BijnierNET

Information for patients and their families and friends about

Adrenocortical Carcinomas

Appendix to the 'Quality of Care Standard for Adrenal disorders in the Netherlands'

Introduction

This brochure provides information about adrenocortical carcinomas. The text has been written for patients who have an adrenocortical carcinoma, and also for those closest to them. The brochure explains what the disorder means and what treatment options are available in the Netherlands. At the end, you will also find a list of addresses where additional information can be found and where you can go with any further questions you might have.

This brochure describes the Dutch situation.
Please check with your local healthcare professional if and how this can be applicable in the situation outside the Netherlands

This information is not intended to replace the advice of a competent physician. If you have any queries or need advice, get in touch with your GP or your specialist. They will welcome your questions, and you can never ask too much. This also applies to queries from your family and close friends. Your doctor or specialist nurse will do their best to answer any questions.

adrenocortical carcinoma =
cancer in the adrenal cortex

Say hello to...

Alexander aged 47

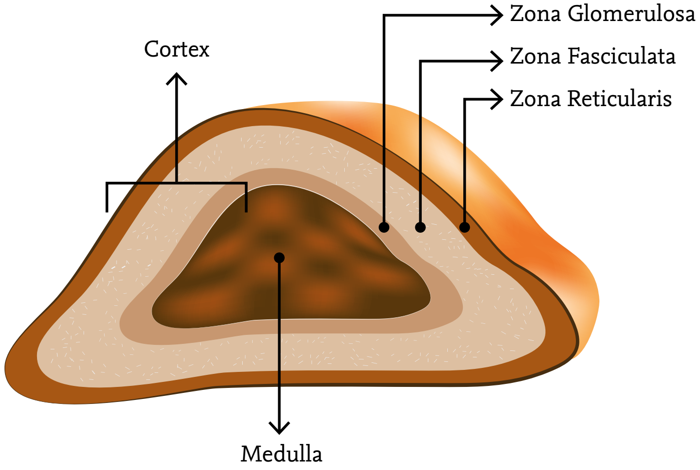
Alexander is 47 years old and runs his own consultancy firm. He is married to Eva and they have two children. They own their own home, but are still paying off the mortgage. The older child recently went off to university to study law. Alexander suddenly started to feel quite unwell. After some tests in the hospital, and a speedy referral to a specialist, he was given the unwelcome news that he had cancer in one of his adrenal glands. The world of Alexander and Eva fell apart, and hundreds of questions raced through their minds. Alexander is doing his best to continue with his normal life and work, and Eva has turned to her parents and friends for support. An emotional roller-coaster ride followed, during which Alexander has done his utmost to keep control of his life and the disease.

The adrenal glands

The adrenal glands are two small glands that produce important hormones; they sit on top of the kidneys at the back of the abdominal cavity. Everyone has two adrenal glands, one on each kidney, right and left. The adrenal glands look like little hats and are about the same size as the end of your thumb. The adrenal glands are not actually part of the kidneys.

Each adrenal gland consists of two components:

- The outside, called the cortex
- The inside, called the medulla.



The cortex completely encloses the medulla. The cortex is where hormones are produced. Hormones are essential to our lives and they regulate everything our body does under different circumstances.

The following hormones are produced in the **adrenal cortex**:

- cortisol
- aldosterone
- androgens (sex hormones).

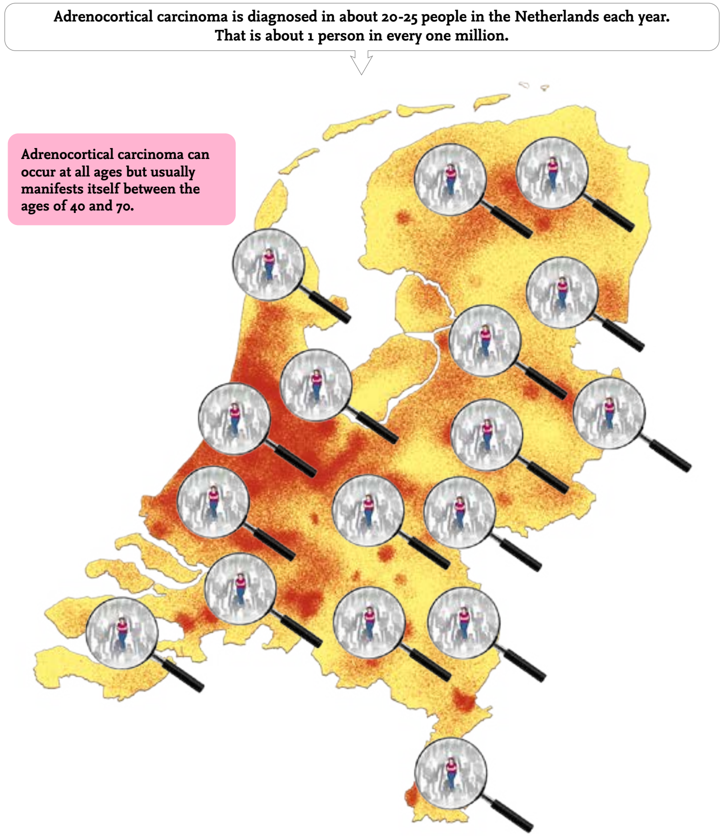
The following hormones are produced in the **adrenal medulla**:

- noradrenaline
- adrenaline

i Further information about the adrenal glands and the hormones that they produce can be found at: adrenals.eu

What is an adrenocortical carcinoma?

