

Treating Cancer with Proton Therapy

Information for patients and family members





**Professor Dr. med. Damien Charles Weber,
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Dear readers

Proton therapy is a special kind of radiation therapy. For many years now, patients suffering from certain tumour diseases have successfully undergone proton radiation therapy at the Paul Scherrer Institute's Center for Proton Therapy.

This brochure is intended to give a more detailed explanation of how proton therapy works and provide practical information on the treatment we offer at our facility. We will include a step-by-step description of the way in which we treat deep-seated tumours. We will not deal with the treatment of eye tumours in this brochure. If you have further questions on the proton therapy carried out at the Paul Scherrer Institute, please do not hesitate to address these by getting in touch with our patient office. Contact details are provided at the end of the brochure.



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Radiation against cancer





Because it can be used with great accuracy, proton therapy is a particularly sparing form of radiation treatment with lower side effects. This kind of treatment is suitable above all for young cancer sufferers and for the treatment of tumours located close to radiation-sensitive organs.

Cancer and cancer therapies

Every third person develops a malignant tumour over the course of their life. In Switzerland, about 45,000 people face a cancer diagnosis every year. There are many different kinds of cancers. Many have become easier to cure than they were just a few years ago. Each kind of cancer reacts to certain kinds of therapy or to a specific combination of therapies.

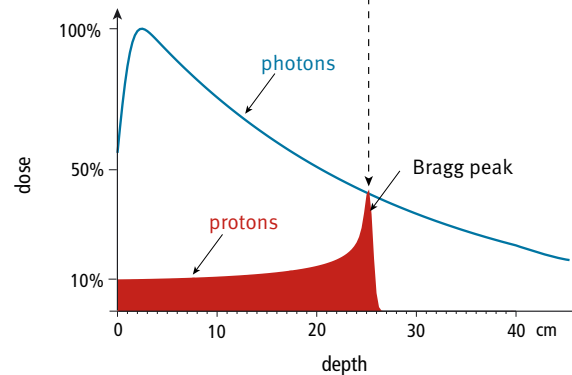
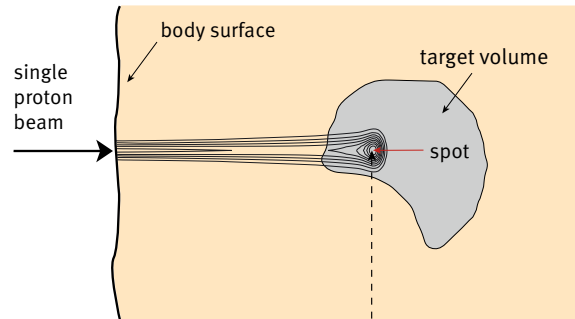
The most important cancer therapies are:

- surgery (operation),
- radiation (also known as radiation therapy),
- drug-based therapy (such as chemotherapy, immunotherapy, anti-hormonal therapy).

More than half of all cancer patients receive radiation therapy in the course of their treatment. In most cases, radiation is combined with one other method of treatment: those affected are treated either before, during or after radiation with a second type of therapy. In some cases, even an inoperable tumour can be cured with radiation. Like operations, radiation therapies belong to the category of local therapies. This means that the treatment targets only the tumour itself and possible side effects are limited to the affected area. Chemotherapies and other so-called systemic therapies are necessary when small clusters of tumour

Radiation dose delivered by a pencil-thin proton beam penetrates body tissue to a specific depth determined by beam energy at point of entry.

In the top picture is a graphical representation of the dose distribution. In the bottom picture the proton dosage compared to the photon dosage (X-ray) as a function of depth.



cells or metastases – cells that have detached themselves from the original tumour – need to be targeted and destroyed elsewhere in the body.

Radiation therapy

In radiation therapy, cancer is treated with the help of ionising radiation. Such radiation damages the genetic material located in the nucleus of the cancerous cell. As a result, the irradi-

ated cancerous cell is unable to proliferate and subsequently dies.

Two kinds of ionized beams are used in cancer therapies: X-ray radiation or charged particles.

Traditional radiation oncology works with X-rays. However, more and more treatment centers are being established around the world where patients are treated with protons. The Paul Scherrer Institute is one of the pioneers of this comparatively new form of

therapy. Protons are positively-charged particles, which is why these therapies are also referred to as particle radiation. Proton beams are the most common form of radiation used in particle therapy.

What are protons?

Protons are parts of atoms, just like neutrons and electrons. Neutrons and protons are found in the nucleus of an

atom. Electrons are found in the atomic shell. Protons carry a positive electric charge. They constitute atoms, along with the uncharged neutrons and negatively-charged electrons. As the basic element of all solid, liquid and gaseous materials, atoms constitute the building blocks of all objects and living things.

The protons used for proton therapy at the PSI are extracted from hydrogen, the principal component of water. The hydrogen atom is the simplest of all atoms: it consists of only one proton and one electron and has no neutrons. The negatively-charged electrons are separated from the atomic nucleus of hydrogen atoms through a process of electrical discharge, leaving only the positively-charged protons. For the purposes of proton therapy, these remaining protons are subjected to rapid acceleration and are bundled into a beam form by a large, ring-shaped machine (cyclotron). The beam is then directed at the tumour. By the way: tiny amounts

of hydrogen are needed for proton therapy: one course of treatment with 35 sessions requires only one sixth of a billionth of a gram. Or in other words: in theory, 1 gram of hydrogen would be enough to treat the entire world population with protons.

How protons work in the body

Like X-rays, proton beams damage the genetic make-up of cancerous cells, robbing those cells of the ability to proliferate, and eventually causing them to die off.

