# Making a decision about gallstones





#### What is this leaflet?

This leaflet is for people with **gallstones**. It can help you decide whether you want treatment and which treatment to choose. You should go through it and then talk to your healthcare professional. There are some parts you can fill in to prepare for your next appointment.

Pages **1 – 5** are about **gallstones**  Pages 6 – 10 are about treatments

Pages **5 & 11** are for you to **fill in** 

Page 11 is for use with your doctor / GP

# What is a gallbladder and what are gallstones?

The **gallbladder** is a small bag that stores and releases bile.

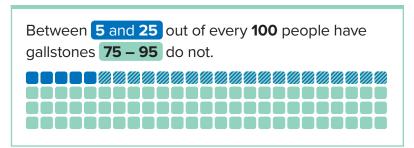
**Bile** is a liquid that helps digest fatty foods. It is made by the liver. When we eat, the gallbladder squeezes to release bile into the intestines (gut), which then mixes with food. If the gallbladder is removed, bile goes directly from the liver into the intestines.

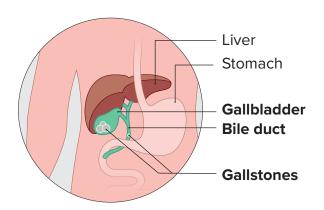
**Gallstones** are small stones made of cholesterol and bile. They form in the gallbladder. They can take many years to form. They can be there for many years without ever causing symptoms or pain.

Gallstones can cause pain if they:

- irritate the gallbladder and it becomes inflamed
- · move and block the flow of bile
- move into the bile duct

# How common are gallstones in the UK?





# What are the treatments for gallstone pain?

# Do nothing Things I can do myself (diet & being a healthy weight) Medicines

Which treatment is best for you will depend on your situation and how your symptoms are affecting your life.

Surgery



# **About symptoms of gallstones**

# What are the symptoms of gallstones?

# Sometimes gallstones cause mild symptoms

- Discomfort in the abdomen.
- Feeling of heaviness under the ribs on the right hand side.
- Bloating.

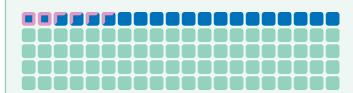


# Sometimes gallstones cause sudden attacks of pain. This is called biliary colic

- You might have sudden severe pain in the abdomen.
- Pain might spread from the right hand side of your abdomen (tummy) to your back or shoulder.
- Pain might feel like it is stabbing from your abdomen to your back.
- Pain often comes in waves of intensity. This is because the gallbladder is contracting (squeezing) against the stones.
- Pain might happen after eating because the gallbladder and duct contract (squeeze) to release bile.
- Pain can be constant and not relieved by going to the toilet, passing wind or being sick.
- Pain usually lasts for about 30 minutes.

# Sometimes gallstones cause serious conditions that need urgent treatment

- Cholecystitis (Inflammation of the gallbladder).
- Pancreatitis (Inflammation of the pancreas).
- Cholangitis (Stones get stuck in the bile duct and become infected).



Around 20 out of every 100 people with gallstones will have **painful symptoms**, 80 do not.

2 – 6 will develop a serious condition within5 years needing urgent medical treatment.

Gallstones are often found when you are having a scan for something else. They do not always cause pain. If you have not had symptoms for 5 years it is less likely that you will ever get pain from your gallstones. If you have symptoms, they usually go away when the gallstones are removed.

# When to get urgent medical help (visit A&E or call 111)

- You feel unwell with a **high temperature**, **chills and jaundice** (the whites of your eyes and skin look yellow) and might be **sick** (vomit).
- You feel unwell with pain in the upper right hand side of your abdomen and you have a fever.
- You have **pain that is so intense** you can not find a position to make it better, or pain that does not go away with normal pain relief.

# More about gallstones

# **Gallstones are more likely** in people who:

- are living with obesity (BMI over 30)
- are over 40 years old
- are female
- have a family member with gallstones
- use HRT or the combined oral contraceptive pill or are pregnant
- have had surgery to remove part of their bowel
- take certain medicines
- have Crohn's disease
- have diabetes
- have lost a lot of weight very quickly

#### Why do gallstones form?

We don't know exactly why gallstones form. Bile is made up of cholesterol, bilirubin and other substances. It is thought that if the liver makes too much of one of these substances then stones form.

#### What does bile do?

Bile helps digest what we eat. If you have your gallbladder removed, the liver will still make bile and you can still digest fats.

# How many gallstones might I have?

Some people have just one gallstone, others can develop many. Treatment is the same if you have one or more than one.

