Kidney Stones in ADPKD

Kidney stones are common in people with autosomal dominant polycystic kidney disease (ADPKD). Learn here about causes, symptoms, diagnosis, treatment and prevention.

Kidney stones are formed when crystals of salts and minerals group together in the urine [1]. They are also called ‘renal calculi’ or having ‘nephrolithiasis’. Kidney stones can vary in size from small particles like gravel to large stones with branches [1]. The stones are formed in the kidney and may stay there [1]. However, they can move into a ureter (one of the two tubes connecting the two kidneys to the bladder) and the bladder [1].

Kidney stones are especially common in people with ADPKD [2]. Around 2-3 in every 10 people with ADPKD get a kidney stone at some time in their life [2-4]. As a comparison, roughly 1 in every 10 persons in the general population get a kidney stone in their lifetime [5]. You might get kidney stones more often as your ADPKD progresses and your kidneys enlarge [2,4].

Treatment of kidney stones depends on their size and position [1]. Small stones (less than 6-7 mm) can often be passed in the urine without causing problems or much discomfort [1,5]. Larger stones may cause severe pain, blood in your urine, or a blockage making it hard for you to urinate [1]. You may need a procedure to break up a large stone so that you can pass it, or have surgery to remove it [1,2,6,7].
Causes of kidney stones

Kidney stones are formed when crystals of substances found in the urine, such as calcium and uric acid, group together [1]. It is thought people with ADPKD are more likely to get kidney stones because [8]:

- Urine flows more slowly through the kidney, meaning that crystals causing kidney stones have more time to form and group
- People with ADPKD sometimes have imbalances in their urine that make stones more likely to form:
  - More acidic urine
  - Lower levels of substances that help to stop stones forming (citrate, ammonia)

Symptoms of kidney stones

Kidney stones often cause no symptoms and might be spotted on a scan you have for other reasons [1,2]. However, stones can cause symptoms including severe pain, particularly when they move. You may experience [1,4]:

- Sudden, agonising pain in your back, side or groin
- Chills and fever
- Pain or difficulty urinating
- Blood in the urine
- Nausea and vomiting
Diagnosing kidney stones

Your doctor will examine you physically and perform some simple tests to check whether you have a kidney stone or another problem. For example, these symptoms may also indicate that you have an infected cyst in your kidney.

These tests usually include [1,2]:

- Blood tests to check levels of blood cells, your kidney function and levels of substances that can cause kidney stones
- Urine tests, to check for blood in your urine and signs of infection

You’ll be referred to a urologist (a doctor specializing in the urinary tract) to confirm you have a kidney stone [2]. This should happen within 24 hours if you have severe pain in your kidney area [7]. Alternatively, your doctor may suggest you visit accident and emergency (A&E) [9].

To locate the stone and check its size, you’ll need imaging of your kidneys and bladder [2,4,6]. For example, computed tomography (CT) scanning can be used [2,4,7]. A CT machine uses X-rays to develop an image of the inside of your body. Sometimes, other types of imaging such as ultrasound (which uses soundwaves) can be useful [2,4,6,7]. Pregnant women and children will usually have an ultrasound rather than a CT scan [7].

Treating kidney stones

You may be able to pass small stones (up to 6-7 mm) in your urine at home [5]. Most kidney stones pass in 1-3 weeks. During this time, you should increase your fluid intake and may need some treatment including [1,6,7,10]:

- Painkillers (a non-steroidal anti-inflammatory drug such as ibuprofen is usually the first choice, but your doctor can prescribe stronger painkillers if needed and you should always ask your kidney doctor if it’s safe to take ibuprofen and similar types of drugs)
- Drugs to make it easier to pass small stones when you urinate (known as alpha blockers)
Kidney stones in ADPKD, v2.0

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- Rehydration treatment
- Drugs to stop nausea and vomiting
- Supplements and treatments (e.g. potassium citrate or allopurinol) to try to dissolve the stone or stop it worsening

It’s helpful for doctors to have the kidney stone to test which salts and minerals it’s made of [1,7]. This can help your doctor to give advice or medication to reduce your chance of having another stone in the future. For this reason, your doctor will ask you to urinate through a sieve or gauze to catch the stone if possible [1].

If your stone is large or you have not been able to pass it, you may need a procedure to break it up or remove it. Common procedures are listed below [2,4,7,11]. You should be offered one of these within 48 hours if your pain is ongoing and intolerable, or if the stone is too big to pass naturally [7]:

- Shattering the stone with a special machine that delivers shockwaves from outside the body (extracorporeal shockwave lithotripsy). This breaks up the stone into small pieces that you can pass when you urinate. This technique is commonly used for stones less than 1 cm in size.
- Using a thin, tube-like camera (a ureteroscope) that is guided through your urethra, bladder and up a ureter (tube to a kidney) to view the stone. A laser is then used to break the stone into smaller pieces (called laser lithotripsy). This is usually done under general anaesthetic. This technique is often used when stones are 1-2 cm in size.
- ‘Keyhole’ surgery under general anaesthetic, through a small cut in the skin to remove the stone (percutaneous nephrolithotomy). Open surgery has greater risks, so this technique is only used for particularly large stones if other procedures fail.

These procedures generally work well, solving the problem in about 9 out of 10 patients, although sometimes lithotripsy procedures need more than one session [2]. The procedures are usually straightforward, but some complications can occur, such as an infection [2]. Ask your doctor to explain the benefits and risks to you,
and to outline the different procedures that may be suitable for you. This will help you to make decisions about your treatment.

Preventing kidney stones

Having ADPKD increases your chance of having a kidney stone, and they often recur [1,2]. You can reduce your general risk by [7]:

- Drinking plenty of fluid to avoid dehydration
- Avoiding carbonated drinks
- Adding fresh lemon juice to drinking water
- Cutting down salt to a healthy level
- Eating only a normal amount of calcium (so, having a healthy diet but not using calcium supplements)

See our diet and lifestyle factsheet for more advice on diet, including a healthy amount of fluid and salt.

If tests have shown your kidney stones are caused by a particular salt or mineral, your doctor may recommend certain foods to avoid [1,7]. They might also prescribe supplements or medications to correct imbalances in your urine [1].

Learn more from the PKD Charity

- Pain from ADPKD
- Blood in the urine
- A healthy diet for people with ADPKD

More information from others

- The British Association of Urological Surgeons has information on percutaneous nephrolithotomy, extracorporeal shockwave lithotripsy (ESWL) and ureteroscopy
- NHS Choices has information of CT and ultrasound scans
References


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