

Information for patients and their families and friends about

Primary aldosteronism

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

Introduction

This brochure is about the adrenal disorder known as primary aldosteronism. The text has been written for patients who have primary aldosteronism and also for those closest to them such as their partners, parents and children. Primary aldosteronism is often abbreviated to PA.

This brochure explains what the disorder means and what treatment options there are.

Although we use the pronoun 'you' and 'our' throughout this brochure, it is also intended for people in the immediate circle of a person with primary aldosteronism. Healthcare practitioners can also use this brochure as a source of information.

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.



The medical information in this information brochure is based on the Quality of Care Standard for Adrenal Disorders (in Dutch only) and The Management of Primary Aldosteronism: Case Detection, Diagnosis, and Treatment: An Endocrine Society Clinical Practice Guideline (JCEM 2016 101 (5) 1889-1916)

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.



Adrenal disorders are complex illnesses and explanations can be difficult to understand. If you come across unfamiliar words when reading this brochure, the website BijnierNET.nl includes a Thesaurus, an explanatory list of definitions (in Dutch). For healthcare practitioners, the Thesaurus on www.adrenals.eu provides a comparative overview of applicable codes.

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Say hello to... Trudy aged 58

She works in the Personnel Department at an insurance company. She enjoys her work and her contacts with colleagues. She works long hours and there have been a lot of staff changes recently because of a reorganisation. She has noticed that she has been suffering from headaches a lot recently and doesn't feel so well. Could she be going through the menopause? Is it her work?

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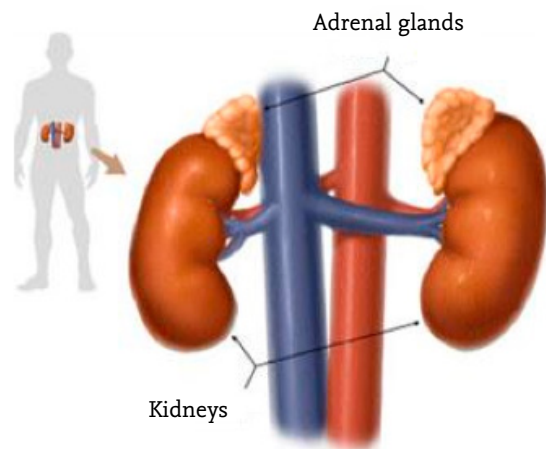
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The kidneys, the adrenal glands and the regulation of blood pressure

To understand what primary aldosteronism is, it is important to understand how the blood pressure in your body is regulated. Raised blood pressure is one of the biggest problems with primary aldosteronism. That will be the focus of the next paragraph.

The paragraph starts with an explanation of the **kidneys**. Next, we will look at the **adrenal glands**.



The adrenal glands sit on top of the kidneys in the abdomen, just like hats.

The kidneys lie at the back of the abdominal cavity. Their job is to filter waste products out of the blood and to remove it via the urine. From the kidneys, the urine passes to the bladder.

The kidneys also keep the sodium and potassium levels in the body in the proper balance. They also produce the hormone renin, a hormone that is important for the regulation of your blood pressure.

The adrenal glands sit on top of the kidneys. Everyone has two adrenal glands, one on each kidney, right and left. Healthy adrenal glands are about the size of the top joint of your thumb. The adrenal glands consist of two components: the cortex (the outside) and the medulla (the inside), and these two components produce different hormones. Hormones are essential to our lives and they regulate everything our body does in different circumstances. One of the hormones that are produced in the adrenal cortex is aldosterone.

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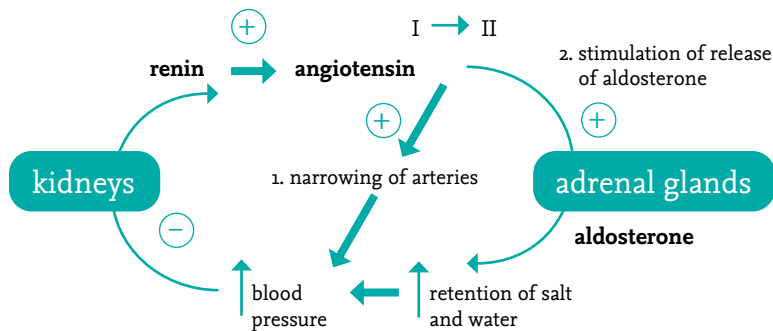
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Aldosterone and renin form part of the Renin-Angiotensin-Aldosterone System (RAAS). RAAS regulates the blood pressure in the following way:



RAAS regulates the blood pressure

1. If there is a slight reduction of blood pressure, the kidneys produce more of the hormone renin.
2. Via angiotensin I, renin indirectly stimulates the formation of angiotensin II, which narrows the blood vessels and in turn causes the blood pressure to rise. Angiotensin II also stimulates the adrenal glands to produce aldosterone.