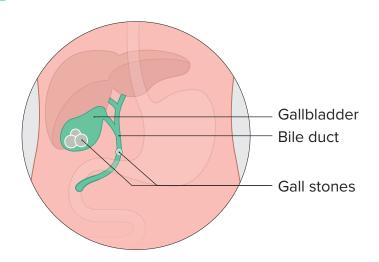
# How big are they?

Stones can be as small as a grain of salt or sometimes even as big as a golf ball. Small stones can move and block the bile duct causing pain. Larger stones can cause problems and pain in the gallbladder itself.

# How big is a gallbladder?

The gallbladder is about 7 - 15 cm long.

## Gallstones can be in the gallbladder or they can move into the bile duct



## How long does it take for gallstones to form?

It can take 10 - 20 years for gallstones to form. This is why they are more common in people over 40.

## Will I make more gallstones if you remove these?

If you have your whole gallbladder removed it's unlikely you will make new gallstones.

If you have stones removed from your bile duct but your gallbladder is left intact, you may still have pain from stones in the gallbladder and they may get bigger. You might also develop new gallstones.

## Can gallstones cause problems to other organs in the body?

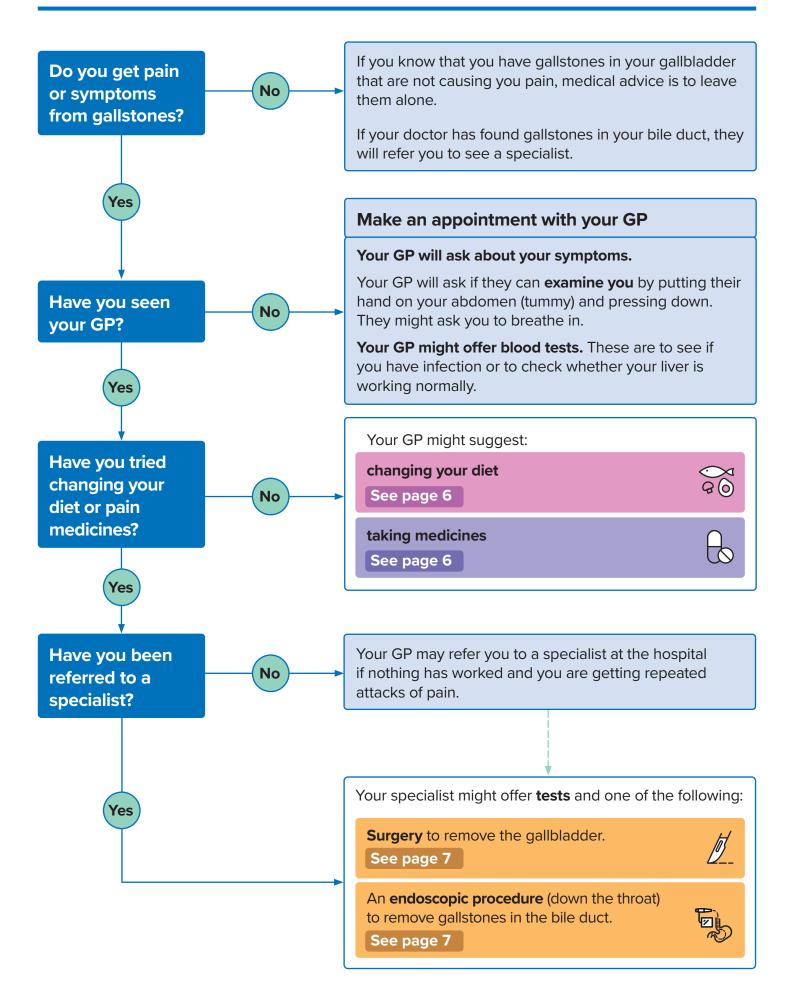
If they move from the gallbladder, they can:

- block the bile duct causing jaundice
- block the pancreas tube causing pancreatitis
- sometimes block the intestine

## Can you 'zap' gallstones with ultrasound like kidney stones?

Gallstones and kidney stones are made up of different things. Kidney stones can sometimes break up with ultrasound but gallstones can not.

# What can I do if I have gallstones?





# How are gallstones affecting my life?

#### The treatment that is right for you depends on how your symptoms are affecting you.

You might want to use this page to write down what's important to you and then talk about your answers with your doctor.