However, both kinds of radiation treatment affect not only cancerous cells but also healthy ones. Traditional radiation carried out with X-rays can't avoid damaging the tissue surrounding a tumour. This side effect is significantly less pronounced during proton therapy. Surrounding tissue and vital organs are not harmed significantly. Proton beams

give the most impact where they are most needed: in the tumour itself. The penetration depth of protons can be precisely calculated in advance, enabling the proton beam to develop maximum dosage within the area of the tumour. Most of the proton's energy is released when the proton stops travelling at a spot called the Bragg peak, named after its discoverer William Henry Bragg. No radiation penetrates further than this spot. On its way from body surface to tumour the proton beam emits only small amounts of radiation into the healthy tissues, as can be seen in the diagram on the opposite page. Proton therapy is only half as damaging to the body than a comparable dose of traditional radiation: neighbouring structures and sensitive organs such as the brain, the eyes, the spine, the heart or the intestines are not harmed as much. As a patient, you benefit from fewer side effects. The precision of proton therapy makes it possible to treat some cancers with

higher radiation doses, improving a patient's chances of being cured.

For which patients is proton therapy suitable?

In many countries, proton therapy is still considerably more expensive than conventional radiation therapy with photons. For this reason, the therapy is currently only considered for patients for whom significant advantages can be expected compared to conventional radiation therapy. In Switzerland, these cancers are listed on the so-called medical indication list for proton therapy drawn up by the Bundesamt für Gesundheit (Federal Office of Public Health – see page 16).

Children suffering from cancer are especially likely to benefit. The younger the patient the more important it is to minimize the long-term effects of radiation, including those for which the therapy might affect growth and

development. The risk of developing secondary tumours in healthy tissue at a later stage (sometimes years or decades later) is minimised. This is why the Paul Scherrer Institute specialises in the radiation treatment of children. For more information on the treatment of children, go to page 30.

At a glance: the advantages of proton therapy

- high precision tumour irradiation
- high radiation dose within the tumour with favourable dose distribution
- minimal damage to healthy cells of the body
- few side effects, good quality of life
- good, sustained chances of recovery





Physics in the service of medicine

The PSI has over thirty years experience in the use of proton therapy. Our research laboratories developed the spot-scanning procedure that pin-points and destroys tumours.

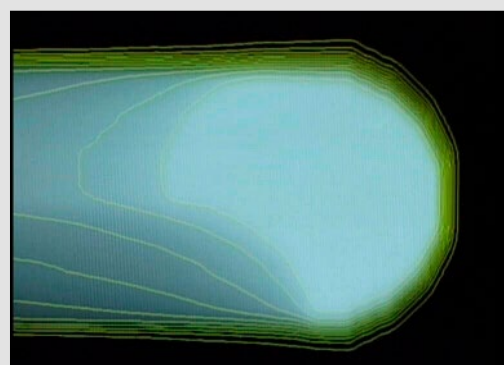
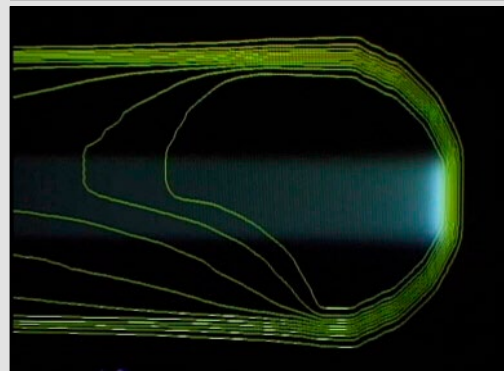
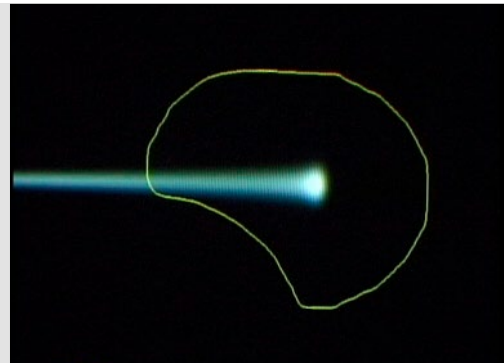
Innovative spot-scanning

The spot-scanning procedure developed by the Paul Scherrer Institute makes it possible to accurately irradiate tumours with a precisely defined radiation dosage. The spot-scanning technique is now used all over the world and has established itself internationally as the most promising development in proton therapy.

This method has been implemented at PSI since 1996. It is also called pencil-beam scanning, based on the fact that the proton beam is only as thick as a pencil: about five to seven millimetres.

The principle of the spot-scanning technology developed at PSI

The three pictures show how the proton beam progressively encompasses the entire tumour volume. The first picture shows a single proton beam within the targeted area outlined in yellow, schematically representing the tumour. The beam emits its maximum dose at the end of its trajectory. Bit by bit, layer by layer, the beam scans through the targeted area. As can be seen on the third picture, the entire tumour is then targeted with the maximum dosage. To the left of the tumour, the proton beam gives a lower dose than within the target; there is no more proton radiation on the right-hand side of the picture, beyond the edge of the tumour.



Point by point, layer by layer

What makes spot-scanning special: the pencil-thin beam starts by scanning a given layer in the tumour. The beam is directed into all possible corners and recesses of that layer, developing its destructive impact spot by spot. The same process is carried out on the next layer and repeated, layer by layer, until the proton beam has spot-scanned through the entire tumour volume. About 10 000 spots are required to scan a tumour with a volume of one litre. Within this process, it's possible to calibrate the radiation dosage very accurately: every point emits a precisely defined radiation dose. The pencil-thin beam scans through the tumour more than once. At PSI, tumours are irradiated from several directions (or fields).

As a result, spot-scanning has a number of advantages: proton beams adapt themselves with great precision to a tumour's three-dimensional form. Healthy areas are barely affected. The distribution of spot doses within the tumour can also be adjusted depending on patient requirements.

A further advantage of intensity-modulated proton therapy is the ability to perform a dose boost to the tumour. This is the term given by radiation oncologists to the extra dose of radiation directed at a small area within the tumour in which the danger of recurrence is greatest. Generally, the boost is administered at the end of treatment.

PSI as pioneer

Proton therapy has a long tradition at the Paul Scherrer Institute: doctors and medical physicists working in Villigen in the Swiss Canton of Aargau began irradiating ocular tumours with highly successful courses of proton treatment as early as 1984.

