infection.

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Orencia®. Orencia® should not be used during pregnancy or breastfeeding.

Actemra® (tocilizumab)
In rare cases, infusion reactions similar to allergic reactions (reddened skin, chest tightness and difficulty breathing) – increased susceptibility to infection

Sexually mature patients (male and female) must use a reliable form of contraception during treatment with Actemra®. Actemra® should not be used during pregnancy or breastfeeding.

The aim of treatment is to reduce disease activity and prevent joint damage!

Anti-rheumatic drugs and having children:

Men and women who regularly take anti-rheumatic drugs and plan to have children should discuss this with the doctor first.

Operations

In the past 10 years, the appearance of RA on all joints, but especially on the hand, has changed dramatically. This is due to the introduction of DMARDs, particularly biologics and specifically TNF-alpha inhibitors.

The inflammatory components of joint and tendon damage can now be very successfully treated in most patients. This also causes the pain and swelling to disappear. The crucial aspect, however, is that in most cases the progression of the joint destruction can be slowed down, or even stopped, at the same time.

Unfortunately, this doesn't happen in all RA sufferers, whether because the drugs are not effective enough, or because they are not tolerated due to the side effects. Since RA ultimately is not curable, even with the best drug treatment joint destruction and tendon lesions are still possible in the long term in some cases. There is also the risk that, with the pain eliminated, the joint deterioration will continue to progress unnoticed and the optimal time for a reconstructive intervention will be missed.

Any loss of functional capabilities in work, sport, hobbies or in everyday life must be taken seriously, especially if it sneaks up on you. Any such 'kink in the activity curve' often indicates joint destruction that can be treated.

During the same period in which the drug treatment has been 'revolutionised', an impressive level of specialisation has been achieved in orthopaedics. The division of orthopaedic surgery into the fields of upper extremities, lower extremities and spine has been followed by further sub-divisions, right up to specialisation in individual joint regions such as shoulder, elbow, hand, hip, knee and foot surgery.

For rheumatism patients as well, the joint specialist will find the best solution and perform any joint replacement that may be necessary.

Close collaboration with rheumatologists, new developments in the field of quality assurance (subjective and objective measurement of pre-operative limitations and post-operative outcomes), and a robust infrastructure in physiotherapy and occupational therapy contribute to the proficient and tailored, holistic treatment of the patient.

Surgery is not an anti-inflammatory treatment in rheumatoid arthritis.

Living with RA

Being diagnosed with any illness can turn your social, professional and private life upside down. Despite the fact that rheumatoid arthritis is still incurable, it's extremely important to understand that there are things you can do help yourself have a life that, with a few adjustments, is completely normal.

In recent years, medical research has made great strides forward in drug treatment, which is enabling sufferers to achieve a quite satisfactory quality of life.

The diagnosis of RA throws up numerous questions – including, of course, the question of what the future holds. There is really no easy and universally valid answer to this question, as the course of any RA case cannot be predicted. The symptoms are different for every sufferer, and even the severity of the symptoms can vary from one day to the next.

In the following we discuss some topics which should help you to better cope with the disease.

What is a flare-up?

A flare-up is identified as the continuous or recurrent tender, painful swelling of at least two joints. The hands in particular are affected. There is also morning stiffness in the affected joints, which subsides gradually only after a minimum of 30 minutes and leaves a significant loss of strength (particularly in the hands). Sufferers may also experience flu-like symptoms and general tiredness or abnormal fatigue. A flare-up may last from a few days to a month.

Recognising a flare-up

- Your morning stiffness lasts longer than usual
- You are wearier or more fatigued than usual
- Your blood test results show clear signs of inflammation
- The symptoms intensify and last more than two days
- Significant swelling, stiffness and pain in the joints and muscles
- Sleep disturbances
- Significant difficulties in going about your daily routine

Causes of a flare-up

- Stress
- Another illness, such as an infection
- Medication – are you taking your medication regularly? Does your medication need to be adjusted/changed?
- Overexertion
- Overloading a joint