Both benign and malignant tumours can occur in the adrenal glands. An adrenocortical carcinoma is a malignant tumour in the adrenal glands. Malignant means that the tumour grows into nearby healthy tissue and disrupts the function of that healthy tissue. In addition, cells from a malignant tumour can migrate to other parts of the body and continue growing there: they are then said to have metastasized (i.e. produced secondary tumours). Consequently, an adrenocortical carcinoma is a rare but serious condition.



Adrenocortical carcinoma is diagnosed in about 20-25 people in the Netherlands each year. That is about 1 person in every one million.

Adrenocortical carcinoma can occur at all ages but usually manifests itself between the ages of 40 and 70.

Adrenocortical carcinomas are rare, so patients tend to be spread thinly all over the country.

What are the symptoms of an adrenocortical carcinoma?

An adrenocortical carcinoma might be discovered coincidentally during an echo or a scan of the abdomen (CT or MRI), without any symptoms being noticed. In about 40% of cases, the adrenocortical carcinoma does not cause an over-production of hormones. As a result, the carcinoma can exist for quite a while without the patient experiencing any physical symptoms.

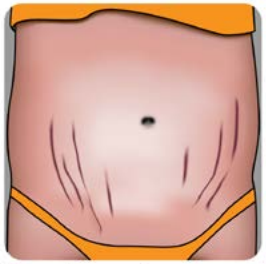
In approximately 60% of the cases of adrenocortical carcinomas, the disrupted function of the adrenal glands does cause the uncontrolled over-production of one or more of the hormones, and this over-production of hormones Itself gives rise to a variety of symptoms and problems. The symptoms are often the first reason why the patient gets in touch with his GP.

Below you will find a list of symptoms that commonly occur if too much of a particular hormone is being produced. But even when the carcinoma is diagnosed, not all patients will have experienced all of these symptoms.

An excess of **cortisol** can give rise to symptoms and problems such as:

- a typical distribution of fat around the abdomen (central obesity) and the neck (buffalo hump)
- loss of muscle tone, resulting in thin arms and legs and reduced muscle power
- a round and bloated face (moonface)
- raised blood pressure
- thin and fragile skin, which bruises more easily than normal
- purple stretch marks (striae) on the abdomen and buttocks
- tiredness
- sleep problems
- memory and concentration problems
- mood swings (sometimes severe) and mental problems such as depression, euphoria or psychosis
- excess blood-sugar levels (diabetes)


Typical distribution of fat


Strech marks


Loss of muscle tone


Moonface

High blood pressure


Thin skin, bruising


Tiredness


Cognitive problems and mood swings

An excess of **aldosterone** can give rise to symptoms and problems such as:

- raised blood pressure
- headache
- palpitations and heart rhythm disorders (arrhythmia)
- muscle cramps
- frequent need to urinate
- low potassium levels in the blood


Muscular cramps

High blood pressure

Headache


Palpitations

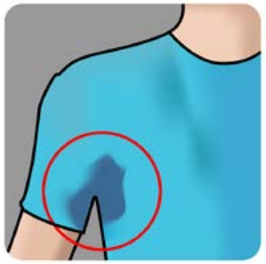
Low potassium levels

An excess of **androgens** can give rise to symptoms and problems such as:

- excessive hair growth
- deeper voice
- for women: menstruation problems and reduced fertility
- excessive sweating
- acne of the skin


Acne of the skin


Excessive hair growth


Excessive sweating

Reduced fertility


Menstruation problems


Deeper voice

Because of its size, and possible ingrowth and pressure on other tissues, the tumour can also give rise to other symptoms. The type of symptoms that develop, and their severity, depend on the actual location and the size of the tumour. Examples are pain, nausea and vomiting, breathlessness, and poor bowel movement.

Pain

Nausea and vomiting

Shortness of breath

Poor bowel movement

What causes an adrenocortical carcinoma?

It is not known what causes adrenocortical carcinomas. Somewhere in the development of the disease, errors occur in the DNA - the genetic material - of the cell. The error allows the cell to divide uninhibited and it becomes malignant.