From 1996 onwards, we expanded our therapy to include treatment of deep-seated tumours. Since that time, patients have benefited from the spot-scanning procedure invented by PSI, which destroys tumours with a finely modulated beam. Since 2004, we have been able to treat infants (under anaesthetic) with this therapy. A team of anaesthetists from the Zurich Chil-

dren's Hospital (Kinderspital Zürich) is responsible for administering anaesthetics to children undergoing treatment at PSI.

Combined strength: clinic and research

The Center for Proton Therapy (CPT) is part of the PSI research facility. As such, we guarantee state-of-the-art, on-site expertise based on our continued research into and development of new technical procedures aimed at improving cancer treatments. At the same time, your needs as a cancer patient, as well as the results of medical evaluations, continue to inform our research at CPT. Patients at CPT receive qualitatively outstanding treatment. The therapy is reliable and effective, and is carried out under strict supervision.

Proton therapy research for patients

The Paul Scherrer Institute leads the field in research. Scientists are dedi-

cated above all to progress in the field of proton therapy with particular emphasis on the question: how is optimum treatment possible without damaging healthy tissue?

At PSI scientists are exploring the best approach to treating moving tumours with protons. Moving tumours are those that change position minimally as a result of breathing and can include lung or breast cancer tumours.

We are continually evaluating clinical patient data within the framework of scientific projects. We also carry out studies on quality of life after proton therapy or on other specific, therapy-linked issues. We welcome the participation of any patient willing to take part in these studies, which are carried out according to Switzerland's strict legal guidelines. Such studies serve as an ongoing quality control as well as improving the range of therapies we are able to offer. Study results are published in scientific journals and presented at specialist conferences.

Great technology for small particles

The centrepiece of the PSI's proton therapy facility is the particle accelerator COMET (COmpact MEDical Therapy Cyclotron). The accelerator weighs 90 metric tons and supplies all treatment areas with protons.

COMET accelerates protons to a speed of about 60 per cent of the speed of light. This corresponds to about 180,000 km per second. During this procedure, the particles circle around the cyclotron ring several hundred times, picking up speed and energy. They are subsequently catapulted out of the cyclotron, bundled and slowed down where necessary. At PSI, this part of the process is carried out by so-called "degraders" or brake plates, which are inserted into the radiation beam. Magnetic fields direct the beam to the respective radiation treatment rooms.

A sophisticated, five-step control system carries out checks every hundredth of a microsecond to ensure that proton beams are being correctly directed. In this way, the safety of the cyclotron, the distribution system and the treatment areas are guaranteed.

Successful treatments: the numbers

By the end of 2022 PSI had treated over 8000 patients with ocular tumours and more than 2000 with deep-seated tumours. Among them more than 770 children and young persons were able to benefit from this more sparing form of therapy.

In over 98 per cent of ocular cancers treated in Villigen since 1984, tumour growth was arrested. In over 90 per cent of these cases, the affected eye was saved.

In contrast to ocular cancers, the deep-seated tumours constitute a more diverse group. Successful treatment depends largely on the location, size and type of tumour, as well as on various forms of pre-treatment. For example: a given course of cancer treatment results in long-term tumour control in up to 90 per cent of cases, whilst for other types of tumour 66 per cent of patients can expect at least five years of tumour control.



Competence at the Center for Proton Therapy

What does a Medical Physicist do?



What does a medical physicist do?

Medical physicists are responsible for the technical quality of the proton therapy administered at CPT. A team of specialists makes sure that patients are treated safely and responsibly. On the one hand, they make sure that technical devices are kept in perfect running order. On the other hand, they also draw up individual, computer-supported therapy plans for every single patient.

Do medical physicists work side by side with doctors?

Doctors take care of the patients. Medical physicists are the “doctors in charge of the machines and software systems”. Cooperation is close and starts with the tumour board that helps us assess patient suitability for proton therapy. They also take joint responsibility for the therapy planning: medical physicists are interested, above all, in matching the best form of radiation with the individual’s specific condition. That includes decisions on the beam direction and the level of individual doses emitted by the spot-scanned beam in different parts of the body.

What makes spot-scanning special?

The spot-scanning method was developed here at the PSI and has become the modern standard for proton therapy worldwide. The reason why spot-scanning is so successful is that it allows every point of the targeted tumour tissue to be irradiated using only a pencil-thin beam, with minimal effect on the surrounding organs.

Do medical physicists also carry out research?

The CPT employs not only medical physicists working in clinical surroundings but also those involved in research. I myself coordinate our research projects. Research is important for the continued improvement of treatment. Being close to the clinic is essential in this process since it allows them to investigate and adapt methods to real-life issues and problems. Patients need to know that every new development or technical improvement is a long process. Applying research results to treatment methods is subject to strict control mechanisms.

Practical information on treatment at PSI

The following pages contain the most important information on proton therapy carried out at PSI, from treatment duration and costs to a list of tumours that we treat here at CPT. This brochure provides information on the irradiation of deep-seated tumours. Treatment of ocular tumours is not covered in this brochure.

Professional competence at all levels

The Center for Proton Therapy CPT works with an expert team of doctors, medical physicists, radiation therapists (RTTs), a nurse, a psycho oncologist and other specialised professionals.

Our treatment team is on hand to take care of you before, during and also after therapy if needed.

Indication list BAG (Federal Office for Public Health)

- all tumours afflicting infants (including anaesthetic), children and young people
- benign or malignant meningioma (tumours that develop in the cerebral membrane)
- so-called low grade glioma (brain tumours arising from glial cells in the supportive tissues of the brain)
- tumours of the skull base
- tumours in the head and neck area (ENT tumours)
- sarcoma, chordoma and chondrosarcoma (cancers that grow in connective and supporting tissue)
- intraocular melanoma (cancer that grows at the back of the eye)

The CPT maintains intensive cooperation with numerous partner clinics in Switzerland and beyond. Both the Zurich University Clinic (USZ) as well as the Inselspital hospital in Bern offer consultations for proton therapy. Our work is subject to specific quality standards and our facilities are regularly checked by the Federal Office for Public Health (Bundesamt für Gesundheit – BAG).