# Circle what you need help with

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Pain		:	Sleep		Mental well-being		Physical Activity			,	Work	
Circle	on the	scale	where	your	pain is	whe	n you	get	an a	ttack		
0	1	2	3	4	5	6	7		8	9	10	
No pain									(una		Severe pair hink clearly	
Think	about	these	statem	ents a	and pu	ıt an 🛚	k on t	he s	cale			
								No/n	ot at all		Yes/a lot	
I am un	able to go	to work	or stay at v	vork due	e to attac	ks						
I worry	I might ha	ave an unp	oredictable	attack								
My sym	nptoms are	e affecting	g my menta	al health	n and wel	l being						
	ried chan ave you ch											
Pain fro	m gallsto	nes is affe	ecting ever	y aspec	ct of my li	fe						
I have tried medicines												

Use this space to write down anything else you're worried about regarding gallstones

What triggers an attack for you and what helps if you have an attack?				
What does an attack feel like for you?				



# Treatment options for gallstone pain

If you have gallstones, only **surgery** can remove them.

**Changing your diet** will not get rid of gallstones once they have formed because gallstones take many years to form. It might help prevent new gallstones forming (we don't have enough evidence to say yet).

It is possible to manage attacks of pain or discomfort from gallstones by avoiding things that trigger attacks. You can also take **pain relief** when you get an attack.

# Things I can do myself



If you don't have other conditions that could cause complications, you can try to manage attacks yourself.

**Avoid foods that trigger painful episodes.** Keeping a food and symptoms diary can help you identify foods that trigger pain for you. These might be fatty foods, spicy foods or something else. Everyone is different.

**You don't need to remove all fat from the diet.** Choose foods like oily fish, avocado, nuts, seeds, olives and olive oil, which contain 'healthier' fats.

**Eat lots of fibre** (fruits, vegetables and wholegrains such as oats and wholewheat bread). This might help prevent new gallstones or stones getting bigger. Fruit smoothies do not count as a good fibre source and are often very high in sugar.

**Keep active.** You might want to choose exercise activities that you enjoy to help you maintain a healthy weight.

**Eating smaller meals** more often rather than large portions can help some people's symptoms.

#### **Medicines**



Talk to your pharmacist or GP about safe medicines to take for gallbladder pain. There may be some that are good to take for a short time and others you can take longer term.

For example you can take pain relief such as ibuprofen or paracetamol to help when you get an attack. You should not take ibuprofen long term without talking to your doctor first.

Your pharmacist might suggest other medicines such as antispasmodics e.g. Buscopan.

Your doctor can prescribe stronger pain relief if needed.



# Treatment options for gallstone pain at the hospital

# If you are referred to hospital you might be offered tests

Tests help your doctors understand where your stones are and which treatment to offer.

**An ultrasound scan** is the best way to see if you have gallstones, where they are, how big they are, and how many there are. A device is put on top of your abdomen and sound waves create a picture of your gallbladder. It usually takes about 10 - 15 minutes.

You will be asked not to eat before you go for the scan. This is important so that your specialist can see your gallbladder when it is full and makes it easier to see the stones.

If your specialist needs to investigate further they might offer an MRI or CT scan.

# If you have gallstones you might be offered surgery

Which surgery or procedure you will be offered depends on where your gallstones are, your preferences and other things about you and your health.

You will be offered surgery if:

- your symptoms are severe and frequent
- your gallbladder becomes inflamed (cholecystitis). You might be admitted to hospital and offered antibiotics and surgery right away

# If your gallstones are in the gallbladder



You will usually be offered surgery to remove the gallbladder and gallstones.

- Surgery is usually done as a laparoscopy (keyhole). You will have a number of small cuts in the abdomen. You will be asleep (general anaesthetic).
- If keyhole surgery is not suitable for you, you will be offered open surgery. Your surgeon will make one larger cut in your abdomen.



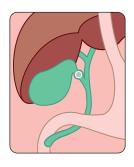
#### If your gallstones are in the bile duct



**ERCP** (endoscopic retrograde cholangio pancreatography) is a procedure to remove stones in the bile duct through a long tube called an **endoscope**. The endoscope goes down your throat. You have sedation to make you sleepy and you should not feel any pain. You are usually offered surgery later to remove the gallbladder.

In some hospitals you might be offered **keyhole surgery to remove stones in the bile duct and your gallbladder**. It is not yet done in all hospitals. Ask your specialist if you want to know more.

You usually have stones in the gallbladder if you have them in the bile duct.





# What if I'm offered surgery or ERCP?

This page will help you compare the options to remove gallstones. Which you will be offered depends on where your gallstones are and other things about you.

