# Making a decision about abdominal aortic aneurysm (AAA)



#### What is this document?

This document is called a decision aid. It is designed to help you decide between treatment options.

It is for people who have an **abdominal aortic aneurysm** (usually called AAA or triple A for short) and who have been asked to think about surgery for it.

You can use this decision aid to help you talk to the team of healthcare professionals looking after you. This team is often called the **MDT** (short for **multidisciplinary team**), because it includes people from different health professions and specialties.

Go to page 3 for more information on your options

Go to page 5 for more information on surgery

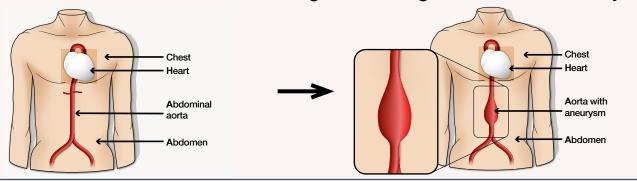


Go to page 9 for help with making your decision



# 1 What is AAA?

The aorta is the main blood vessel that supplies blood to your body. It runs from your heart down through your chest and abdomen (tummy). In some people, as they get older, the wall of the aorta in the abdomen can become weak. It can then start to bulge. This bulge is called an aneurysm.



#### My risk

An AAA does not cause symptoms for most people.

In some people it can cause a pulsating sensation in the abdomen, or back pain.

It's possible that your AAA could burst (rupture). This does not happen to most people who have an AAA, but it would be very serious if it did.

A burst AAA is usually fatal. But most people who have an AAA do not die because of problems from their AAA.

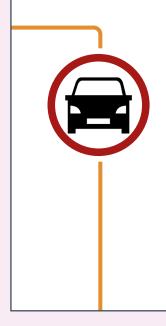
The risk of your AAA bursting depends on how big it is, and certain other things. There is more information about this on page 4.

#### **Driving with AAA**

If you have a car or motorcycle licence you must tell the DVLA if your AAA is 6 cm or more. You are not allowed to drive if your AAA is 6.5 cm or more. If it is, you must give up your licence. You will get your licence back if your AAA is successfully treated.

If you are a bus, coach or lorry driver you must tell the DVLA whatever the size of your AAA. You are not allowed to drive if it is 5.5 cm or more and you must give up your licence. You will get your licence back if your AAA is successfully treated.

If you have surgery, you will not be able to drive until your surgeon says you are fit enough. This will not usually be for several weeks after the operation. If you had to give up your licence you will need to tell the DVLA that your AAA has been successfully treated.





#### Travel and insurance with AAA

There is no increased risk if you travel by plane if you have an AAA. It is no more likely to burst because of cabin pressure at a high altitude than on the ground. If you have surgery, you may not be allowed to fly for a short while afterwards.

You should declare your AAA when applying for insurance. You may be charged a higher premium or have AAA excluded from cover.

# 2 What are my options?

#### You have 4 options:

- Stay as I am (do nothing)
- Medicines, lifestyle changes and regular monitoring
- Open surgical repair of your AAA
- Endovascular repair of your AAA (EVAR)

Each option is covered briefly below. You can click on the 'more information' buttons for details on each of the options (or, if printed out, you can find these pages in the appendix section at the end of this aid).

Your choice will depend on what matters most to you and also your general health and the size and shape of your AAA. Surgery may not be suitable for some people. It's important to make the decision jointly with your MDT. There's more on comparing the types of surgery on page 5.

#### Staying as I am

You could decide not to have any treatment or follow up. Most people will not feel any different, but the risk of their AAA bursting will usually increase over time.

Click here for more on staying as you are



#### Open repair

Open surgical repair is done under general anaesthetic. A long cut is made in your abdomen, and the AAA is repaired with a graft.

Click here for more on open repair



#### Medicines...

You could decide not to have surgery now, but do things to reduce the chance of your AAA bursting. You could also have scans from time to time to see if your AAA is growing.

Click here for more on medicines...



#### **EVAR** surgery

EVAR can be done under general, spinal or local anaesthetic. A small cut is made in your groin, in both legs. The AAA is repaired with a stent graft that is passed up your leg arteries to the AAA.

Click here for more on EVAR surgery



# 3

# What is the risk if I do not have surgery?

Most people with AAA who are asked to think about surgery for it have an AAA that is 5.5 cm wide, or wider. We cannot say for certain how likely it is that your AAA will burst if you do not have surgery and your AAA is 5.5 cm or wider. This is because there is not enough information from studies.