3. Aldosterone ensures that the kidneys retain sodium and fluids, while potassium is removed via the urine. The retention of sodium attracts water, as a result of which the blood pressure rises.
4. Once the blood pressure is back to normal, less renin is produced by the kidneys and, ultimately, less angiotensin II as well. Aldosterone production ceases and the blood pressure does not rise further.

This balancing act will normally ensure that the blood pressure remains stable. But the balance is upset if someone has primary aldosteronism.

That will be the focus of the next paragraph.



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

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What is primary aldosteronism?

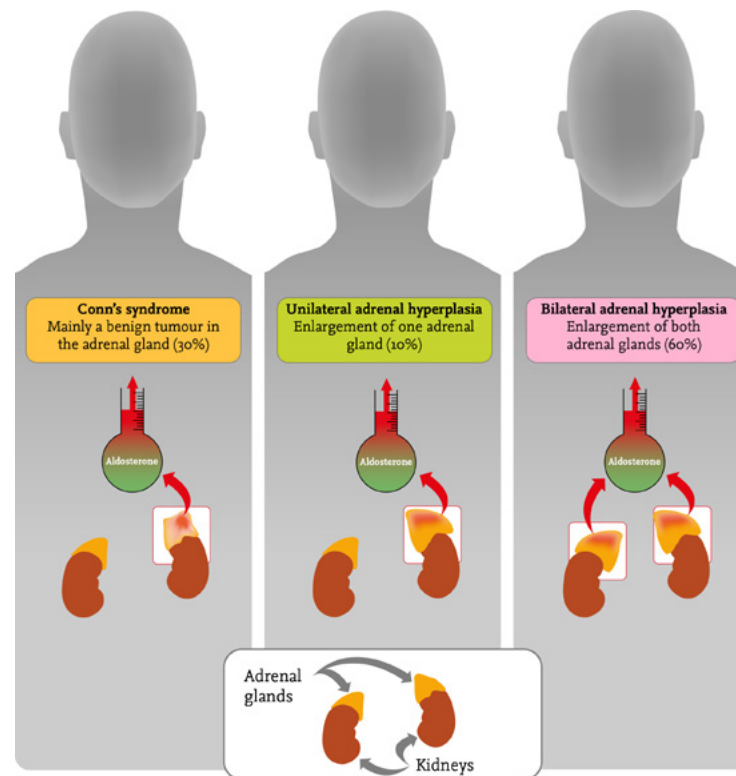
If you have primary aldosteronism, you have too much of the hormone aldosterone in your blood.

Three types of primary aldosteronism have been distinguished.

- Conn's syndrome, or high aldosterone as the result of a benign tumour (adenoma) in the adrenal gland (30%)
- Unilateral adrenal hyperplasia, in other words: one enlarged adrenal gland (10%)
- Bilateral adrenal hyperplasia, in other words: two enlarged adrenal glands (60%)

In all these three types of primary aldosteronism, the body produces too much aldosterone. More than you need. And this causes the symptoms.

Primary aldosteronism affects approximately 5 to 10% of people who have raised blood pressure. The chance of developing primary aldosteronism increases with the severity of the rise in blood pressure. It is estimated that between 17 and 23% of the cases of untreatable high blood pressure can be attributed to underlying primary aldosteronism.



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What are the symptoms of primary aldosteronism?