Very occasionally, an adrenocortical carcinoma can occur in the context of a hereditary syndrome such as the Beckwith-Wiedemann or the Li-Fraumeni syndrome.

Adrenocortical carcinomas can occur at any age, but most patients are between 40 and 70 years of age when the disease first presents. Approximately 2 in every million people in the Netherlands are affected by the disease every year.

How is an adrenocortical carcinoma diagnosed?

After examining the patient, the GP will refer him to a hospital for further tests. Possible results from previous tests and examinations will be made available.

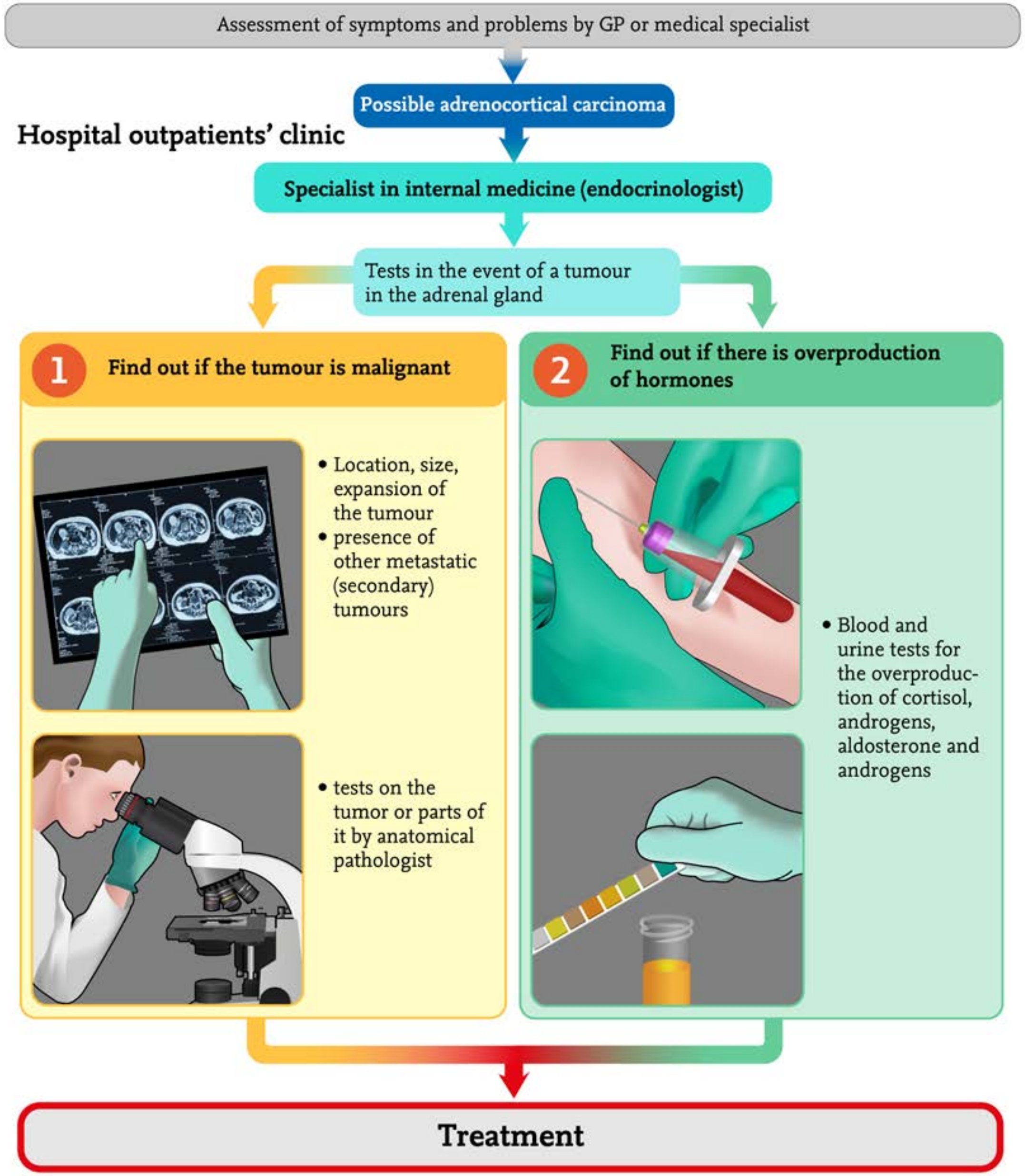
The referral will be to a specialist in internal medicine. The specialist will carry out additional tests with a view to finding an explanation for the symptoms or problems. Further tests are necessary if a tumour is detected in the adrenal gland, aimed at finding out:

- whether the tumour in the adrenal gland is benign or malignant
- whether the tumour is producing excess hormones

The location and size of the tumour will be determined by means of a radiological examination (CT or MRI scan), and the radiologist will check whether the tumour has spread. Unfortunately, in more than one third of cases, the tumour is found to have already spread by the time the diagnosis is made.