What to do during a flare-up

- Recognising a flare-up at an early stage enables you to do something about it immediately.
- Keep a diary of your symptoms – this will help your rheumatologist identify the possible triggers
- Take painkillers if necessary
- Try to avoid stressful situations
- Hotpacks, hot-water bottle, paraffin wax baths (for hands), a warm bath or a warm shower can provide relief for painful joints. Coldpacks or letting cold water run over the affected joints several times a day can reduce the pain and swelling.
- Do gentle movement exercises
- Try to relax with breathing techniques

- Try to get plenty of sleep
- Don't be afraid to ask for help
- Find the right balance between rest and activity
- Plan and prioritise the tasks you want to achieve on a given day. This will help make sure you don't overexert yourself.
- Perhaps big tasks could be broken down into several small tasks.
- Talk to your doctor and your therapists. Arrange an appointment in the very near future

Dealing with pain

Pain is a very personal matter, as it presents or is perceived differently from patient to patient.

Pain may be dull, felt as short stabs, or it may come and go in waves. There are various options for dealing with the pain and breaking the pain cycle:

- Take painkillers
- Do gentle movement exercises
- Go for a gentle massage
- If possible, wear a splint to immobilise the inflamed joint for a short time
- Find the right middle ground between resting and being active. Do something to distract yourself from the pain, e.g. by telephoning a loved one or watching an amusing television programme or a film
- Take time out to read a book, have a bath, listen to music, etc.
- Try to be patient. Sometimes it takes a while to see any improvement.

The balance between rest and activity helps you do the things you love for longer periods.

Taking care of your joints

Joint protection and energy management is extremely important in RA. Joint protection techniques reduce pain and improve functional capability. This is achieved by reducing the effort and relieving the pressure on the small joints. The following points make everyday life easier:

- Use both hands when carrying and lifting
- Vary your sitting position, or stand up and walk a few steps occasionally, to prevent any potential stiffness
- Simplify tasks (have frozen vegetables, use an electric toothbrush)
- Use ergonomic devices and aids (serrated knife, opener for screw caps, handle thickeners and special scissors)

'Protect your joints' brochure available at:
www.rheumaliga-shop.ch
Available in german, french and italian

Tiredness/fatigue

Fatigue is different from normal tiredness. Exhaustion is a corollary of RA. It can be very irksome and may also occur in flare-ups. The need for sleep is increased, leading to difficulty in concentrating and lack of energy. This state can affect you mentally. No longer being able to live as actively as you used to can make everything seem an effort, and non-sufferers sometimes do not fully appreciate this. The following may help you cope with the fatigue:

- Learn to say no once in a while. Don't take on too much
- Plan activities carefully, give yourself time
- Stay active – do light movement exercises, go for short walks, because stronger, exercised muscles get tired less quickly

- Take a break before the exhaustion becomes too much
- Learn to accept limits. Ask for help in good time
- Go to bed early; take an afternoon nap if possible
- Learn relaxation techniques
- Don't be out and about in rush hour, whether for shopping or when travelling
- Compare notes with other sufferers in order to learn from their experiences

RA takes up a lot of your energy. So it's important: not to take on too much, to accept limits, and to prioritise.

Sleeping – finding peace

In RA, fatigue and sleeping problems often occur simultaneously. Getting a good night's sleep is important for RA sufferers. Achieving it can be quite a challenge. How much sleep each person needs is very individual. Some need at least eight hours, while others are on top form with five hours. Being overtired can make your everyday life harder. Here are some suggestions for a better sleep routine:

- Relax before going to bed – take time to let go of the cares of the day
- If possible, always go to bed at the same time
- To relax, have a warm bath (can also help with pain) and then go straight to bed
- Remove sources of interference from the bedroom (electronic devices (TV, phone, computer, etc.))
- Avoid caffeinated and alcoholic drinks before going to bed
- Have good, comfortable pillows to support your neck and shoulders, and your legs if necessary
- Don't toss and turn needlessly in bed. If you've been lying awake longer than 20 minutes, it's better to get up and do something relaxing.

Healthy eating

When we are in good health and also when we are sick, our personal diet preferences, attitude to food and eating habits often have a decisive influence on our individual quality of life. Our dietary choices are an expression of our personality: eating and drinking are part of (social) life, offer an occasion for enjoyment and relaxation, and enrich our day-to-day routine in the truest sense of the word 'meaningful'.