List of tumour types treated with proton therapy

At PSI, proton therapy is used to treat patients with tumours specified on the tumour-type list published by the Federal Office for Public Health (Bundesamt für Gesundheit - BAG). Compulsory health insurance covers the cost of these. Other types of tumours are only treated at PSI in exceptional cases.

PAUL SCHERRER INSTITUT
PSI

**Protonentherapie
OPTIS**





Duration of therapy

A course of proton therapy takes between six to eight weeks. During this time, you or your child will generally receive radiation four to five days per week, excluding the weekends, during which treatment does not normally take place. The overall total number of radiation sessions ranges from 30 to 40. If you or your child are also undergoing chemotherapy, you will still receive radiation on weekdays at PSI. On some days, chemotherapy takes place after a radiation session or on the weekend

and is carried out by your university clinic, your oncologist or your cancer specialist.

Outpatient treatment

Treatment of you or your child takes place at PSI on an outpatient basis. You are allowed to return home after each radiation session.

If you live further away and prefer to avoid a daily commute to Villigen, our patient office is happy to organise a furnished flat or hotel room near the

PSI on a daily or weekly basis. They are happy to help with these questions and other practical issues concerning accommodation or driving directions. Should it be medically required, you will also be entitled to accommodation in a local hospital close to PSI during your radiation treatment. These include the hospital in Leuggern or the county hospitals in Baden and Aarau. Transport to and from these hospitals will be arranged.

Costs of proton therapy

In many countries, including Switzerland, proton therapy tends to be more expensive nowadays than normal radiation therapy.

For persons covered by Swiss health insurance, the costs of treatment for tumours listed on the tumour-type list of the Federal Office for Public Health (BAG) are covered by the compulsory health insurance.

Treatment costs for patients from the rest of Europe are normally covered by the E112 or S2 form in direct cooperation with the patient's health insurance provider. These forms are provided by the health insurance companies.

Generally very well tolerated

Radiation itself cannot be felt. Some sensitive organs and body regions can be better protected during proton therapy than during best possible forms of traditional radiation, which also means that there are fewer side effects.

During the weeks over which the radiation sessions take place, patients sometimes feel increasingly tired and listless. This effect is referred to as fatigue. Treatment of a brain tumour may also lead in some cases to temporary dizziness and headaches as well as nausea and vomiting. Hair loss is only experienced when the radiation reaches the hair roots. Hair generally

grows back within a few months of completing treatment.

This brochure does not go into the details of possible side effects or long-term damage since these vary considerably depending on the type of tumour, its location, as well as the patient's individual situation. In principle, however, such damage can only take place in the parts of the body that lie within the radiation field. There is no damage

away from the treated area. Before the start of proton therapy, the attending physician will give a detailed explanation of the kind of side effects that may affect you personally, or your child.

Why are so many radiation sessions necessary?

Before beginning the radiation sessions, radiation oncologists calculate the overall dosage of proton radiation that a patient requires. This dosage is divided into so-called fractions: If a tumour is to be destroyed with an overall dosage of 60 Gray (the measure of energy deposited in the body), every individual radiation session needs to administer one thirtieth of this amount (2 Gray). Four or five days of radiation sessions are followed by a pause. The basic idea behind this fractionated therapy is to completely destroy the genetic material in the cancerous cells so that these cells die off. This requires many sequential radiation sessions. Pausing between sessions allows the surrounding tissue to recover and repair itself. Cancer cells are not as good at repairing themselves. That is why the radiation damage in the tumour accumulates after many sessions and finally destroys the tumour.

Competence at the Center for Proton Therapy

What does a Radiation Oncologist do?



What does a radiation oncologist do?

A radiation oncologist analyses the individual tumour situation and decides which patients are eligible for proton therapy. They are subsequently responsible for therapy planning and implementation, as well as patient care. As a senior physician they are also in charge of supervising and training assistant radiation oncologists.

Which patients are eligible for radiation treatment at CPT?

We do not carry out irradiation on all types of cancer, but only on those likely to derive considerably greater benefit from this form of treatment than from traditional radiation. Our patients come from Switzerland and abroad. Since proton therapy has comparatively few side effects and barely affects healthy tissue, it is especially suited for the treatment of children. This is why more children receive radiation treatment here at CPT than in any other radiation oncology clinic in Switzerland.

How does proton therapy differ from traditional radiation therapy?

Both X-rays and proton radiation have the same effect on tumour cells: they damage the genetic material located in the nucleus of the cancerous cell so that the cells are unable to proliferate and subsequently die. Since our proton irradiation is carried out with pinpoint accuracy, the surrounding healthy tissue suffers less damage, thereby minimising the risk of developing long-term side effects. In some cases, this enables us to increase the radiation dosage within the tumour and this, in turn, improves recovery rates.

How does the CPT differ from a hospital?

Most treatments are carried out on an outpatient basis. If it is necessary to be treated as an inpatient, patients are accommodated in neighbouring clinics and are driven here once a day to receive radiation treatment.

In good hands during treatment

This chapter is devoted to a step-by-step explanation of how PSI uses proton therapy to treat deep-seated tumours in order for you to better understand the procedure, and specific details of your therapy and help you find your way around the Center for Proton Therapy.

Request or referral

Most of our patients are referred to us by radiation oncology departments of university clinics and hospitals at home and abroad.

If the tumour with which you have been diagnosed is one of those listed in the indication list published by the Federal Office of Public Health (Bundesamt für Gesundheit – BAG, see page 16) you,

yourself, are entitled to approach us. Contact with your own doctors is of paramount importance since it guarantees that you will be taken good care of before proton therapy begins and after it has been completed.

The tumour board

The decision to administer proton therapy to you or your child at PSI is taken by an interdisciplinary team of doctors and medical physicists that constitute a so-called tumour board. The tumour board meets once a week. In addition to our in house specialists, most tumour boards also involve physicians from other hospitals who participate in tumour board consultations via video conference.

The specialists review your medical history taking into consideration all relevant scans and reports, and results from previous examinations and treatments.