But a large UK study looked at what happened to men with an AAA slightly smaller than this (5.0 cm to 5.4 cm) who did not have surgery - see the study results infographic below. (Men are more likely to get an AAA than other people. This means that most information on the risk of AAAs bursting comes from studies in men.)

Results: in the study of men with a slightly smaller AAA (5.0 cm to 5.4 cm), the AAA burst in fewer than 1 man in 100 per year (0.4%), and did not burst in more than 99 men per 100 per year (99.6%).



The risk of your AAA bursting is higher than this:

- the **bigger** your AAA is (most people's AAA grows over time, so their risk also increases over time)
- if your AAA is growing more quickly than a few millimetres a year
- if you are a **woman** (there is very little information about the risks in trans or non-binary people)
- if you smoke or have smoked in the past
- if you have **high blood pressure**, or certain other medical conditions.

Your MDT will advise you more.

It is important to remember that this is the risk **per year**. This means it keeps being a risk over time. It is not a one-off risk, like crossing a busy road just once. It is more like crossing a busy road many times. So after a few years, more people from that original group of 100 who did not have surgery will also have had their AAA burst.

Even so, it is important to remember that **AAAs do not burst in most people who have them**.

## 4 How do the types of surgery compare?

#### How long will I have to stay in hospital after the operation?

#### Open repair

You will usually need to stay in hospital for about 6 to 10 days.

Many people need to go to a high dependency unit (HDU) and some need to go to an intensive care unit (ITU) for a few days after surgery.

More people need to go to HDU or ITU after open repair than after EVAR, but this depends on your general health.

#### **EVAR**

You will usually need to stay in hospital for 1 to 3 days.

Some people need to go to an HDU and a few people need to go to an ITU for a few days after surgery.

Fewer people need to go to HDU or ITU after EVAR than after open repair, but this depends on your general health.

# **Open repair**

#### How long will it take me to recover from the operation?

It will usually take at least 3 to 6 months to recover from the operation. This depends on your general health but is usually longer than with EVAR.

You are likely to need a lot of practical help to cope at home, especially at first.

It will usually be several weeks before you can drive again.

#### **EVAR**

It will usually take a few weeks or perhaps longer to recover from the operation. This depends on your general health but is usually shorter than with open repair.

You are likely to need practical help to cope at home, especially at first.

It will usually be several weeks before you can drive again.

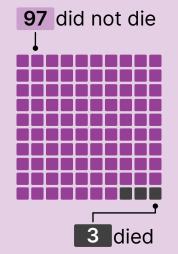
# What is the chance of dying during or soon after the operation?

(These risks are averages. They are higher for women and some other people, and lower for some others. Your MDT can explain the risk for you.)

#### **Open repair**

Studies show that on average, about **3 people in 100** die in hospital shortly after open repair and 97 do not.

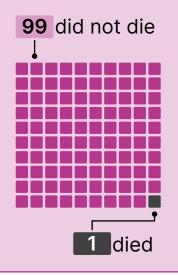
The risk for you will depend on your general health.



#### **EVAR**

Studies show that on average, about 1 person in 100 dies in hospital shortly after EVAR and 99 do not.

The risk for you will depend on your general health.



# What are the other main risks of surgery?

(Your MDT will explain about complications and the risk of getting them in more detail if you are thinking of choosing surgery.)

#### Open repair

Complications tend to be more likely after open repair than after EVAR. Some can cause long-term problems if they happen. These include:

- a heart attack or stroke
- kidney damage
- damage to the blood supply to the legs.

#### **EVAR**

Complications tend to be **less likely** after EVAR than after open repair. Some can cause long-term problems if they happen. These include:

- a heart attack or stroke
- kidney damage
- damage to the blood supply to the legs.

# What is the effect on the chance of dying from AAA complications in the future?

(If you choose to have surgery, having either open repair or EVAR makes it much less likely your AAA will burst.)

#### **Open repair**

In the first 8 years after surgery, it is not clear from studies whether the type of surgery you had (open or EVAR) makes any difference to the chance of dying from AAA complications.

The risk might be higher with open repair than with EVAR, but we cannot be sure.

However, after 8
years and up to 15
years after surgery,
a large study found
that people who'd
had open repair were
less likely to die from
AAA complications
than people who'd
had EVAR.

#### **EVAR**

In the first 8 years after surgery, it is not clear from studies whether the type of surgery you had (EVAR or open) makes any difference to the chance of dying from AAA complications.

The risk might be **lower** with EVAR than with open repair, but we cannot be sure.