The excess aldosterone makes you feel less fit, or perhaps even ill. The most common signs and symptoms of primary aldosteronism are:



1 High blood pressure



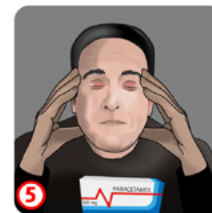
2 Weakness



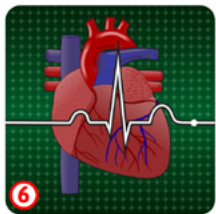
3 Muscle cramps



4 Tiredness, lack of energy



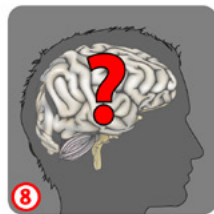
5 Headaches



6 Palpitations of the heart



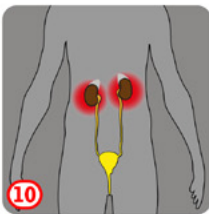
7 Frequent urination, also during the night



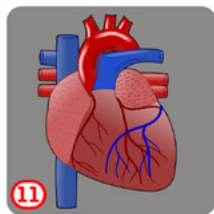
8 Problems with memory, concentration, attention span



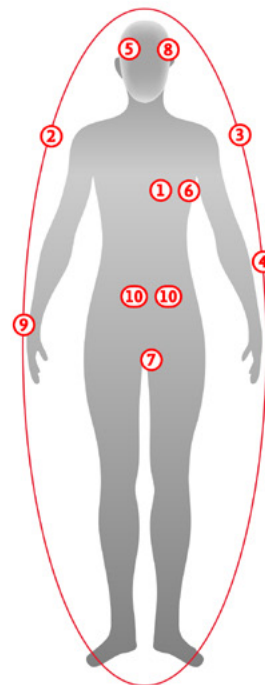
9 Sometimes: low potassium salts in the blood



10 Sometimes: reduced kidney function



11 Sometimes: problems with heart and blood vessels



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But not everyone experiences these symptoms. Sometimes, the only symptom is high blood pressure and that may not even give rise to any other symptoms. In addition, the symptoms are often so unspecific that the cause is assumed to be something else. Examples are: sleep problems, tension/stress or even the menopause. As a result, it often takes quite a long time before the correct diagnosis is made. And this can have unpleasant consequences.

People with a permanently high blood pressure are given lifestyle advice (e.g. eat less salt) and are sometimes treated with medication to reduce the blood pressure. If the blood pressure doesn't reduce sufficiently, despite various types of blood pressure medication, the reason could be primary aldosteronism. Low potassium levels would support a suspicion of primary aldosteronism. In that case, it is important that the person is tested for an adrenal gland disorder.

Long-term raised blood pressure causes damage to the body, for example to the kidneys, the heart and the blood vessels. Having persistently high levels of aldosterone can also damage the heart and blood vessels. This can result in heart-rhythm disorders, a loss of kidney function, a mini stroke, stroke, or a heart attack. In addition, the excess aldosterone can cause psychological symptoms such as depression, anxiety, sleep problems and concentration disorders.



The infographic and the animated clip entitled "[What is primary aldosteronism](#)" provide a simple explanation of what the disorder entails.



Jaap Deinum, a Dutch specialist in internal medicine, published a [blog about PA](#) In 2016; he works in the Vascular Medicine Department at the Radboud University Medical Center in Nijmegen..

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What causes primary aldosteronism?

Aside from a number of rare hereditary disorders, experts have not been able to pinpoint any reasons why a person might develop primary aldosteronism. In most cases it boils down to bad luck.

There are, however, a number of hereditary disorders that can lead to primary aldosteronism.

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Delayed diagnosis

It is possible that you have felt unwell, or possibly even quite ill, for some time and that various doctors have been unable to pinpoint the precise diagnosis. This is because the symptoms are not exclusively linked to this particular - and relatively unknown - adrenal disorder. Even for doctors, this turns the diagnosis into a treasure hunt.

But if a patient has persistently high blood pressure that is difficult to reduce despite the daily intake of three or more blood pressure reducing medicines, this should make a doctor's alarm bell ring (your family doctor, for instance).

When a diagnosis can only be reached after a relatively long period, we speak of a delayed diagnosis. Research has shown that the average time it takes to get the correct diagnosis is eight years. The intervening period is characterised by a great deal of uncertainty and doubt, and in the case of primary aldosteronism it can even mean that further damage can occur to other organs in your body.



Have a look at the mini-documentary and a second one (in Dutch only) in which a patient relates how the diagnosis was finally made in his case. You will probably recognize various elements in the story told by this patient. This can help. You are not the only person who is experiencing these symptoms; quite a few other people have exactly the same symptoms.



Read more about diagnostic delay (Dutch only) on the special theme page.

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How is the diagnosis PA established?