Blood and urine tests, and possibly saliva tests as well, can also help to pinpoint the diagnosis. Doctors also consider any possible excess of hormones: cortisol, androgens and aldosterone. A nuclear scan (known as a PET scan) is also sometimes carried out.

The definite diagnosis of an adrenocortical carcinoma can only be made after the tumour has been examined and tested by a pathologist. He (or she) will confirm the diagnosis on the basis of tests on all or part of the tumour.



* Diagnosis should preferably be carried out in a hospital associated with the Dutch Adrenal Network (i.e. the 7 university medical centers and the Máxima Medical Center).

For a correct diagnosis you should visit a hospital that is affiliated to www.nve.nl/stichting-bijniernetwerk-nederland/. The Dutch Adrenal Network brings together the medical specialists from seven university medical centers and the Máxima medical center. They work closely together to ensure that patients with an adrenocortical carcinoma receive the best possible treatment. If you have not yet been referred to one of these centers, ask your doctor to refer you to one of these specialized hospitals.

The website of the Dutch Association for Clinical Chemistry & Laboratory Testing (NVKC) provides an overview of the tests that are carried out in the laboratory. Unfortunately, the website is only in Dutch. If you type in the substance that is being tested for in your blood or urine, it provides you with a summary of what the test entails, when it is carried out and what the results mean.
If you have any further questions you can contact a clinical chemist via the same website.

How is an adrenocortical carcinoma treated?

An individual care and treatment plan is always drawn up. This care plan is compiled in consultation with you, the patient, after the medical specialist has discussed the case with other experts in a multidisciplinary team.

The specialist will discuss the possible treatment options with you. The options will depend on the extent of the tumour, whether there are secondary tumours elsewhere, and whether the tumour is producing hormones. The option of not treating the tumour will also be discussed with you. You can then make your choice.

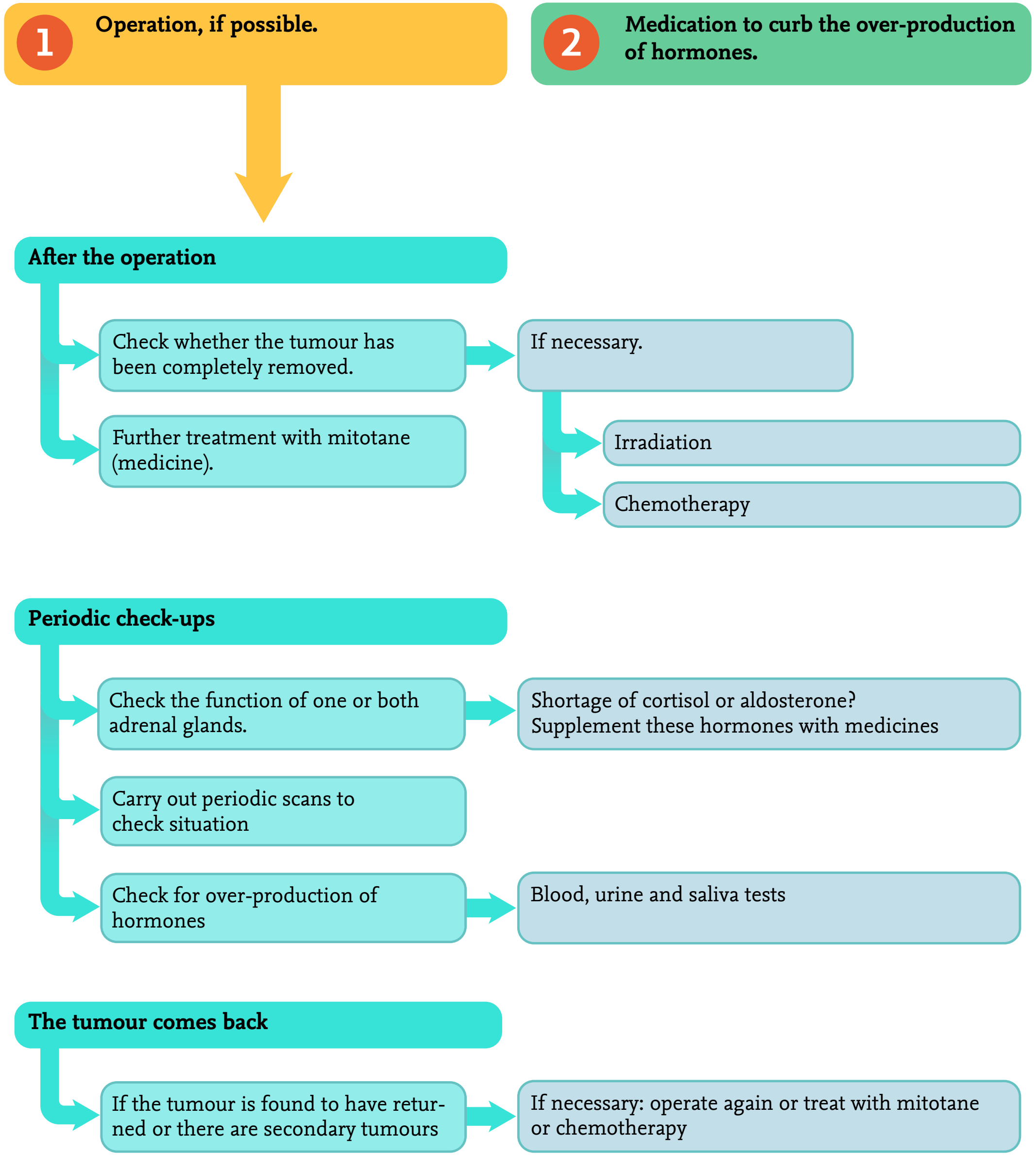
If the tumour is small, and has not yet metastasized, it will be surgically removed. This operation should be carried out in a center of expertise by an experienced surgeon. Quite often, patients are then treated with the medicine Mitotane (Lysodren) for a further two years.