However, after 8
years and up to 15
years after surgery,
a large study found
that people who'd had
EVAR were more likely
to die from AAA
complications than
people who'd had
open repair.

When all the numbers were added up over the whole 15 years of the study, things averaged out so there was **no clear difference** between open repair and EVAR.

#### What is the effect on the chance of dying overall in the future?

#### **Open repair**

There is no good evidence to say that the type of surgery makes a difference to the chance of dying overall in the longer term (over the 15 years after the operation).

#### **EVAR**

There is no good evidence to say that the type of surgery makes a difference to the chance of dying overall in the longer term (over the 15 years after the operation).

# What is the chance of needing further procedures in the future?

(These risks are averages. The risk for you will depend on your particular circumstances.)

#### **Open repair**

Some people need surgery or other procedures later on to deal with problems with the graft. On average, **fewer** people need this after open repair than after EVAR.

Studies show that on average:

 By 4 years after surgery about
 9 people in 100 had needed further procedures and 91 had not.

9 91

 By 8 years after surgery about
 13 people in 100 had needed further procedures and 87 had not.

13 87

 By 15 years after surgery about
 15 people in 100
 had needed further procedures and 85
 had not.

15 85

#### **EVAR**

Some people need surgery or other procedures later on to deal with problems with the stent graft. On average, **more** people need this after EVAR than after open repair.

Studies show that on average:

 By 4 years after surgery about
 20 people in 100
 had needed further procedures and 80
 had not.

20 80

 By 8 years after surgery about
 23 people in 100 had needed further procedures and 77 had not.

23 77

 By 15 years after surgery about
 33 people in 100
 had needed further procedures and 67
 had not.

33 67

# 5 What's important to you?

What matters to you is an important part of making a decision about treatment. It might help you to think about each of the things below, and put a mark on the scale where it applies to you. You can also write down your own thoughts or concerns. You might want to talk about your answers with your MDT and your family and friends.

#### Thinking about having surgery or not having surgery

#### **Definitely**

#### No strong opinion

#### **Definitely**

#### Thinking about the chance of your AAA bursting

I am **very worried** about my AAA bursting if I do not have surgery

I am **not especially worried** about the chance of my AAA bursting if I do not have surgery

#### Thinking about driving

Losing my driving licence would be a big problem for me

Losing my driving licence would **not be** a **problem** for me or does not apply to me

#### Thinking about the risks of surgery

I am **not especially worried** about the risks of surgery

I am **very worried** about the risks of surgery

#### More marks left side:

Leaning towards surgery

#### More marks right side:

Leaning towards non-surgical treatment or doing nothing

# Thinking about after surgery and the long term

Definitely	No strong or	oinion	Definitely
Thinking I'll have lots of practical held leave hospital	about recove		to get much practical
Taking time to recover would <b>not be a big problem</b> for me		Taking time to rec problem for me	cover would be a <b>big</b>
Thinking abou	ıt the long-ter	m effects of	surgery
I am <b>comfortable</b> with the I might not make a full recove surgery			ned about the chance a full recovery from
More marks left side	•	More ma	rks right side:
Leaning towards surge	ry	non-surg	ng towards lical treatment ng nothing
My thou	ghts, concerns	s and questior	ıs

#### **Definitely**

#### No strong opinion

#### **Definitely**

#### Thinking about the time to recover from surgery

It does not matter too much if I take a bit longer to recover from surgery

It is **very important** that I recover from surgery as quickly as possible

#### Thinking about needing to have my graft checked regularly

Needing to have regular checks would be a **big problem** for me

Needing to have regular checks would **not be a big problem** for me

#### Thinking about the short-term risks of surgery

I am **not especially worried** about the higher short-term risks of open repair compared with EVAR I am **very worried** about the higher shortterm risks of open repair compared with EVAR

#### Thinking about the longer term

The **longer-term benefits**, including trying to avoid the need for procedures in the future, are very important to me

I'm focussed on the **shorter-term benefits**, and I am prepared to have procedures in the future if I need to

#### More marks left side:

Leaning towards open repair

#### More marks right side:

Leaning towards EVAR

#### My thoughts, concerns and questions

#### Where can I go for more information?

#### **Circulation foundation:**

https://www.circulationfoundation.org.uk/help-advice/abdominal-aortic-aneurysm/open-aaa-repair-operation



#### **British Heart Foundation:**

https://www.bhf.org.uk/informationsupport/conditions/abdominal-aortic-aneurysm

#### NHS:

https://www.nhs.uk/conditions/abdominal-aortic-aneurysm/

# Royal College of Anaesthetists (for advice about preparing your mind and body for surgery):

https://www.rcoa.ac.uk/patients/patient-information-resources/preparing-surgery-fitter-better-sooner/fitter-better-sooner