Diet is not the cause of RA. It is therefore important, in addition to the possibilities offered by diet options in RA, to clearly be aware of its limitations as well.

Diet cannot replace a medically prescribed therapy, and according to the current state of knowledge no diet is able to cure RA.

The opportunities and objectives of a diet adjusted to RA consist inter alia in influencing the inflammatory factors. That means the supply of inflammation-reducing dietary factors should be optimised, and the supply of inflammation-boosting factors decreased. The aim is to reduce pain and morning stiffness. By inhibiting the inflammatory factors and optimising cell protection, the disease progression can best be slowed. In addition, a targeted diet can counteract side effects of drugs, unwanted weight changes, cardiac conditions, osteoporosis and gout, and prevent or remedy any nutrient deficiencies.

'Eating for rheumatoid arthritis' information brochure available at: **www.arthritis.ch**
Available in german only

The Mediterranean Diet

A diet that is intended to holistically enhance health and well-being is varied, full of colour and gives top priority to vegetable food products. The diet of the Mediterranean countries has been found to be a good idea in RA.

- Eat in a relaxed atmosphere
- Lots of vegetables and fish, little (red) meat
- Regular fresh fruit
- Rice, potatoes, dark cereal products or pasta as a side dish
- Water as the main drink

A Mediterranean diet guards against arteriosclerosis, and due to the high proportion of vegetables it fills you up while remaining low in calories, thus having a preventive (but also therapeutic) effect against excess weight. In addition, the micronutrients contained in vegetables and fruit are valuable substances for essential functions.

Excess weight and digestive disorders

People taking medicines containing cortisol often notice unwanted weight gain. The Mediterranean diet counteracts this too: large portions of vegetables and fruit; at main meals always high-quality dietary protein from fish, dairy products, pulses or occasionally meat, along with small portions of wholemeal grains as a side dish; as snacks, low-fat dairy products or fresh seasonal fruit.

For gastrointestinal disorders, the consumption of mainly (gently) cooked foods can provide relief. Raw fruit and vegetables, especially in the form of cold, unripe, acidic fruit or salad, should be avoided as far as possible. Steamed vegetables, light vegetable soups and warm salads made from boiled vegetables are much easier to digest. Vinegar can be replaced with sour milk or mild fruit juice. Potatoes (including potato salad) are acceptable acid neutralisers, and chamomile or yarrow tea, perhaps with a teaspoon of freshly grated ginger, relieve stomach upsets.

Alcohol and smoking with RA

Restraint should be exercised when it comes to alcoholic drinks. This is especially true for patients who are being treated with drugs.

Smoking should be avoided, because it may aggravate a genetic predisposition to RA.

Complementary and alternative medicine approaches

In complementary and alternative medicine (CAM) there is not (yet) any method that has been found to be generally suitable for treating RA. That may be mainly attributable to the nature of such practices, because complementary medicine models and methods are generally geared to the individual patient and not to a disease.

However, the interplay of conventional and complementary medicine has produced therapeutic possibilities in which one option is taken, but the other need not be left out. Optimal monitoring of the patient through this expanded treatment option is a prerequisite for success.

CAM is a collective term for various healing doctrines which are presented as an alternative or complement to science-based medicine (conventional medicine). Alternative medicine, naturopathy, holistic medicine, biological medicine, gentle medicine, regulatory medicine, empirical medicine, natural healing and many other terms are synonyms that are also used. Several hundred types of practice which may be gathered under this generic term are known world-wide.

Some of these have now been well studied and proven, while others – however visionary they may

be – have yet to demonstrate proof of their effectiveness. This in particular can make it difficult for sufferers and those seeking help to find the combination of complementary medicine treatment options that is appropriate for the individual.

Efforts to integrate complementary medicine concepts into the range of available treatment options have made great advances in recent years in Switzerland in particular. Patients have access to a controlled selection of diverse schools of thought and approaches; specialists working across disciplines offer this 'integrative medicine' to those seeking help.

Complementary medicine methods can be used in both acute and chronic complaints, whether in the form of physical or emotional symptoms. In RA, CAM can be used to provide supplementary treatment of the disease, or to prevent or alleviate drug side effects and interactions. It can also be used to generally enhance quality of life.