Having an operation can be a distressing experience and you will have to absorb a lot of information.

The following three questions are good and sensible questions to ask the medical specialist.
Never be afraid to ask the question again if the answer is not clear to you.
Don't worry, that is part of the process.

- Has the medical specialist discussed your case with a multidisciplinary team from a specialized center?
- What treatment options are there for me?
- What choices can I make, and what are the pros and cons of those choices?

How is an adrenocortical carcinoma treated?



1 **Operation, if possible.**

2 **Medication to curb the over-production of hormones.**

After the operation

Check whether the tumour has been completely removed.

If necessary.

Irradiation

Chemotherapy

Further treatment with mitotane (medicine).

Periodic check-ups

Check the function of one or both adrenal glands.

Shortage of cortisol or aldosterone? Supplement these hormones with medicines

Carry out periodic scans to check situation

Check for over-production of hormones

Blood, urine and saliva tests

The tumour comes back

If the tumour is found to have returned or there are secondary tumours

If necessary: operate again or treat with mitotane or chemotherapy

* Diagnosis should preferably be carried out in a hospital associated with the Dutch Adrenal Network (i.e. the 7 university medical centers and the Máxima Medical Center).

Adrenocortical carcinomas are surgically removed whenever possible. If the tumour is producing hormones uncontrollably, and that gives rise to symptoms, these must be treated.

The aim of treatment is as follows:
- to reduce the production of hormones to an acceptable level,
- to deal with high blood pressure,
- to correct the shortage of potassium in the bloodstream,
- to deal with excessive blood sugar levels.

As a result, you will feel better and the risk of complications in connection with an operation will be reduced.

The standard surgical practice in the Netherlands is to remove an adrenocortical carcinoma in an open abdominal operation, but an exception can be made if the following criteria are met:
- the tumour Is less than 6 cm;
- there are not likely to be secondary tumours or in-growth into surrounding tissue;
- an experienced surgeon is available.

If these criteria are met, a laparoscopic or keyhole operation can be considered, either via the abdomen or the back.

After the operation, the tumour that was removed can be examined by the pathologists. By assessing the outer cut edges, he can determine whether the entire tumour has been removed. He can also study how rapidly the cells in the tumour are dividing. Subsequently, a scan will be taken at regular intervals to make sure the disease has not returned and that no secondary tumours have developed. If the tumour is also producing hormones, blood and/or urine tests will be carried out to assess whether the body is still (or has once more started) producing excess hormones.

Secondary tumours (metastases)

Treatment with mitotane

After the operation, it is usual to continue treating patients with a medicine called mitotane. This medicine is specifically aimed at neutralizing any residual malignant cells. The dosage of mitotane needs to be carefully calculated so that just the right amount of the medication is administered. This can be checked by measuring the mitotane level in the bloodstream at regular intervals.

Just like any other medicine, mitotane often gives rise to different side-effects. The most common side-effect is feeling nauseous. If this is how you are affected, there are several good medicines available. Many patients also report diarrhoea and an altered or reduced appetite. If you have high levels of mitotane in your blood, you can also suffer from dizziness and concentration problems.

Because mitotane damages the cells in the adrenal cortex, and hinders the production of adrenal hormones, the healthy adrenal gland can also be affected and this often leads to adrenal insufficiency. In addition, mitotane changes how the hormone cortisol is broken down in the body, so reducing its effectiveness. For all these reasons, it is often necessary for patients to take extra cortisol (and sometimes aldosterone as well) by way of medication. The medicines in question are hydrocortisone and sometimes fludrocortisone.