Testing towards the diagnosis

Blood tests

Blood tests are carried out to determine whether a person is suffering from primary aldosteronism. Scientists determine the amount of the hormones aldosterone and renin in your blood. The aldosterone to renin ratio (ARR) is calculated by dividing the amount of aldosterone by the amount of renin. If a person has primary aldosteronism, the aldosterone level will be higher and the renin will be lower than usual. So the ratio will be higher too.

Salt-loading test

An increased ARR can be an indication of primary aldosteronism. To be sure that the diagnosis is correct, doctors carry out what they call a confirmation test. In most hospitals this is carried out by means of a salt-loading test via an infusion into the blood stream. The test has to be requested by your specialist and you spend time in the hospital as a day patient while it is carried out.

How does the salt-loading test work?

After an initial blood sample has been taken, you will be hooked up to an IV line through which a salt solution will be dripped into your blood stream for four hours. At the end of the four hours, blood samples will again be taken so that the aldosterone level can be measured.

In healthy patients, the aldosterone level will fall. But if the aldosterone level remains high after the infusion, this means that the aldosterone production is not responding to the body's blood pressure regulating signals. And the fact that aldosterone is not being suppressed confirms the diagnosis of primary aldosteronism. The test can also be carried out by eating extra salt for a few days and then measuring the aldosterone.

As certain blood pressure reducing medicines can affect the test results, the tests are preferably carried out when a person is not taking such medicine, or no longer taking it. The medication can also be adjusted.

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This should only be done in consultation with your doctor: you should never stop taking blood pressure reducing medication without speaking to your doctor. It is also important that the potassium level in the blood is normal at the time the test is carried out. For that reason, you will be given potassium tablets or a potassium drink ('Slow K') if necessary.

If the aldosterone level remains too high after the salt-loading test, primary aldosteronism can be diagnosed.



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, the site 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.

The abbreviation CT stands for Computed Tomography.

Tests used to determine the type of primary aldosteronism

CT scan

Once the diagnosis of PA has been made, there will usually be a number of tests to establish the type of PA: unilateral or bilateral. This is important for the further treatment process. In the Netherlands, a CT scan will always be made of the adrenal glands. The scan is carried out in a tunnel-shaped X-ray machine. A CT scan uses the same X-ray technology as a normal X-ray scan, but the result is a series of images of virtual slices through the body instead of a straight-on view. The scan is not painful, but it does take between 30 and 60 minutes. [An example of a CT scan can be found here.](#)

If the scan shows that just one adrenal gland is enlarged, this is probably a case of unilateral disease. If both adrenal glands are enlarged, or if both adrenal glands are not enlarged, it is more likely to be a case of bilateral disease.

The advantages of a CT scan are that they are more readily available, cheaper to use and quicker to produce results. Moreover, they can produce an image in various directions or planes. Sometimes it is not possible to have a CT scan, if the person concerned is allergic to the contrast dye, for example, or if their kidney function is impaired or - for a woman - in the case of pregnancy.

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MRI

An MRI scan does not use X-ray emissions but works with a strong magnetic field and radio waves. The adrenal glands can also be clearly seen with an MRI scan. The MRI machine is a sort of tunnel, which you lie in. [An example of an MRI scan can be found here \(Dutch only\)](#). An MRI will not be the preferred option, however, if you suffer from claustrophobia, or have certain implants such as a pacemaker or neurostimulators, for example, or if you have recently had a stent fitted.

The abbreviation stands for Magnetic Resonance Imaging. The abbreviation CT stands for Computed Tomography.



Are you looking for a hospital where they have the necessary experience? Then check out the website of the Dutch Federation of University Medical Centers via the [TRF portal](#). Choose the tab 'Zoek TRF' and type in 'sampling' and then '[bijnierfunctiestoornissen](#)' (only in Dutch). A list of the relevant centres will be presented.

Adrenal venous sampling (AVS)

To be definitely sure whether just one or both adrenal glands are overactive, adrenal venous sampling will be carried out. A sampling of the adrenal vein entails taking blood directly from the blood vessel that comes out of the adrenal gland. The purpose is to measure the amount of aldosterone in that blood.

In the Netherlands, adrenal vein sampling is only carried out in a small number of hospitals. The test is carried out in the medical imaging department by an experienced interventional radiologist. Your medical specialist will explain the procedure to you carefully so that you fully understand and it causes the least possible stress or pain.

Before the start

For adrenal venous sampling it is also necessary to stop taking certain blood pressure reducing medicines, because they affect the amount of aldosterone in the blood. The potassium level also has to be normalised.