The most common complementary medicine concepts and methods are briefly presented below:

Traditional Chinese medicine (TCM)
Traditional Chinese medicine (TCM) is one of the oldest and most comprehensive known sets of medical beliefs, now drawing on a wealth of experience dating back several thousand years. Chinese healers treat the person as a complex entity. Observations have given rise to various diagnostic methods such as tongue diagnosis, pulse diagnosis, facial diagnosis, systematic questioning and treatment methods such as classic acupuncture, use of remedies, massage techniques (Tui-na An Mo), heat applications, toxin removal and cleansing procedures, special dietary regimes, as well as breathing, movement and concentration exercises (Qi Gong).

Doctors, naturopaths and complementary medicine therapists often work hand in hand.

Neural therapy
Neural therapy is based on the idea that human connective tissue holds an important function in the body's information exchange. Connective tissue disorders, in the form of deposits (metabolic end products, heavy metals), papules (granulomas, especially in the teeth area), scars, etc., can produce interference fields which may be 'contributors' to chronic diseases.

In neural therapy, a low-dose anaesthetic is injected into specific body parts, nerves, muscles or joints, which has an effect on the corresponding internal organs. According to the ideas of the discoverers of this method, the Huneke brothers, this application via the nervous system should result in a 'readjustment' of the metabolism and thus re-regulation of the body's rhythms. Neural therapy is used in acute pain and inflammatory conditions (various types of headache, musculoskeletal pain) and in chronic pain. A treatment interval usually comprises 8 to 12 treatments; after that, the outcome achieved should be measured against the treatment target and reviewed. The practice requires extensive medical expertise and is usually carried out only by doctors with additional training.

Herbal medicine, phytotherapy
Phytotherapy is the study of medicinal plants, medicinal plant parts and their preparations as remedies. Phytotherapy is without a doubt one of the oldest forms of treatment. Depending on the type of formulation, various ingredients and active substances are dissolved out of a plant and used to produce a range of remedies that are applied to treat different symptoms: tincture, juice, tea, cream, ointment, emulsion, poultices or extracts for use as inhalants.

Many complementary medicine models have a treatment arm with herbal remedies: traditional Chinese medicine, Tibetan medicine, traditional European medicine and others. Depending on the underlying 'medicine model' and its diagnostic system and interpretation, the production and the preparation form developed, the dosage, drug administration and expected effect vary. Within the scope of their practical activity, many complementary medicine therapists act mainly in an advisory capacity, and refer patients to the chemist or pharmacist to buy the medicine recommended. An optimal form of allocation of competences and quality assurance for the patient.

Classic homeopathy

'Similia similibus curentur' – like cures like – is probably the best-known principle of homeopathy, a doctrine created by German doctor Samuel Hahnemann. Homeopathic remedies that cause healthy people to exhibit symptoms of a disease for which those seeking help require treatment are therefore used in accordance with the 'law of similars'. An important point in homeopathic treatment is that the homeopath obtains as much information from the patient as possible. The initial patient consultation is therefore very much a priority. Along with the acute treatment of symptoms, homeopathy is also used in the area of chronic diseases. Homeopathic remedies differ from conventional medications in both production and dose. Homeopathy uses highly diluted and potentiated medicines in which the chemical substance is usually no longer detectable. More than two thousand herbal, animal or mineral substances are available to the homeopath as drug deliverers.

Physical activity and sport

In addition to any physiotherapy treatments which may be necessary, in the remission phase it is important to be physically active.

Remission phase: Temporary or continuing easing of the symptoms in chronic illnesses, without cure being achieved.

What applies for healthy people is also particularly true for RA sufferers: Each step away from passivity – however small – is important. Even everyday activities have a positive impact on health and well-being. For RA sufferers, there are many good reasons to exercise regularly:

- Especially with endurance activities, pain is perceived less strongly and the need for painkillers decreases.
- Having a good level of fitness can better offset the effects of RA and its flare-ups.
- The consequences of secondary arthrosis are often surprisingly well counterbalanced if the musculature around the affected joint is in good physical condition.
- Exercise and sport affect the mind: They brighten the mood and have an anti-depressant effect.
- Self-esteem and stress intolerance increase.
- Physically active people live longer and are more mobile in old age, more independent and less reliant on assistance.
- Regular physical activity provides protection against many illnesses, particularly cardiovascular diseases.