To remove gallstones in the <b>gallbladde</b>	er and bile duct	To remove gallstones in the <b>bile duc</b>	
aparoscopic keyhole) surgery	Open surgery	Endoscope (tube) down the throat (ERCP)	
	You may be offered open surgery if keyhole surgery is not suitable for you.	You are usually offered an operation t remove the gallbladder after ERCP.	
How common is it?			
About 57,000 each year in England.	About 3,000 each year in England.		
How will they access the gallsto	nes?		
Your surgeon makes a number of small cuts in your abdomen.	Your surgeon makes one cut about 10 – 15 cm.	Your doctor puts a long thin tube with camera at the end, an endoscope, int your mouth, down your throat and into your intestine.	
What does the procedure involve	re?		
Your surgeon removes your gallbladder with special tools through one of the small cuts.	Your surgeon removes your gallbladder through the cut in your abdomen.	Your doctor widens the opening of the bile duct and removes your stones with the endoscope. Sometimes they leave them to pass out in your poo. Sometimes they put a stent in. This can prevent jaundice and other complications. Usually you have another ERCP later on to remove the stent and the stones.	
Will I have stitches?			
Cuts usually closed with di	ssolvable stitches and glue.	Not applicable	
Anaesthetic or sedation?			
You will have a go (you will l	Usually you will be sedated which means you will be awake but sleepy and should not have any pain.		
How long does it take?			
Takes 60 – 90 minutes	Takes 2 – 2.5 hours	Takes 30 – 60 minutes	
Hospital stay			
Usually you go home the same day. Sometimes you need to stay overnight.	You might stay in hospital for up to 5 days.	Usually you go home the same day Sometimes you need to stay overnight in hospital.	
Recovery			
If it all goes smoothly, 7 – 10 days. It can be much longer for some people.  You can exercise when you feel comfortable and drive when you can safely perform an emergency stop without pain.	About 6 weeks to get back to a normal routine.  You can exercise when you feel comfortable and drive when you can safely perform an emergency stop without pain.	You can't drive for 24 hours after the procedure due to the sedation.	

You can try to eat normally after these operations. Food should be digested normally.

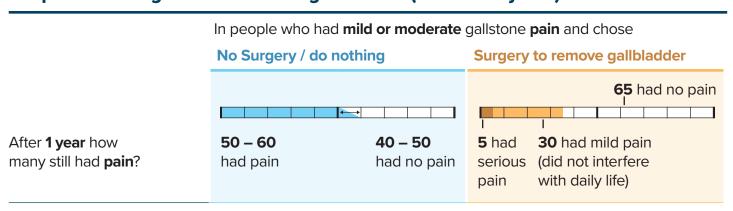


colic-like pain?

# Potential benefits and risks of treatments

The numbers here are based on research studies (see **page 12** for details). These numbers are averages. What works well for one person may not work for another.

#### People who had gallstones in their gallbladder (out of every 100)



It seems that people who have their gallbladder out because their pain is more severe, have more improvement than those who had mild pain.

Why did people still have It is likely the gallstones were not the cause of their pain. About a pain after having their third of people do not find the cause of their pain. If you still have gallbladder removed? pain after you have recovered from your operation, see your GP. How many needed urgent medical treatment due to \*\* pancreatitis or stones in 2 - 6 did **94 – 98** did not 1 - 4 did **96 – 99** did not the bile duct? How many needed urgent medical treatment due to

# People who had keyhole/open surgery to remove their gallbladder (out of every 100)

**96 – 97** did not

Less than 1 did

Over 99 did not

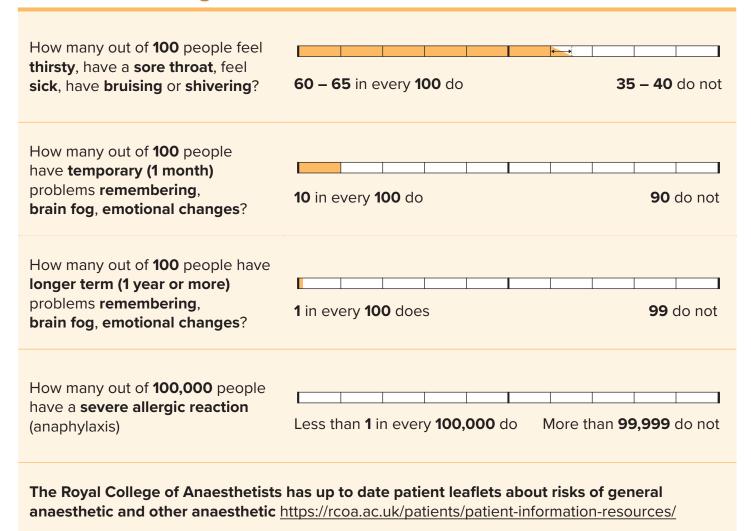
3 - 4 did

How many had <b>damage to the bile duct</b> needing another surgery?	Less than 1 did Over 99 did not
How many had <b>bile leaks</b> that need another surgery or drain?	Less than <b>1</b> did Over <b>99</b> did not
How many people <b>found their stools (poo) were looser</b> after their gallbladder was removed?	About <b>10</b> did About <b>90</b> did not

Some people can have treatment with a medicine for this. If you have **loose stools** after having your gallbladder removed, **see your GP**, they can help.