To start the sampling, most hospitals will put an IV line into your arm. An amount of a certain hormone (ACTH) will be administered via the IV line. This stabilizes hormone production in the adrenal gland so that the results can be more easily assessed.

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During the sampling

During the sampling you lie on your back. You will be given a local anaesthetic in your groin area. After that, a thin tube will be introduced into the vein in the groin. An even thinner tube (a catheter) can be pushed up through the tube in the direction of the small blood vessels in the adrenal glands.

Once doctors have checked that the catheter is in the right place, blood will be taken from the left hand adrenal vein, the right hand adrenal vein and from the femoral vein in your groin. The levels of aldosterone and cortisol in those blood samples will then be determined in the laboratory.

For the sampling to be successful, it is important that you lie still. It will sometimes be necessary for you to hold your breath. The laboratory assistant will explain all this to you. Contrast fluid is used so that images can be recorded during the test. The sampling itself will take approximately one to two hours.

After the sampling

After the sampling, you must stay in bed, resting, for about three hours, during which time a nurse will carry out checks every hour. The nurse will check that there has been no bleeding from the site where the catheter was put in. If the wound has healed properly, and you feel alright, you will be allowed to go home.

It is important that you take it easy for the first 24 hours afterwards. You must not lift anything heavy, not play any sport and not walk up and down stairs too often. In order to expel the contrast fluid from your body, it is important that you increase your intake of fluids for the first 3 days, so that it will be removed via your urine.

Complications

It is possible that this type of test can lead to complications. There might be bleeding or bruising at the site of the catheter, damage to the adrenal gland vein (although this is quite rare), you might develop a thrombosis (a blood clot) or there could be bleeding in the adrenal gland. There is only a small chance of complications if the sampling is carried out by an experienced interventional radiologist (the complication rate in experienced medical centres is less than 1%).

It is important that the AVS is carried out in a hospital where they have a lot of experience with carrying out this form of test and with interpreting the results. The results of the blood samples taken during the AVS will indicate clearly to the medical specialist whether there is excess aldosterone production in just one or both adrenal glands. The specialist needs this information to determine the further treatment process.

Both forms of treatment will be explained in the next paragraph.

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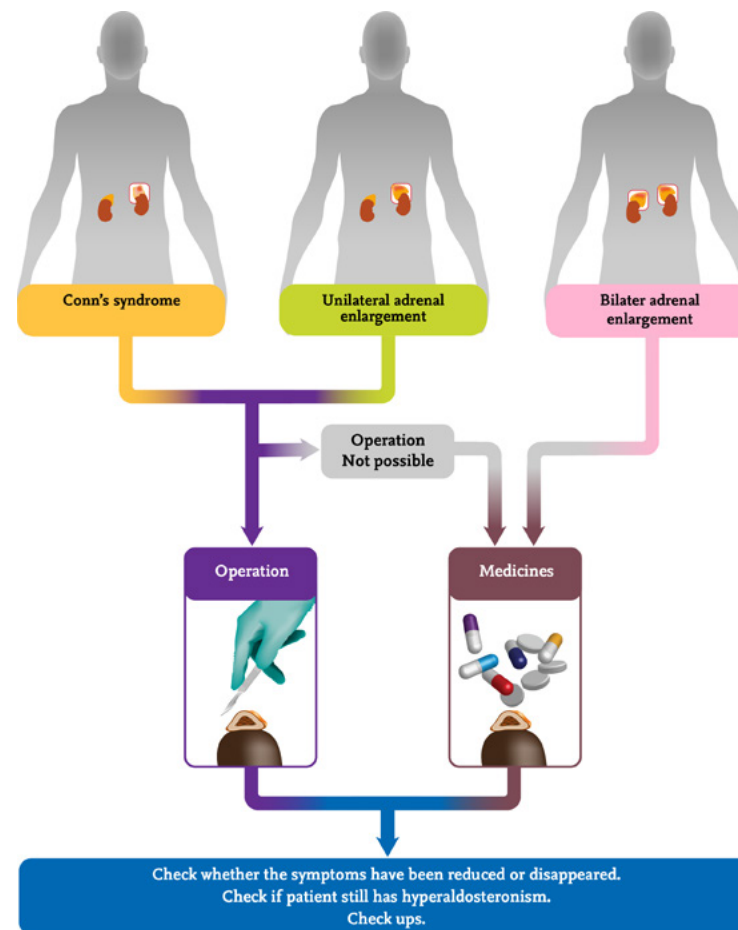
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The treatment of primary aldosteronism depends on the type of primary aldosteronism and on your general health.