Following joint discussions, the board decides whether proton therapy is suitable for you or your child and how best to administer it. If the board decides that proton therapy is not suitable for you or your child, the doctors recommend an alternative form of treatment.

First consultation with the doctor

Our patient office will invite you to a first consultation with one of our radiation oncologists, where you will be informed in greater detail about the therapy, treatment objectives and possible side effects. Within the framework of this consultation you will also be informed (where applicable) of the possibility of taking part in appropriate studies. You can decide at your leisure whether or not you wish to participate. A physical exam is also part of this first consultation, providing the doctor with a comprehensive picture of you and



your illness, or that of your child. You are welcome to ask any questions you may have regarding treatment during this consultation.

Preparatory examinations

In general, two medical imaging examinations are necessary in order to plan radiation treatment: a Magnetic Resonance Imaging (MRI) and a CT (computed tomography) scan, the so-called planning CT. The images are superimposed over one another, giving an accurate picture of the location and extent of the tumour, and allowing the therapy planning team to begin drawing up treatment procedures.

Important and highly individual: positioning

Immediately before or after the medical imaging examination, the radiation

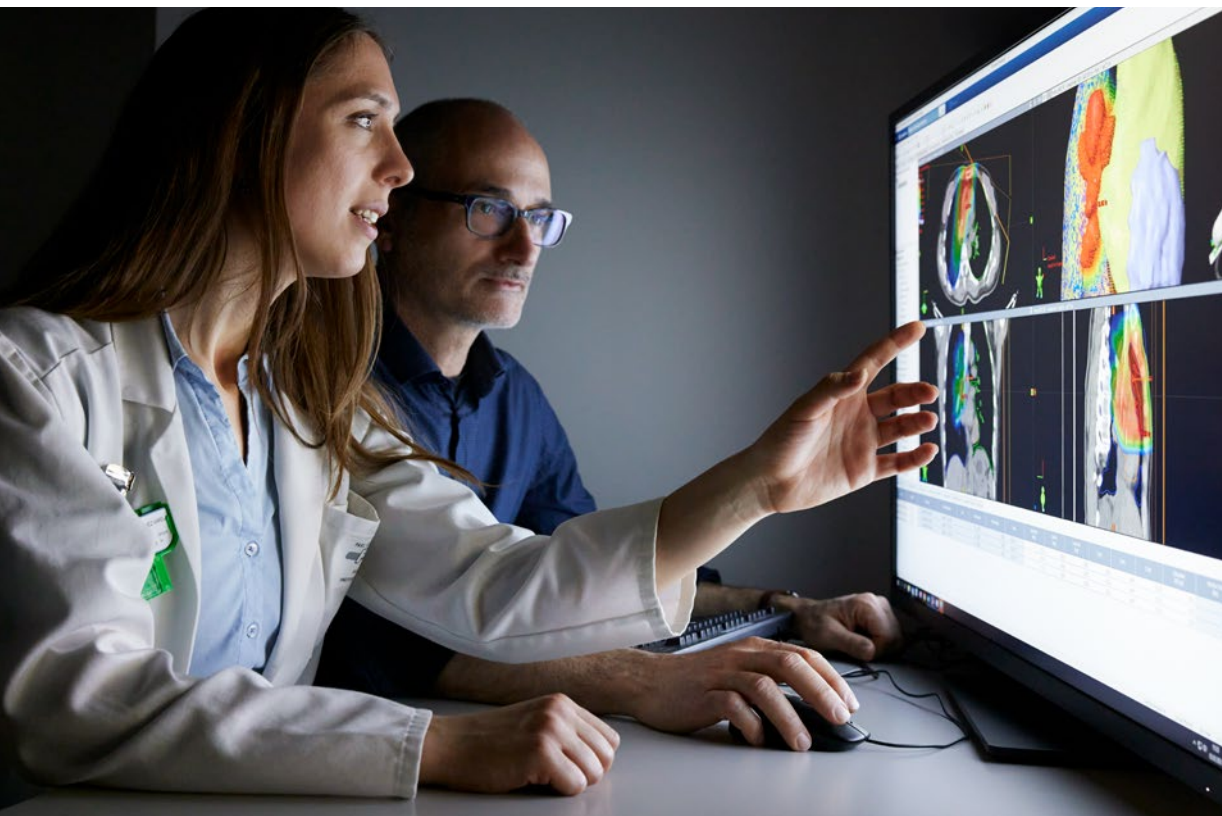
therapists (RTTs) construct the patient's individual positioning cushion. This is a cushion made either for the whole body or for the body area to be irradiated.

The cushion is intended to help you or your child maintain the same position during each radiation session. This is a very important factor in precision-based proton therapy. It also ensures that you, as the patient, are as comfortable and relaxed as possible for the entire duration of the radiation treatment.

We use two kinds of positioning cushions: vacuum cushions or those made with the material used for especially fine-grained contour mattresses (resin-coated Styrofoam pellets). If an area of the head is to be irradiated, you will be given a fitted face mask or a specially made device fitted with your dental impression onto which you can bite during treatment.







Treatment planning

Treatment planning is based on the planning CT and MRT results. Radiation oncologists draw up a treatment plan in cooperation with medical physicists using computer programmes developed at PSI.

Therapy planning contains information both on the precise arrangement of the designated treatment equipment for

you or your child, and on proton beam intensity and direction.

Our objective is to optimise proton therapy so that the dose reaching the tumour is high enough to destroy the tumour, while inducing minimal side effects on the tissues immediately surrounding the tumour. To achieve this result, the planning team calculates the optimum beam projection as well

as proper dosage, setting the required radiation dose for every spot of the tumour target volume. In order to ensure that all tumour cells are reached, a safety margin around the tumour itself forms part of this calculation. The planning process also takes into account and limits the level of (undesired) normal tissue irradiation around the tumour.

Regular radiation sessions

Once the treatment plan has been drawn up, you will be asked to start your course of radiation. From this point onwards, you'll be coming to PSI four or five times per week over a period of one-and-a-half to two months. If you need to attend other important appointments during this time, please inform the secretaries early on so that we can make an effort to accommodate these obligations when planning your radiation sessions.