# **10** Potential risks of treatments

# Potential risks of general anaesthetic



#### Out of 100 people who have ERCP

How many have damage to their oesophagus (food pipe), stomach or intestines (gut)?	Less than <b>1</b> does Over <b>99</b> do not
How many have <b>mild pancreatitis</b> that needs treatment in hospital?	<b>5</b> do <b>95</b> do not
How many have <b>moderate</b> to <b>severe pancreatitis</b> that needs treatment in hospital?	1 – 2 do 98 – 99 do not
How many have <b>other major complications</b> like <b>bleeding</b> that needs treatment in hospital?	Less than <b>1</b> does Over <b>99</b> do not

# 11 Preparing for your appointment

# **Questions for my doctor**

These can be about any concerns you have, for example what you hope from your treatment decision, what will happen next.					

#### **Contacts**

Name of doctor, nurse or specialist:
What are their contact details:

# **Next steps**

What will happen next (treatment / tests?)
When will these happen?
When will I be reviewed next?
Do I need to decide anything today? When do I need to make a decision?

# Thinking about your decision

I know enough about the potential benefits and harms of each option	Y/N
I am clear about which potential benefits and harms matter most to me	Y/N
I have enough support and advice to make a choice	Y/N
I feel sure about the best choice for me	Y/N
I need more information to make this decision	Y/N
I have decided what to do next	Y/N

# Your specialist might ask you:

- about your prescriptions and doses so it might help if you take your repeat prescription if you have one or note them down
- about your symptoms and how long you have been having problems
- about any other operations you have had in the past and when

# **12** More information

# Where can I go for more information?

Find out how long waiting times are for surgery in your area

https://www.myplannedcare.nhs.uk

#### Information on nutrition and eating to avoid gallstone pain

**Patient information** 

https://patient.info/news-and-features/gallstones-diet-sheet

**NHS Eat Well Guide** 

https://www.nhs.uk/live-well/eat-well/

NHS Being a healthy weight

https://www.nhs.uk/better-health/lose-weight/

#### **Patient Support Groups and Charities**

Guts UK

https://gutscharity.org.uk/advice-and-information/conditions/gallstones/

**British Liver Trust – Gallstones page** 

https://britishlivertrust.org.uk/information-and-support/liver-conditions/gallstones/

Royal College of Anaesthetists - Information about general anaesthetic

https://www.rcoa.ac.uk/patients/patient-information-resources/anaesthesia-risk/risk-explained

# Where did we get our numbers from?

The numbers of people who have symptoms from their gallstones: from an expert review from 2013 <a href="https://doi.org/10.1002/14651858.CD005440.pub3">https://doi.org/10.1002/14651858.CD005440.pub3</a>

The number of people who have bile duct stones: from reviews in 2006

https://doi.org/10.1016/j.bpg.2006.05.009 and 1987 https://doi.org/10.1002/bjs.1800740703

Numbers of those whose pain was relieved by either doing nothing or having their gallbladders

removed: from the SECURE trial of over 1000 people from 2019

https://doi.org/10.1016/S0140-6736(19)30941-9 an observational study in 397 Swiss patients from 2000 https://doi.org/10.1007/s002680010243 1998, and a study of 92 UK patients

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2502763/

The risks of surgery: from reviews of studies, published in 2006

https://doi.org/10.1002/14651858.CD006231 and 2013

https://doi.org/10.1002/14651858.CD005440.pub3 and from the C-Gall trial from 2023.

Risks of ERCP: from a review of over 1000 patients in the US from 2002

https://doi.org/10.1016/S0016-5107(02)70112-0

Diarrhoea from two reviews of data, from 2012 and 2022

https://doi.org/10.4236/ss.2012.36065 and https://doi.org/10.1136/bmjopen-2020-046172

For declarations of conflicts of interest, to see other decision support tools in the series, or to find out more about how this one was created, go to:

https://www.england.nhs.uk/personalisedcare/shared-decision-making/decision-support-tools/

Produced by Winton Centre for Risk and Evidence Communication and NHS England

Date last updated: September 2023

Funding: NHS England

This decision aid was created with input from patients and healthcare professionals.