Surgery

If there is a tumour (adenoma) or hyperplasia in just one adrenal gland, doctors usually opt to remove the 'offending' adrenal gland in a surgical operation. These days this procedure is usually carried out as keyhole surgery (laparoscopy). For the patient this means a relatively short recovery period and the risk of complications is much reduced.

After the operation, tests are carried out to determine whether the high aldosterone level in the body has been corrected. This is done by measuring the levels of aldosterone and renin in the blood, often followed by a salt-loading test. The blood pressure and the potassium level in the blood can have returned to normal after the operation. If the patient has had high blood pressure for a long time, it may still be high but can probably be reduced with the aid of blood pressure



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reducing medicines. It is important to continue taking medication, because high blood pressure means an increased risk of damage to the heart and blood vessels.

Quite often, the patient has had high blood pressure long before primary aldosteronism was diagnosed (see delayed diagnosis). This might already have caused damage and it may never be possible to return the blood pressure to normal levels again, even after the operation. Then, too, it is important that you continue to take medication to combat high blood pressure.

A surgical operation is usually a good choice, for the following reasons:

1. After successful surgery, the levels of aldosterone and potassium in the blood are usually normal and you will not need to take medicines in the future. The damage which primary aldosteronism causes to heart and blood vessels is almost certainly not only due to the high blood pressure but also to the hormone aldosterone itself. Medicines such as spironolactone or eplerenone reduce the impact on the heart and the blood vessels, but it is not certain whether this reduction is sufficient.

2. Once the primary aldosteronism in the blood has been cured, the blood pressure problem is easier to deal with. Patients will not need to take spironolactone, but can just be prescribed 'normal' blood pressure reducers which are often easier to cope with.
3. After a successful operation, you will soon start to feel better; there will be a huge improvement to your quality of life. This is probably the most important argument to always opt for an operation if you have a unilateral tumour (adenoma).
4. Recent research also suggests that an operation also reduces the chance of heart rhythm disorders.

Unfortunately, in around 10% of cases the primary aldosteronism does not disappear after the operation. The remaining adrenal gland is apparently still producing too much aldosterone. These patients will have to take special blood pressure regulating medication that also suppresses the harmful effects of aldosterone on the heart and blood vessels (such as spironolactone or eplerenone). There are few, if any, alternatives.

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No operation but medicines

In the case of a bilateral enlargement of the adrenal glands (bilateral adrenal hyperplasia), or when surgery is not possible, treatment will be offered in the form of medicines. The most commonly prescribed medicine is spironolactone. If the patient is unable to tolerate spironolactone, eplerenone will be prescribed. The doctor will usually prescribe spironolactone first, because this has the strongest effect. But side-effects can occur at higher doses, and then eplerenone will be prescribed because this produces hardly any side-effects; it does, however, have to be taken twice or three times a day. These medicines block the effects of aldosterone. Sometimes other medicines are still needed to reduce the blood pressure.

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How is patient care organised?

The care for people with primary aldosteronism is complex. While this is a disorder that is no longer quite so rare, specific knowledge and expertise are still essential to carry out both the tests and the treatment. A wide range of different healthcare practitioners are involved in patient care. We have already mentioned the internal medicine specialist and the interventional radiologist, and they are supported by a multidisciplinary team which includes nurses.

The family doctor also plays an important part in identifying primary aldosteronism. Your family doctor is the person who should be wondering what the underlying cause of your high blood pressure might

be. It is therefore important that your family doctor should discuss your case with a specialist as early as possible if your pressure remains high, or too high, in spite of a daily cocktail of various blood pressure reducing medication.

It is also important that your medical specialist should inform your family doctor fully about the diagnosis of primary aldosteronism.

If any damage has been caused to the kidneys or to your heart, the treatment team will be supplemented to include a nephrologist (kidney specialist) and a cardiologist (heart specialist).

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Hospital check-ups

After the operation, if you have been cured of the disease and your blood pressure is under control, you will continue to see the hospital specialist for no more than a year. After that, your blood pressure check-ups will be transferred to your family doctor. It is important that you have your blood pressure and potassium levels checked at least once a year, or preferably more often. If you are taking spironolactone or eplerenone it is possible that you will continue to be seen by the hospital specialist.