#### **DVLA (for information about driving with an AAA):**

https://www.gov.uk/aneurysm-and-driving

#### Making the decision

Think about which option is the best one for you at the moment. This will depend on what matters most to you and also your general health and the size and shape of your AAA. It's important to make this decision jointly with your MDT. Remember:



- You do not have to make a decision straight away. You can take some time and ask your MDT for more information. Do not be afraid to ask them about the results in their centre. MDTs really want people to make the decision that feels right for them.
- You might also want to discuss things with family and friends. It might be helpful to ask a friend or family member to talk to your MDT with you. But remember that although your decision may have an impact on them, it is you who will be directly affected, whatever you decide on.
- It's OK to change your mind. If you choose surgery you can change your mind right up to the day of the operation.

## Things to check

I feel sure about the best choice for me	Yes	No
I know enough about the potential benefits and harms of each option	Yes	No
I am clear about which potential benefits and harms matter most to me	Yes	No
I have enough support and advice to make a choice	Yes	No
If you said 'no' to any of these, tell your MDT and ask ther	n for help.	

### My thoughts at the moment

I'm not sure what to do	
I'm leaning towards	
This is because	

Contacts
Name of my surgoon:
Name of my surgeon:
Contact details:
Name of my specialist nurse:
Contact details:
Next steps
What will happen to me next? (treatments or tests)
When will these happen?
When will I next see someone from my MDT?
What decision do I need to make next? When do I need to make it?
Things I want to talk about with my MDT
These can be concerns or questions you have, or what you hope to get from what you decide to do.

## 8 How this decision aid was produced

#### Who made this decision aid?

This decision aid was developed in line with the NICE process guide for decision aids. It was produced with a project group of clinical and patient experts. A wide range of stakeholders was invited to comment on an earlier draft. This included people with lived experience and frontline healthcare professionals. It is based on the best available evidence and the project group's experience and expertise. The sources of further information were identified by the project group. NICE is not responsible for the content of external websites. Omission of a website in this decision aid does not imply that NICE has made a judgment about its content.

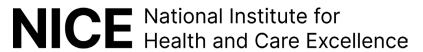
#### You and this decision aid

This decision aid can only be a guide because everyone's situation is different. You will usually be asked to have a number of tests. Your MDT will explain the results and how they might affect your decision.

#### Information we used to make this decision aid

- Abdominal aortic aneurysm: diagnosis and management (2020) NICE guideline NG156; Evidence reviews K and K2.
- Oliver-Williams C, Sweeting MJ, Jacomelli J et al (2019) Safety of men with small and medium abdominal aortic aneurysms under surveillance in the NAAASP. Circulation 139: 1371 to 1380.
- National Vascular Registry (2022). 2022 Annual report.
- Pouncey AL, David M, Morris RI et al. (2021) <u>Systematic review and meta-analysis</u> of sex specific differences in adverse events after open and endovascular intact abdominal aortic aneurysm repair. Eur J Vasc Endovasc Surg 62: 367 to 378.
- DVLA (2022) Cardiovascular disorders: assessing fitness to drive. Accessed November 2023.

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#### Appendix 1: Staying as I am

- It is always an option not to have any treatment or follow up.
- The aim of treatment is to prevent the AAA bursting. For most people, having an AAA does not make them feel unwell.
- If you had surgery you would not feel physically healthier than you do now, even though the risk of your AAA bursting would be much less.
- If you do not have any treatment and your AAA grows, the risk of it bursting will increase each year.
- If you do not have surgery, you will still be able to do most everyday activities. You may be advised to avoid heavy lifting and other things that raise your blood pressure, because this could worsen your AAA. Your MDT will advise you.

#### Things to think about

- Some people feel anxious about having an AAA and worry about it bursting. Other people are not especially worried about that.
- Surgery might be an option for you in the future. But if you develop other health problems as you get older, surgery may be more risky or may not be possible.
- If you choose no treatment, you might like to make a clear statement about your wishes for treatment if your AAA does burst. This is called an advance directive or living will. Your GP or MDT can tell you more.