Chemotherapy is sometimes also chosen
For some patients, it is necessary to supplement the mitotane with chemotherapy. This depends on your physical condition and whether there are secondary tumours. The treatment regime that is used for the chemotherapy in the Netherlands is known as the EDP regime. Under this regime, the patient is treated with the medicines etoposide, doxorubicin and cisplatin (hence the abbreviation). The course of treatment consists of four days of chemotherapy repeated every four weeks. The effectiveness of the therapy will be assessed after 2 or 3 rounds of treatment.

Irradiation
Irradiation of secondary tumours is possible nowadays. Until recently, irradiation was only applied to alleviate the symptoms. But more and more often, irradiation is now being applied to treat secondary tumours (often in combination with localized surgery, radiofrequency ablation and other localized treatments).

Such treatment is radical, and has consequences for your own life and that of those close to you. It is important that you always discuss the care and treatment plan with your treatment provider.

Adrenal insufficiency

Treatment of an adrenocortical carcinoma causes adrenal insufficiency. This means that you are not producing enough cortisol for your body's needs. To balance this out, your medical specialist will prescribe hydrocortisone. Under normal circumstances you take this medicine three times a day.

But the adrenal insufficiency also demands extra attention and energy from you. In everyday speech, cortisol is often referred to as 'the stress hormone'. Normally, the adrenal glands will produce extra cortisol under stressful circumstances. But if your adrenal glands are no longer functioning normally, you will need to take hydrocortisone medicine. If you are going through a stressful time, or suffer a sudden shock, you will need to take more. To help you deal with stress, the medical specialist or nurse specialist will give you an information sheet with 'Stress Instructions'. In line with these instructions, you will need to take extra hydrocortisone whenever necessary. If it is not possible to take the medicine in the normal way, it needs to be administered by injection. This is all explained in the video and other information about an emergency injection which you can find at noodinjectie.

Further information about bijnierschorsinsufficiëntie and the stressinstructies can be found on the AdrenalNET website.

Psychological effects

Living with cancer is not simple, or easy. The treatment and its consequences have an impact on your emotions and your wellbeing. First of all, the shock of hearing that you are ill takes a lot out of both you yourself and those closest to you. In addition, the diagnosis and the treatment will bring further changes to your life.

Adrenal cancer is a disease that has a significant effect on your hormone balance. And those hormones in turn have a direct effect on your emotional state. That is the reason why the diagnosis and the treatment can have such a profound effect on your state of mind.

It can sometimes be difficult to pick up the threads of your life again. The hormonal changes can have a noticeable effect on your behaviour, your emotions and your reactions. This can lead to difficult situations with your nearest and dearest, friends and others. Don't be afraid to ask for help!

The Dutch cancer information website kanker.nl provides extensive information about how to cope with a diagnosis of cancer, but is only available in Dutch. See hoe om te gaan met de diagnose kanker. Don't be too hard on yourself, and discuss whether and what help you would like during this difficult time.

Follow-up

After the first operation has been carried out, doctors will keep a close eye on the development of the disease. To do that, it will be necessary for you to have tests and examinations on a regular basis and you will have regular consultations with your medical specialist. Your doctor will ask you how you are coping and whether you are finding it possible to take control of your life once again.

During this period, it is important to keep a fairly short term horizon and to focus on the first achievable treatment target, in consultation with the multidisciplinary team treating you. Of course, you must also try to enjoy a normal life and do things that are meaningful to you. After all, every day is a new day.

Care and treatment plan

The care and treatment plan sets out who your first point of contact is, how and when you can get in touch with your medical specialist. The plan also sets out what extra support you need and whether there are any other issues in connection with your family or relatives.

If the tumour recurs after a lengthy time, a year after the operation, for example, or if there are some (but not many) secondary tumours, the team will consider the option of a new operation. The aim will then be to slow the disease down, as much as that is possible. You might be asked to agree to a new course of mitotane medicine. The team will also discuss other treatment options with a cancer specialist.

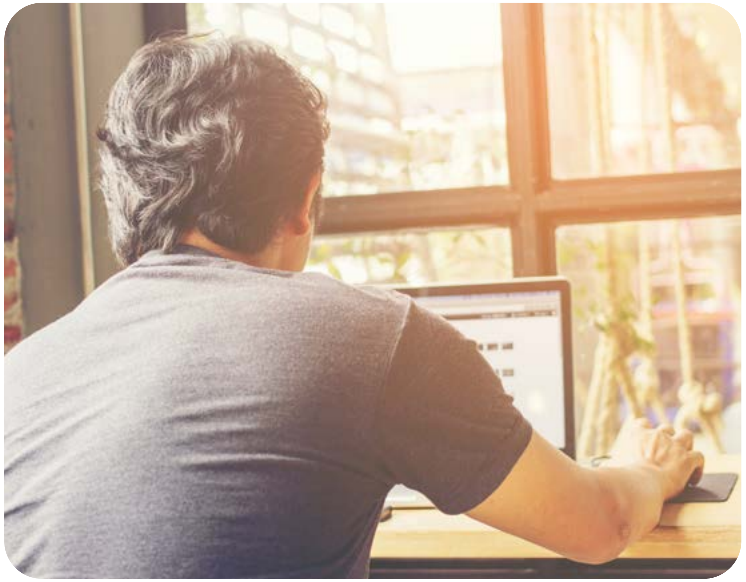
Arrangements for your care will be made for each phase of your illness and treatment, including follow-up care and possibly palliative care such as pain relief.