Any physical activity of at least 10 minutes' duration counts.

Suitable activities

Everyday activities such as brisk walking, climbing stairs and cycling have the advantage that they can be easily integrated into the daily routine.

Types of exercise that require few resources and little training effort, hold a low accident risk and can

be practised for a lifetime are particularly suitable as leisure and sporting activities. These include:

- Hiking
- Walking
- Nordic Walking
- Cycling
- Swimming
- Water aerobics

Depending on your physical condition, endurance, strength and flexibility training can also be undertaken.

All movement-intensive types of sport which work the major muscle groups are suitable for **endurance training,** such as:

- Cycling
- Swimming
- Aquatraining
- Circuit training on fitness equipment

Strength training on equipment builds up and maintains the musculature. Alternatives to training on equipment are strengthening callisthenics or strength exercises with dumbbells or Thera bands. To prevent muscle shortening, strength training must always be supplemented with stretching exercises.

Flexibility training: The aim of flexibility training is to improve or maintain the mobility of the entire musculoskeletal system (joints, muscles, tendons). It includes callisthenics, stretching, yoga, Tai Chi Chuan and other forms of exercise.

'Moving through the day' calendar brochure available at: **www.arthritis.ch**
Available in german and french

Recovery/resting phases
In all disease phases, a balance between work phases and rest phases is important. An imbalance between the two has an unfavourable impact:

With an excessive workload and inadequate regeneration phases, there is a risk that the inflammation and pain will increase. This causes you to tire more rapidly, and ultimately leads to a decrease in physical performance.

But if the rest periods are too long and the physical exertion too undemanding, joint mobility won't improve; it may even decline and increase the risk of joint stiffening. In addition, muscle strength will not increase; it may even decrease. Ultimately, this can also result in a decline in physical performance.

So much is possible despite RA!

Coping with the changed life situation
These days, in many RA sufferers the effects of the disease are barely visible, and unsympathetic comments from friends and acquaintances are therefore on the rise. Such insensitive remarks, usually uttered thoughtlessly, can hurt inwardly and cause people to withdraw (from the social environment, relationship). In the course of the disease, superficial acquaintances become less important, while genuinely good, valuable friendships deepen. These relationships need to be cultivated, in order to draw strength from them and prevent a slide into isolation.

Any chronic illness is a challenge for a relationship. Some relationships fall to bits because of it; most gain new, deeper dimensions. Joint undertakings which are possible despite your RA should be deliberately maintained. Trips to the theatre, concerts or the cinema, holiday trips with plenty of time for unwinding, singing, dancing, swimming, hiking or cycling. Perhaps there's even an opportunity to discover new activities together. Shared experiences connect people. On the other hand, it's also good if the healthy partner is able every now and then to indulge his or her zest for action alone and without a guilty conscience. As a sufferer, one is also glad of the peace sometimes. It's important to live as normal a life as possible in spite of the disease.

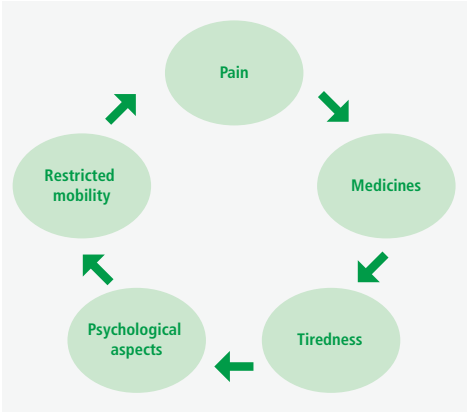
The same is true for your job. Anyone who is struck by a severe case of RA in the middle of an active career will inevitably have to give some though to their professional future. Will I still be able to do my current job in the longer term with the limitations caused by this disease? Is it worth constantly fighting (against the disease) to exhaustion? Would it make more sense to seize the opportunity for a career reorientation? Perhaps the opportunity has arisen for a long-sought change of career. (See also the section 'Working and RA')

Anyone who can't manage alone should feel no embarrassment about asking for professional help (see page 36). It's important not to withdraw because of the disease, but instead to consciously nurture and develop those abilities that you still have.