Residual symptoms

Patients report that they continue to experience some symptoms for a while after the operation. The symptoms they report are:

- muscle weakness, loss of strength
- tiredness
- concentration problems

Patients who take spironolactone, especially if they need higher doses, sometimes experience the following side-effects:

- erectile problems
- loss of libido (sex-drive) and breast formation (in men this is known as gynaecomastia)

- painful breasts and disrupted menstruation (for women)

Reducing salt intake to 1500 microgram can help.

Eplerenone doesn't seem to produce these side effects, but it does have to be taken more frequently. As with all medicines, spironolactone and eplerenone can also produce other side-effects in a very small minority of patients.

The results of a large scale survey carried out at the Radboud University Medical Center (Nijmegen) were published by a group of doctors in the first quarter of 2018. The article showed that the patient's quality of life improves after spironolactone or eplerenone is taken. Unfortunately, the average quality of life rating is still lower than for people who don't have PA. In addition, patients often report depression, anxiety disorders or other psychological problems.

The research was published in The Journal of Clinical Endocrinology & Metabolism, Volume 103, Issue 1, 1 January 2018 (pages 16-24).

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Annual check-up by internal medicine specialist

You can prepare for your appointment with the specialist on the basis of a healthcare diary and checklist.

Examples of the subjects that you can discuss during your appointment are:

- the possible consequences of the treatment and the possibility or impossibility of recovery
- the use of the medicines and the side-effects of spironolactone and eplerenone
- the availability of medicines
- healthy lifestyle and healthy foods, possible physiotherapy to improve your physical condition
- new symptoms, limitations or health problems you have experienced
- collaboration with the family doctor or other medical specialists
- additional help you might need, for example daily nursing care at home
- problems at work and working with the company doctor
- your feelings and how you are coping with the situation
- social or relational problems and possibly information and explanation of the disorder for your nearest and dearest
- arrangements for the next appointment

Primary aldosteronism can have some quite distressing consequences. Your questions are always welcome. The better you have prepared the questions you want to ask, in advance, the better the doctor will be able to give you the right advice or assistance.

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Living with primary aldosteronism

In the past 15 to 20 years there has been a lot of research carried out into the reduced quality of life experienced by patients with primary aldosteronism. Patients are affected by both physical and psychological symptoms.

The physical symptoms include: general or muscle pain, cramps, tiredness, headaches, heart palpation, reduced libido, sleep problems and dizziness. Examples of the psychological symptoms are: depression, anxiety disorders, behavioural problems, reduced social functioning and mood swings.

The low levels of potassium in the blood also cause muscle (including heart) problems.

On the whole, women with primary aldosteronism experience a lower quality of life than male patients do.

Research has shown that a patient's quality of life after a surgical operation (removal of one adrenal gland) is almost the same as that of the general population. After patients start taking spironolactone or eplerenone, the quality of life also starts to improve,

but it is hardly ever as good as it is experienced to be after an operation.

Life with primary aldosteronism is far from easy. The best advice for most patients is to seek help from a physiotherapist and a psychologist.

It is important to offer help to the people who are most closely concerned with the patient: to offer support and give them information about the disorder and the problems that could possibly occur in connection with it.



It might help you to watch the mini-documentary entitled “Primary aldosteronism”. In the documentary, a patient with primary aldosteronism speaks about the search for a diagnosis, the tests, the treatment and what life is like for a patient with PA.



It might also be useful to have a look at the animated clip entitled “The unknown psychological consequences of adrenal disorders” (at the moment, this clip is only available in Dutch).

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Do you want to know more about primary aldosteronism?

Further information about primary aldosteronism can be found on:

- <https://adrenals.eu>
- www.bijniernet.nl
- www.bijniervereniging-nvacp.nl

Membership of a patient association brings a lot of benefits, so membership is a serious option for you to consider. In addition, the patient organisations in the Netherlands promote the interests of their members by entering into discussions about the care to be provided and the availability and supply of medicines. They also provide reliable information about the various clinical aspects of the disorders. In addition, they organise meetings so that patients can meet each other and/or learn about the latest developments. Some Dutch healthcare insurers will pay part or all of the membership fee.

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The text of this brochure (Dutch and English versions alike) has been compiled with the greatest possible care. Despite this, they might contain errors. We request that you submit any additions or corrections to info@bijniernet.nl

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