You should calculate about one hour for each radiation session—including preparation and minimal waiting time. At the start of each radiation session, the team will carry out precise controls

to ensure your correct positioning on the treatment machine, or that of your child. This is essential to ensure that the beam targets the tumour with optimum accuracy. For this purpose, two X-rays are taken using a small dose of radiation. The radiation therapist (RTT) then compares these with the planning CT: if your current body position differs from that on the planning CT scan, either you or the treatment couch will be re-positioned until you are correctly aligned.

You will not feel anything during the irradiation itself. If you are being irradiated from different directions, you'll notice that the radiation device and possibly also your treatment couch is moving to find its new position.

Depending on the size of the tumour being irradiated, each radiation session takes between 1–45 minutes. During this time, you or your child are alone in the room, but will receive a microphone so that RTTs in the adjoining room can constantly monitor the radiation session via intercom and cameras.

During irradiation you can listen to music. Some patients sleep during treatment. A weekly consultation with your radiation oncologist is part of the planned schedule.

Competence at the Center for Proton Therapy

What does a radiation therapist do?



What does a radiation therapist do?

Radiation therapist (RTT) is a profession that is uniquely concerned with radiation and its medical uses. Radiation oncology uses radiation to treat cancer. They carry out this therapy and supervise patients for the entire duration of its implementation—generally over a period of several weeks. This is why they are both a person of trust and source of information during this time.

How do you prepare patients for radiation?

One of the most important factors during proton therapy is arranging patients in a position that enables them to be treated with maximum precision and comfort. RTTs prepare and control the individual positioning of each patient. One of their tasks is to construct fitted positioning cushions or other fixation devices that help patients to remain still during treatment. They also explain the irradiation procedure and device functioning and answer questions put by patients and family members. One of the great advantages of treatment here at the PSI is the time the RTT take for each patient. Our approach to patient care is based purely on the individual's requirements, not time restrictions.

How do patients experience proton therapy?

Radiation treatment is not felt which is why most of the patients at the CPT do not consider the treatment as particularly burdensome. If patients are afraid, it is generally helpful to consider their individual needs in greater details. For some patients it is helpful to imagine the weeks during which they receive treatment and spend time here in Villigen, or its surroundings, as a kind of holiday.

Treating infants and children





For very young patients, cancer treatment needs to be particularly effective but also very sparing, which is why CPT at PSI is specialised in the treatment of children.

Children and cancer

Cancer is less prevalent in children than in adults. Nonetheless, in Switzerland alone more than 200 children under the age of 15 develop malignant tumours per year. About half of these children are under the age of six. Leukaemia and brain tumours as well as tumours of the central nerve system are the most frequent types of cancer in this age group. The last two types can generally be treated at PSI.

In principle, the same therapy options are available to children and adults:

operation, drug-based therapies and radiation. Cancer treatment of children has progressed significantly over recent years and thanks to these therapies, many children can be cured.

Children suffering from cancer have been treated with proton therapy since 1999. Since 2004, we have also made treatment available to babies and infants.

When your child needs radiation treatment

When a child develops a malignant tumour not only the child him- or herself but also his or her parents and siblings are affected. Further questions arise if radiation is required. You may feel insecure. Whatever the case, your everyday life and that of your family will change, not least because you'll be accompanying your child to radiation sessions four or five times a week over a period of up to two months.



In this chapter, we want to help you deal with various fears and anxieties arising from this situation. We want to do everything in our power to help you and your child feel comfortable with us. Experience has shown that children manage to deal with their cancer diagnosis and the resulting changes in their daily life better than expected by most adults. In this context, please take a

look at the section “Children’s questions about treatment” on page 36 where you’ll find the questions asked most often by children answered in child’s terms by a radiation oncologist. If your child can already read, he or she might like to read the questions and answers by him- or herself or together with you.

Proton therapy: the best option for infants

Proton therapy is the best form of radiation therapy for babies, infants and young people. This is why radiation oncologists refer to this form of treatment as the “therapy of choice”. The main advantage of proton therapy is of particular benefit to children: the tumour cells are destroyed with great precision, without significantly harming the healthy tissue around the tumour.

We use the spot scanning technology developed at PSI, during which a pencil-thin proton beam targets the tumour – and only the tumour - spot by spot with the greatest possible precision, avoiding any unnecessary damage to the child or young person’s body. This is of central importance because the body is particularly sensitive to ionising radiation during growth phases, which means that children benefit even more than adults from

proton therapy with the spot-scanning technique.

Traditional radiation therapies with X-rays can have undesired long-term effects as a result of the so-called low-dose bath that develops around the irradiated area. This poses a greater problem for children than adults. When children become adults, their body grows on the basis of multiple cell di-

visions. Cells previously damaged by radiation therapy, because they were located in the low-dose bath near the tumour, can propagate the sustained damage to more cells every time they divide. Years, or even decades later, these damaged cells can develop into a so-called secondary tumour.

Other longer term side-effects of traditional radiation treatment on children

include growth or developmental deficiencies, learning difficulties, as well as heart and circulatory disorders. The proton therapy carried out at PSI can minimise the risk of these later complications.

Standardised treatment

In order to treat children suffering from cancer in the best possible way, treatment is generally carried out within the framework of international study protocols. This enables radiation oncologists all over the world to learn as much as possible from the (very rare) cases of paediatric or childhood cancers. These protocols are based on knowledge gained in past radiation treatments. They aim to help improve the therapies and the chance of cure for children.

This procedure contains specific provisions on the type of treatment best suited to your child at a given moment.

Radiation under anaesthetic – what you need to know

During your first visit to the Center for Proton Therapy, you will have a consultation prior to the procedure with an anaesthetist to inform you of the procedural details and risks involved in sedation. Anaesthetics are administered on an empty stomach to reduce the risk of inhaling stomach contents. Your child should have his or her last light meal four hours before being anaesthetised and should drink a little tea, water or syrup two hours before proton treatment is scheduled.