Be happy about what is still possible, instead of regretting the things you can no longer do.

Relationships – love life
The diagnosis of RA can be a big challenge for a relationship. Both partners need to learn to adjust to the disease with its symptoms such as limited mobility, pain and fatigue. Often, this calls for a rearrangement of the daily routine and a new way of being with each other. For single people, RA can be an obstacle in the search for a partner.

In addition to the gender-specific differences, there is also a whole host of physical (organic) causes for love life problems:



Furthermore, many RA drugs can interfere with the ability to enjoy a fulfilling sex life (loss of libido).

These problems also happen to people who are not suffering from a rheumatic illness. But rheumatic patients in particular often have additional problems which adversely affect their love lives. Often, chronic pain or special rheumatic drugs take away the appetite for pleasure, or flexibility restrictions mean certain positions can't be achieved at all. Added to this is tiredness and sometimes a lack of self-esteem.

But sex also has painkilling effects. During intercourse, a whole host of hormones and neurotransmitters are released, such as the body's own opiate, endorphin, which relieves pain.

Unfortunately, the subject of sex is still taboo in doctor's offices. A sense of shame, uncertainty and fear of invading people's privacy are common reasons why it is not talked about.

But how can a problem be solved if nobody talks about it? Both doctors and patients, and couples among themselves, should not be afraid to talk to each other. Only by doing so can fears be dispelled and solutions found. Talk to each other about your idea of a fulfilling sex life and how you could achieve it. Choose other forms of sexual intimacy – tenderness, relaxation, mutual massaging. Talk to your doctor – maybe 'passion-killing' drugs can be reduced or stopped. Erection aids or lubricants/care products may also enhance your love life.

Don't forget humour – after all, sex is supposed to be fun!

Tips for relationships

- Talk openly with your partner about your needs
- If you are worried that the rheumatism drugs will result in a loss of libido or have other effects, ask your doctor for advice.
- Compare notes with other sufferers, including in self-help groups.
- Don't put pressure on yourself. Relaxation and warmth help – perhaps through a soothing bath.

Pregnancy

For an RA patient, it would be ideal to fall pregnant in a quiet phase of the RA – that is, when there are no symptoms and therefore no medication is needed. Since an active illness not controlled by medication has a negative effect on the embryo, it is sometimes necessary to take medication during the pregnancy, to keep mother and baby as healthy as possible. Some drugs can be taken safely during pregnancy; others are not suitable. Anyone planning a pregnancy should inform the doctor treating them at an early stage, so that any drugs that would be harmful for the unborn child can be stopped.

Women with RA usually have just as many children as healthy women. However, RA patients have more difficulty getting pregnant. A number of causes could be acting together here: very active RA can negatively influence hormone balance, and also prevent the frequency of intercourse. In addition, some drugs can prevent conception, or at least make it difficult. Women who fail to fall pregnant within a year should see a gynaecologist to have the possible causes clarified.

Pregnancy usually has a favourable effect on the symptoms of RA. 60 to 75% of all pregnant women with RA experience an improvement in their joint pain during their pregnancy, although only one third achieve complete freedom from symptoms. The patients feel better than usual and notice a reduction in pain, joint swelling and stiffness.

Unfortunately not all RA patients experience an improvement. In 10 to 25% of patients, good days alternate with bad days just as they did before the pregnancy.

Some patients even experience a worsening of their joint pain. Unfortunately it is not known why

these differences exist, and it cannot be predicted which patients can look forward to an improvement in their disease during pregnancy, and which cannot. Nor are there any blood tests that could provide information in advance on how the disease will behave during a pregnancy.

Even if a pregnancy significantly improves the mother's illness, in about 90% of RA patients there is a renewed increase in activity of the joint pain (flare-up) several weeks to months after the birth. Breastfeeding does not prevent this flare-up, because usually symptoms occur in the same joints that were previously affected. But new joints may also be inflamed. However, in the course of the first year after the pregnancy there is usually a slowing-down of the symptoms.