How is patient care organised?

The care for people with an adrenocortical carcinoma is complex. This is a rare disease, and the tests and treatment demand specific knowledge and expertise. The best care for people with an adrenocortical carcinoma can only be provided in a hospital where an experienced and dedicated team is available. In general, those hospitals are affiliated to the Dutch Adrenal Network.

A lot of different people are involved in the care process, each with their own specialisms but working together in a multidisciplinary team. The treatment calls for teamwork and the team generally consists of: endocrinologist, endo-oncologist, surgeon, anesthesiologist, radiologist, nuclear medicine specialist, clinical geneticist, pathologist and a nurse specialist. They work together to arrive at the right decisions.

You are an important member of that team. Your opinion has extra weight. The team works best if everyone is open and honest with each other. So never be afraid to ask questions or make comments.



Quite often, you will be supported by a particular nurse (or nurse specialist) who will coordinate the care process. Some patients also need to be supported by a physiotherapist, a dietician, psychologist or rehabilitation specialist. Yes, all that is possible as well. Ask how the care process is arranged in your own hospital.

Quality criteria

The Dutch Standard of Care for Cancer Patients (2014) identifies five generic quality criteria to assess the care provided to patients with cancer. Those five criteria are as follows:

1. The patient has an individual care and treatment plan
2. The plan sets out who is the primary treating physician, who is responsible for the coordination of care, and who is the first point of contact.
3. The care provider is affiliated to a national care-content registration system (to facilitate continuity of care in various settings)
4. The care provider takes part in patient experience surveys with the aid of the Consumer Quality Index (CQI) for Cancer Care Survey
5. The care provider takes part in patient experience surveys with the aid of the Patient Reported Outcome Measures (PROM) questionnaire.

Each hospital fulfils these criteria in its own way. Discuss this with your doctor.

The animated clip about adrenocortical carcinomas (see Bijnierschorscarcinoom, only available in Dutch at present) explains how important it is that the treatment of these cancers is carried out in a center of expertise.

Living with an adrenocortical carcinoma

In this brochure we have used various terms to describe the people around you: your life partner, parents, family, relatives, co-workers and friends. Such people are important in everyone's life, and even more so when you have a serious illness. They are also pulled on to the emotional roller-coaster when they hear the diagnosis and have to absorb the associated information. They all want to be involved, but will also feel completely powerless. In general, fortunately, they manage to convert their powerlessness into help and support. And that's a good thing. They can offer moral support, share your sorrow, and provide practical help for your daily life. Don't hesitate to ask your GP or a social worker from the hospital about getting help for your family and friends if they need it.

Hold on to hope, that's the important thing. Everyone is different, and individuals can never be compared to statistics. Everyone can have hope of a solution. Hope is a state of mind that is very important for people with cancer. The ultimate hope is one of cure. When there are secondary tumours associated with adrenal cancer, there is still the hope that the disease can be stopped in its tracks and perhaps even forced into retreat. And in the latter case, you hope that the retreat holds as long as possible.

i The Dutch cancer information website Kanker.nl contains information (in Dutch) about how to cope if a loved one has cancer. There are similar sites available in other countries and in other languages. It is well worth reading through this sort of information now and again.

The best advice consists of four practical rules:

- sleep well
- eat well
- get some exercise
- find sufficient distraction

In the mini documentary Bijnierschorscarcinoom (only in Dutch) a patient speaks open-heartedly about the entire process from symptoms and tests through to diagnosis, treatment and follow-up in the context of life with an adrenocortical carcinoma.

The chance of recovery and the life expectancy depend heavily on how much the cancer has spread and whether the surgeon could remove it completely. In addition, it depends on the effect and effectiveness of the treatment with mitotane or chemotherapy. And this is different for each individual patient.

The treatments are serious interventions in your life and can have an impact on the way you live from day to day. It is therefore important that you create a network of people around you so that you always have someone to fall back on.

Daily life

People with an adrenocortical carcinoma are confronted with major medical worries. Nonetheless, there is still the need to take responsibility for the other commitments that life brings, however difficult that may be. The children still need to go to school, the electricity bill has to be paid on time and the car needs to go into the garage for maintenance. Alongside the normal distractions of day to day life, this can prove to be quite a strain. A chat with a specialist nurse of social worker can help.