The sedative (sleep medication) that we use is Propofol, which puts patients into a deep, pleasant sleep. It only lasts for a short time and therefore needs to be continuously administered intravenously to your child. Once the infusion has been turned off, children tend to wake up within 15–30 minutes. As soon as your child is awake, he or she is allowed to eat and drink. Once the anaesthesia team is satisfied with your child's condition, you'll be allowed to return home.



It is possible that your child will be registered with us here at CPT half a year before the start of proton therapy, so that your child can be treated with other therapies first.

Small patients have special needs

In general, children who know what to expect during treatment and go through the procedure with a trusted caregiver are not afraid of radiation. If you succeed in familiarising your child with treatment and procedures, radiation sessions soon become a part of everyday life. The child realises that proton therapy doesn't hurt and that you are always close by.

If your child is still small, we try to make sure that his or her treatment sessions always take place at the same time of day. This makes it easier to prepare for the anaesthetic. And it makes it easier for your child to get used to therapy.

If your child has to undergo chemotherapy and proton therapy at the same time, we take care of coordinating both treatments.

Our waiting areas are arranged with particular attention to the needs of small patients. Children who don't require anaesthesia can listen to their favourite music during treatment. A microphone is available if you wish to talk to your child or tell them a story. Children who don't receive anaesthesia can communicate any uneasiness they may feel, both via the microphone and a squeaky toy.

Babies and small children are given a general anaesthetic (sedation) for treatments carried out at CPT so that they stay absolutely still for the duration of the treatment. Sedation is the term used to describe a form of general anaesthetic during which the patient is put into a deep sleep, but continues to breathe spontaneously.

Colleagues from the Department of Paediatric Anaesthetics at the Zurich



Children's Hospital administer anaesthetics at CPT. In some cases, older children are also sedated, especially when individual treatments take a long time, or require uncomfortable positioning. Children whose therapy involves anaesthesia are given a pearl at the beginning of each radiation session. When therapy is completed, the child leaves with a whole chain of pearls (see also: www.mutperlen.ch).

Competence at the Center for Proton Therapy

Children's questions about treatment



What is cancer?

You have become ill because some of the cells in your body are sick. In some children, these cells are in the head. In others, they are in the stomach or somewhere else.

Why do I have cancer?

It's not your fault that you have cancer. Nobody knows what really causes the illness. All we know is that nobody is to blame for your illness. Not you, your parents, nor anybody else. Cancer is not contagious. Anybody can get it, including more than 200 other boys and girls in Switzerland every year. That's about as many children as there are in your school, or in the district or village in which you live. So you're not alone. You'll probably meet other children with cancer in the waiting room at the Center for Proton Therapy.

Why am I being treated with proton beams?

Some beams (or radiation) can destroy cancer cells. We are using these beams to make you healthy again. The beams used at PSI are called proton beams.

Are proton beams like rays of sunlight?

Proton beams are a little like rays of sunlight. They are also a bit like the X-rays that doctors use when somebody has broken their leg and it needs to be examined by taking a special kind of photo. But there are differences between these kinds of beams: proton beams consist of lots of tiny particles, which are especially good at destroying the cancer cells in your body.

Is radiation unpleasant? Will it hurt?

It won't hurt at all. You won't feel or see the proton beams. The only thing that might bother or bore you is lying still for such a long time.

Why do I need a cushion or a mask during radiation?

So that you will be in exactly the same position every time you get treatment and so that the protons can hit the cancer cells exactly where they need to.

Why do small children sleep during their radiation treatment?

Small children can't lie still as well as older children. So sleeping helps them to stay in the right position, just like the cushion or the mask. If you are a bit older, you'll probably manage quite well without going to sleep.

Do you have any tips to help me get through therapy?

If you have any questions, don't be afraid to ask the grown-ups. They'll explain everything you need to know. And always remember that you are here so that you'll feel better afterwards and can get back to living a normal life and go back to playschool or school and play with your friends.

Competence at the Center for Proton Therapy

Enquire about a therapy support



A serious illness and its treatment is almost always a considerable burden for the person affected and their family, affecting all areas of life. A lot of unknowns have to be dealt with, often with the feeling of having to manage it

all alone. But one's own resources are not infinite. Cancer patients must also learn to cope with physical changes. It can be helpful to talk to an outsider about such stresses and strains, and in this way gain new strength.

In addition to purely medical care, such supportive counselling can be an important building block for a successful treatment and a better quality of life.

What is the goal?

This is why the CPT offers patients and their families professional therapy support during the treatment period. This takes place in customised sessions at the CPT. The aim is to support those affected with counselling, relaxation exercises and creative means for the duration of their therapy.

Psycho-oncology, as this task is called in technical jargon, is therefore not about treating mental disorders, but about supporting patients and/or their families during a difficult time.

What does it cost?

The offer is free of charge and requires no administrative effort.

When does the support take place?

The offer is always available, for the entire duration of cancer treatment. It can be started and ended at any time. The counselling sessions usually take place on Wednesdays in a therapy room at the CPT. The frequency of the sessions is agreed individually and according to need.

Who will provide the support?

We are delighted to have Yvonne Mäder as a recognised expert. She is a federally accredited psychotherapist and offers psychological counselling and psychotherapy for adults, adolescents and children as well as their families during proton therapy.

Who can I contact for more information or to make an appointment?

Please contact our patient office:

E-Mail: susanna.bochsler@psi.ch;

Telephone: +41 56 310 20 93.



Post-treatment care

The first check-ups take place around eight to twelve weeks after the end of treatment. It is important to our medical team to monitor the success of the treatment and your or your child's health over many years. Only such a long period enables us to make systematic statements about the success of your treatment.

Follow-up examinations

After completion of radiotherapy, all patients undergo regular follow-up checks for up to 12 years to monitor the condition of the tumour, the success of the treatment and any side effects. The intervals between follow-up checks vary. They depend on the type of cancer. The follow-up checks can be carried out at PSI. If you live further away, the

follow-up checks are usually carried out by your oncologist.

We would be very grateful if you could send us such follow-up reports including imaging. Please also ask your examining doctors to forward your results or those of your child to the PSI Center for Proton Therapy. Ask them to put us on their distribution list.