'Rheumatoid arthritis and pregnancy'
information brochure available at:
www.arthritis.ch
Available in german only

Working and RA

If you are no longer able to provide full job performance due to your illness, it is important to note the following:

- Have the disease progression accurately documented by your doctor
- Do not 'voluntarily' reduce your workload without confirmation from the doctor that it is being done for health reasons
- Do not make a change of position for less pay without medical certification that the change is health-related

because this negatively affects your protection under social security law. The best approach is to have a discussion with your employer and inform him about your health problems, if he is not yet aware of them. Usually the employer contacts the disability insurance provider (IV).

The next step is registration with the IV of your canton of residence. It must be clearly noted here that the IV does not pay benefits only after the waiting year. This is relevant only with regard to arranging a disability pension. The certification of any previous loss of revenue is crucial for any such disability pension; otherwise the IV takes the last earned salary as the starting basis for calculating the degree of disability.

After registration for IV benefits, the IV contacts your employer (subject to your agreement). The IV office will then clarify with you and your employer as part of the early intervention what measures are necessary to enable you to keep your job: for example, a change of role within the company, working part time, or special aids in the workplace. The IV office may also contribute financially to measures such as training courses or structural interventions. Furthermore, the IV will pay your employer a settling-in allowance for a maximum of six months if you are temporarily not fully productive – for instance, after a change of role. Other benefits as part of the early intervention are an employment service, vocational guidance and various aids.

If it turns out that the measures under the early intervention programme are not sufficient (in particular because they are usually only given for six months), further reintegration measures can be claimed from the IV, provided such measures are appropriate to restore, improve or maintain your fitness for work. In addition to vocational guidance

and employment service, the reintegration measures include in particular occupational re-training.

A prerequisite for the granting of occupational re-training is that professional training was completed or a specific earnings level achieved prior to onset of the disability. The IV will pay all costs for the re-training and a daily allowance.

The daily allowance is intended to guarantee a means of subsistence during the rehabilitation, and generally amounts to 80% of the last earned salary.

If you are no longer able to provide full job performance due to your illness, the following applies:

- early intervention
- reintegration
- occupational re-training

Helping people to help themselves

The Swiss Polyarthritis Association SPV has been in existence for more than 35 years and campaigns across Switzerland as a nation-wide patient organisation for a better quality of life and for assistance to enable sufferers of rheumatoid arthritis (RA) or a related illness to help themselves.

The SPV is an independent member of the umbrella organisation Rheumaliga Schweiz and affiliated with the ZEWO. The executive committee and managing board are composed of RA sufferers working voluntarily. The office is managed by an employee with RA.

The SPV achieves its main objectives – enhanced well-being and improved disease management for sufferers – through generating publicity and by providing advice and motivating sufferers to help themselves.

The main concern of the SPV is to provide its members with the most comprehensive information on the latest medical treatment methods, to present modern therapy forms and complementary therapies, but also to continuously adapt to current events any information that affects the environment of sufferers. For this purpose, the SPV publishes the quarterly magazine 'info'.

On the website www.arthritis.ch you can find the regional groups, which are there to support sufferers with a wide range of information, and specific medical questions can be directed to a consultant rheumatologist.

www.arthritis.ch

The website of the Swiss Polyarthritis Association includes a wide range of assistance services, information and contact options

Notes

Annex

Addresses and links

Swiss Polyarthritis Association SPV
Josefstrasse 92, 8005 Zurich
Telephone: 044 422 35 00
spv@arthritis.ch, www.arthritis.ch

Information, advice, courses, talks, 'info' magazine (quarterly)
Annual membership fee: CHF 50.–
(including annual subscription to 'info')

Rheumaliga Schweiz
Josefstrasse 92, 8005 Zurich
Tel. 044 487 40 00
Bookings: tel. 044 487 40 10
info@rheumaliga.ch, www.rheumaliga.ch

Information and brochures, courses and events
Advice, tools and aids for everyday life
'forumR' patient magazine (quarterly)

Centre for Pregnancy in Rheumatic Diseases
University Hospital for Rheumatology,
Immunology and Allergology
Dr Frauke Förger
Inselspital BERN,
3010 Bern
Tel. 031 632 30 20
schwangerschaft-rheuma@insel.ch,
www.muetterzentrum-ria.insel.ch