#### **Appendix 2: Medicines, lifestyle and monitoring**

#### Can I reduce the chance of my AAA bursting?

- It is less likely your AAA will grow quickly or burst if you stop smoking (if you smoke) and manage your blood pressure. Doing these things will also make it less likely you will have a heart attack or stroke.
- Your GP can help you with support to stop smoking. You could make changes to your lifestyle to manage your blood pressure. These include keeping active, maintaining a healthy weight, eating healthily and not drinking too much alcohol.
- You might also be asked to think about taking medicines to manage your blood pressure, and other medicines, such as statins, to lower your risk of having a heart attack or stroke.

#### What about monitoring?

- You might decide not to have surgery now, and have scans from time to time to see if your AAA is growing (surveillance). You could then think again about surgery depending on the scan results.
- Your MDT will be able to recommend how often you should have scans.

#### Things to think about

- Choosing this option may make no difference to how physically healthy you feel, you may feel healthier overall if you make lifestyle changes.
- If you do not have surgery, you will still be able to do most everyday activities. Your MDT may advise you to avoid heavy lifting and other things that raise your blood pressure, as this could worsen your AAA.
- Some people feel anxious about having an AAA and worry about it bursting, even with regular monitoring. But some people are OK with this.
- Surgery might be an option for you in the in the future. But if you
  develop other health problems as you get older, surgery may be more
  risky or may not be possible
- If you choose this option, you might like to make a clear statement about your wishes for treatment if your AAA does burst. This is called an advance directive or living will. Your GP or MDT can tell you more.

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#### **Appendix 3: Open surgical repair**

Open surgical repair is done under general anaesthetic (you will be unconscious and will not feel pain). A long cut is made in your abdomen. The surgeon stitches a tube called a graft inside the AAA. Blood then flows through the graft instead of the AAA. This makes it much less likely that the AAA will burst, although that might still happen. The cut in your abdomen is closed with stiches or staples.

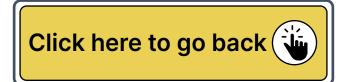
Once the graft has been inserted, you cannot feel it is there.

#### What ongoing treatment will I need after surgery?

- You may be asked to take some medicines, such as aspirin, long term after the surgery to help keep the graft working well.
- You may have a follow-up appointment with your surgeon but you will not usually need regular repeat scans to check the graft is working properly.
- You will still need to think about medicines and lifestyle changes to manage blood pressure and reduce your risk of heart attack or stroke.

#### Things to think about

- Open surgical repair is a major operation and it will usually take several months to recover from it. You are likely to need a lot of practical help to cope at home, especially at first. You should talk to your MDT about this and think about who may be able to help.
- It may be a while before you can get back to normal life. Some people do not make a full recovery from surgery. Some possible complications from surgery can have long term effects on your quality of life.
- Your MDT can advise you on ways to improve your recovery. These
  might include things you can do before surgery to improve your health
  and help you build up your strength and fitness.
- Open surgery may not be an option for some people because of their health conditions, or the shape of their aorta or aneurysm. Those people could still think about medicines and lifestyle changes. These are explained under the option 'Medicines, lifestyle and monitoring'.



#### Appendix 4: Endovascular repair (EVAR)

EVAR can be done under general, spinal or local anaesthetic (where you'll be conscious but will not feel pain). Small cuts are made in your groin, in both legs. The surgeon inserts a kind of graft called a stent graft into the artery and guides it up to the AAA where it is held in place. Blood then flows through this instead of the AAA. This makes it much less likely the AAA will burst, but it still could. Once inserted, you cannot feel the graft.

#### What ongoing treatment will I need after surgery?

- You may be asked to take some medicines, such as aspirin, long term after the surgery, to help keep the stent graft working well.
- You will need regular scans to check the stent graft is still working properly. These may be done every year, but your MDT will advise you.
- Sometimes a leak develops where the stent graft is held in place, or the graft slips out of position. If either of these things happen you may need a further procedure a bit like EVAR, or possibly open surgery.
- You will still need to think about medicines and lifestyle changes to manage blood pressure and reduce your risk of heart attack or stroke.

#### Things to think about

- EVAR is not as big an operation as open surgery, but it will still usually take a few weeks or perhaps longer to recover from it. You are likely to need practical help to cope at home, especially at first. You should talk to your MDT about this and think about who would be able to help you.
- It may be a while before you get back to normal life. Some people do not make a full recovery from surgery. Some possible complications from surgery can have long term effects on your quality of life.
- Your MDT can advise you on ways to improve your recovery. This
  might include things you can do before surgery to improve your health
  and help you build up your strength and fitness.
- EVAR may not be an option for some people because of their health conditions, or the shape of their aorta or aneurysm. Those people could still think about medicines and lifestyle changes. These are explained under the option 'Medicines, lifestyle and monitoring'.

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