The CPT study office

In a dedicated study office at the CPT, three members of staff process the reports, images, questionnaires, photos and personal enquiries received from you or your treating doctor on a daily basis. With your consent, we analyse your coded data, e.g. on treatment, side effects and quality of life,

in scientific studies. The findings from tumour control and on side effects after proton therapy are very important for us in order to continuously review our range of therapies and improve them for the benefit of our patients.

To this end, we send you a questionnaire at regular intervals (usually annually) to obtain information about your or your child's state of health. We ask you to answer these questions and to inform us of any side effects and any tumour relapses. Recent photos of the radiotherapy area are also very valuable for us.

Of course, you, your family doctor or your oncologist are welcome to contact us at any time with questions, even after treatment has been completed.



Data protection

Medical data is considered to be particularly worthy of protection and is subject to the Swiss Data Protection Act and the Human Research Act. At the Center for Proton Therapy, your reports and documents are kept locked away and electronic data is stored in pass-

word-protected, dedicated information systems and secured by firewalls and back-up systems.

Access to the data is restricted to persons who need it for their work. These employees are subject to the provisions of medical confidentiality.

PSI in brief

The Paul Scherrer Institute PSI develops, builds and operates large, complex research facilities and makes them available to the national and international research community. The institute's own key research priorities are in the fields of future technologies, energy and climate, health innovation and fundamentals of nature. PSI is committed to the training of future generations. Therefore about one quarter of our staff are post-docs, post-graduates or apprentices. Altogether PSI employs 2200 people, thus being the largest research institute in Switzerland.

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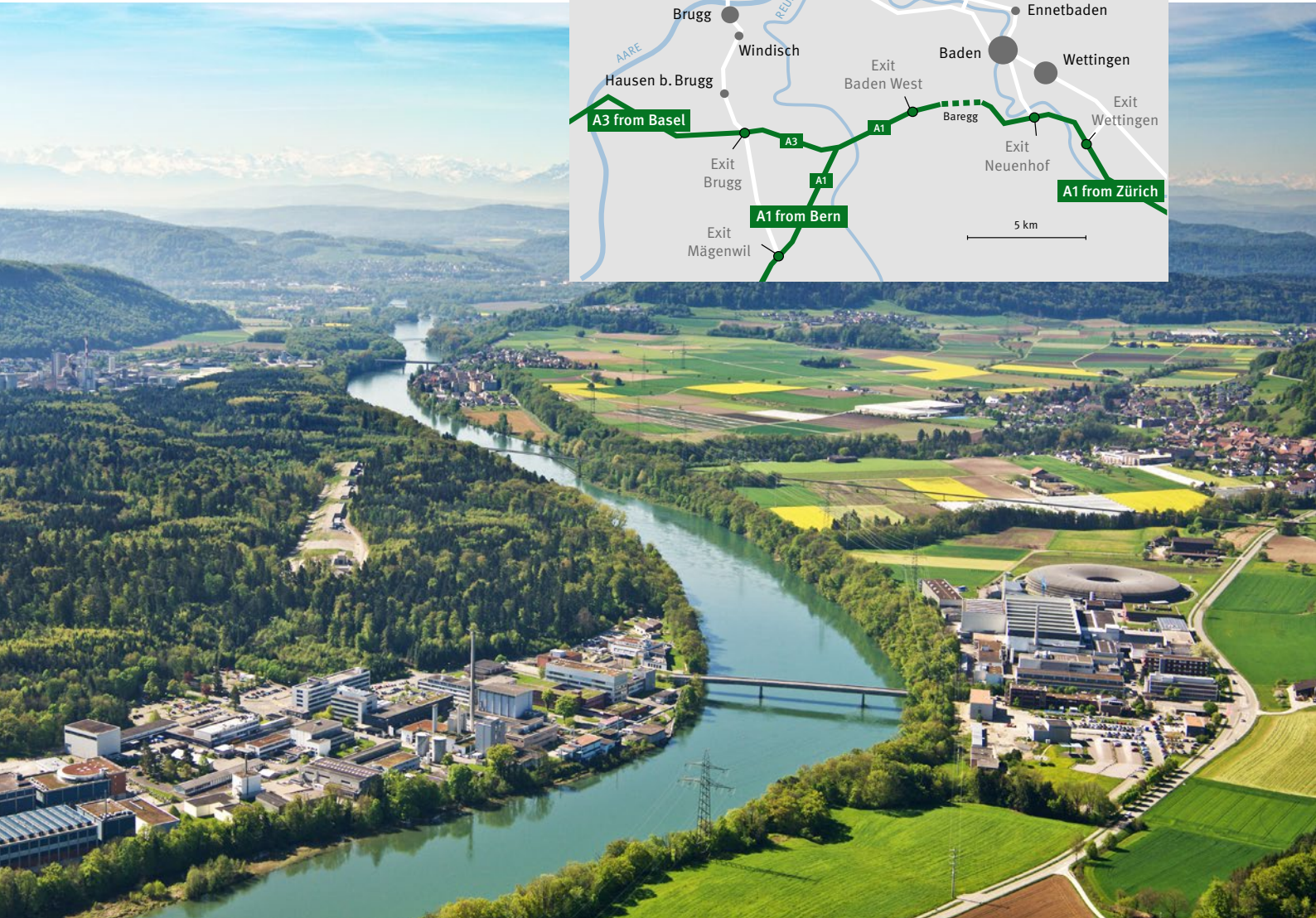
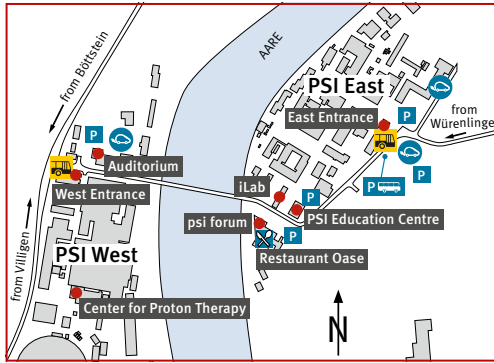
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