Subjects you can discuss include:

- Job or own business
- Money matters
- Insurance
- Legal matters, possibly in consultation with a solicitor
- How you fill the day: sport, visits, etc.
- Pension issues
- Food and drink

The Dutch cancer information website includes a chapter on how to cope if your partner has cancer, see Naasten (only in Dutch) The site has a wide variety of information about practical matters, including a checklist which helps partners and friends up to date.

If there is no hope of a cure

Adrenal cancer is a serious disease, one which patients do not always survive. It may well be that the message you get is that there is no hope of a cure. This will kickstart a new period with all the obvious questions and a great deal of emotion.

Palliative care and terminal care

What is palliative care and when does the terminal care phase start? People often use the terms 'palliative' and 'terminal' as if they have the same meaning, but there is a big difference.

Palliative

The palliative phase of an illness starts at the moment that a medical professional says: "you cannot recover from this disease and you will probably die because of it", but thanks to new treatment methods even people with an incurable disease can often live for years.
The aim of palliative care is to relieve the many symptoms that can arise because of the disease and - if the patient wishes it - to extend life. The aim is not (or no longer) to achieve a cure but to keep the patient's quality of life at as high a level as possible for as long as possible.

Palliative care is not just one type of care. It depends on the progress of the disease and on the possibilities there are for the specific sort of cancer concerned. In the case of some types of cancer, in which the disease progresses slowly, you often go on living for many years with the knowledge that you will not get better. With other types of cancer, the disease progresses more quickly and - at present at least - there are no or very few possibilities of extending life.
Some patients are given palliative care which is so effective that they start to believe that a cure might be possible after all. This can lead to misunderstandings. Even if the doctor tells you that the treatment is effective, it doesn't alter the fact that the treatment won't actually cure you. If you are told that a disease is incurable, there is still a possibility that doctors can slow down its progress for a while, even if it will never go away altogether.

Terminal

The terminal phase is the last portion of the palliative phase. From a medical point of view, life expectancy is then no more than three months. It is, of course, difficult to estimate the remaining period with any accuracy, but a doctor or nurse can usually indicate that the medical condition of the patient has deteriorated badly.

Patients sometimes instinctively know that they don’t have much longer to live. Care - in various forms - becomes more intensive during this phase. Quite often, the home care organization will need to send a specialist team to deal with IV lines or oxygen tanks. In the Netherlands there are also volunteer organizations who provide ‘night nurses’ to keep an eye on the patient and relieve some of the burden felt by family members. The GP will visit regularly and make sure that the patient’s details are known to the after-hours GP service. Agreements about life-extending treatment and how to act in an emergency will be set out in writing so that everyone is aware of them.

In the Netherlands, patients can only be admitted to a hospice if their life-expectancy is no more than three months. People sometimes live longer, of course, and exceptions are made so that the patient does not need to be moved back into their own home for the final days or weeks of their life. And sometimes they actually improve. Then they do move back home but can always return to the hospice at a later stage.

Terminal care is customized care. The aim is to take the wishes of the patient and his or her close family into account and ensure that the patient can die with dignity.

In this phase, your GP is your most important discussion partner. He will support your every step. Further information about the issues that become significant in this period can be found on the Dutch cancer information website, see Kanker.nl is een overzicht opgenomen (only in Dutch).

Scientific research (trials) into adrenocortical carcinomas

National and international collaboration between medical centers and research institutions is necessary if better methods of treatment are to be developed. Adrenocortical carcinomas are extremely rare and a larger group of people needs to be studied before any statistics can be compiled. Fortunately, various international collaborative research projects are already being carried out and they are producing more and more useful information about the prognosis for this disease. Thanks to this collaboration, there is the hope and expectation that better methods of treatment will be found so that the prognosis will improve. The ultimate aim is that people will survive the cancer better and therefore live longer.

Research can contribute to both better diagnostic methods and a better quality of life.

Explicit consent from the patient is always required before research can be carried out on body tissue. In accordance with current privacy regulations, researchers request that patients allow body tissue to be made available for their ongoing research into better methods of treatment. The consent is not limited to today's research methods, but also includes future methods and technologies as well. Consider discussing this issue with your medical specialist, if the subject hasn't already been broached.

Want to know more?

- www.nve.nl/stichting-bijniernetwerk-nederland/
- adrenal.eu (information in English and several other languages)
- www.Bijniervereniging-NVACP.nl (only in Dutch)
- www.kanker.nl (only in Dutch)
- Farmaceutisch kompas (only in Dutch)
- Medicijnkosten.nl (only in Dutch)

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- Dutch Organisation for Health Research and Development (ZonMw)
- Voorzorg Foundation

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