Pro Infirmis
Feldeggstrasse 71, Postfach 1332, 8032 Zurich
Tel. 058 775 20 00
contact@proinfirmis.ch, www.proinfirmis.ch

Cantonal specialist department for social work,
offering online advice

Exma VISION
Swiss exhibition of aids and resources
Dünnerstrasse 32, 4702 Oensingen
Tel. 062 388 20 0
exma@sahb.ch, www.exma.ch

Inclusion Handicap
Mühlematttstrasse 14a, 3007 Bern
Tel. 031 370 08 30
info@inclusion-handicap.ch, www.inclusion-handicap.ch

Umbrella association of the Swiss Disability Organisation, specialist office, experts and legal advisors
Dachverband Schweizerischer Patientenstellen
(umbrella association of Swiss patient offices)
Hofwiesenstrasse 3, 8057 Zurich
Tel. 044 361 92 56
dvsp@patientenstelle.ch, www.patientenstelle.ch

SPO Patientenschutz (SPO patient protection)
Häringstrasse 20, 8001 Zurich
Tel. 044 252 54 22
spo@spo.ch, www.spo.ch

Advice, information and clarification of patient concerns

Schweizerische Gesellschaft für Rheumatologie
(Swiss Rheumatology Society)
c/o Rheumaliga Schweiz, Josefstrasse 92, 8005 Zurich
Tel. 044 487 40 10
info@rheuma-net.ch, www.rheuma-net.ch

More links on the topic

German Rheumaliga: www.rheuma-liga.de
Austrian Rheumaliga: www.rheumaliga.at
Arthritis Foundation: www.arthritis.org
Associazione Nazionale Malati Reumatici:
www.anmar-italia.it
Association Française des Polyarthritiques:
www.polyarthrite.org www.polyarthrite.org

Acknowledgements

The Swiss Polyarthritis Association would like to thank the authors for their articles which appeared in this broschure either completely or in part.

Dr. med. Thomas Langenegger, Zuger Kantonsspital, Baar

Prof. Dr. med. Diego Kyburz, Universitätsspital Basel

Prof. Dr. med. Thomas Stoll, Kantonsspital Schaffhausen

Dr. med. Adrian Forster, Kantonsspital Winterthur

KD Dr. med. Thomas Böni, Universitätsklinik Balgrist, Zürich

PD Dr. med. Beat R. Simmen,
Privatklinikgruppe Hirslanden, Zürich

Prof. Dr. med. Monika Østensen,
Schwangerschafts-Rheumatologie

Dr. med. Mona Riebe, Chur

Prof Dr. Karin Niedermann,
ZHAW, Fachbereich Physiotherapiewissenschaften

Markus Maggi, Fachpsychologe für Psychotherapie FSP

Urs Gruber, Naturheilpraktiker

Annelie Scheifele, dipl. Ernährungsberaterin HF

Uwe Koch, Dozent für Sozialversicherungen und Sozialpolitik

Dr. Elisabeth Surbeck, Präsidentin der SPV 1997 – 2005

The Swiss Polyarthritis Association SPV can carry out its many tasks as an organisation to support those affected only with your support. All donations are welcome. **Thank you!**

Empfangsschein / Récépissé / Ricevuta

Einzahlung für / Versement pour / Versamento per

Swiss Polyarthritis Association
Feldeggstrasse 69
P.O. Box 1332
8032 Zurich

Konto / Compte / Conto **80-37316-1**

CHF

Einbezahlt von / Versé par / Versato da

Die Annahmestelle
L'office de dépôt
L'ufficio d'accettazione

Einzahlung Giro

Einzahlung für / Versement pour / Versamento per

Swiss Polyarthritis Association
Feldeggstrasse 69
P.O. Box 1332
8032 Zurich

Konto / Compte / Conto **80-37316-1**

CHF

105

Versement Virement

Zahlungszweck / Motif versement / Motivo versamento

☐ I would like to become a member (CHF 50.–)
☐ Donation

Versamento Girata

gdz 10.2016 200

Einbezahlt von / Versé par / Versato da

441.02

800373161>

800373161>

Rheumaliga Schweiz
Bewusst bewegt

The SPV would like to thank the following companies for their generous support in the publication of this brochure: