

Managing ADPKD Pain

Find out about the different types of pain ADPKD can cause, and how this pain can be treated

Chronic pain (defined as persistent or longer-term pain) is common in people with autosomal dominant polycystic kidney disease (ADPKD) [1]. About 6 in 10 people who have been diagnosed with the condition have chronic pain [1]. An enlarged kidney or liver pressing on other organs or tissues is often the likely cause of this pain [1].

People with ADPKD can also get sudden, severe but short-lasting pain. This is known as **acute pain**. For example, acute pain can occur when you pass a kidney stone, have a burst cyst, or have a urinary tract infection [1,2]. These problems can be diagnosed from blood and/or urine tests or kidney scans.

Patients with ADPKD can also be affected by pain from other causes, just like anyone else. This factsheet focuses on pain coming from the kidneys or liver in ADPKD, but the information on pain management is relevant to other causes of pain too.

If you experience any unfamiliar or unexpected pain, see your doctor or specialist so he or she can investigate. In many cases, the cause of the pain can be discovered and treated successfully. However, sometimes the cause of the pain can't be pinpointed, and some painful problems caused by ADPKD can't be cured. In those difficult situations, better pain management can help while you and your doctor or specialist work out the best treatments to minimise your pain [3].

Regardless of cause, chronic or recurrent pain can affect your quality of life, cause anxiety, depression, and insomnia, lead to financial worries due to days off work, and stress your relationships and family [1,2,4]. Managing pain is not only about trying to relieve it - it's also about reducing the impact of pain on your life. You can be referred to other healthcare professionals for help to manage your pain.

It's not always possible to relieve ADPKD-related chronic pain entirely [1]. A variety of approaches with different healthcare professionals (a multi-disciplinary approach) is often necessary for the management of severe chronic pain [5]. This can include specialised physiotherapy, psychological approaches and careful medication use, and should be tailored for you and your individual situation [1,2].

Occasionally, cysts causing very persistent (intractable) chronic pain can be removed with surgery or the fluid can be drained out [3]. However, these are high-risk procedures and there is no guarantee that they will relieve pain satisfactorily or long term in all patients [5,6]. So, such operations are not usually recommended solely for the management of pain [7].

Causes of ADPKD-related pain

Acute pain

Acute pain from ADPKD is often caused by [2,8]:

- A urinary tract infection
- A burst or bleeding cyst
- Kidney stones
- Other problems, such as a slipped disc (which can happen if your posture changes)

These problems become more likely as your kidneys increase in size [9].

In people with ADPKD, a very severe headache that comes on suddenly may be a sign of an aneurysm (burst blood vessel) in the brain [2]. Go to our page on brain aneurysm for more information on this rare but serious complication.

Chronic pain

Chronic pain associated with ADPKD is often felt in the side, lower back, or abdomen [1]. It is thought to be caused by [1]:

- The outer lining (capsule) of your kidney or liver being stretched
- An enlarged kidney or liver pressing on other organs and tissues in the body
- Changes in posture (e.g. your back muscles or spine) due to large kidneys or liver
- Other pain triggers in the kidney that researchers and kidney specialists do not yet fully understand

You can find out more about how nerves send pain signals in chronic pain in our research article '[Understanding Pain in ADPKD](#)'.

Symptoms associated with ADPKD-related pain

Pain linked to ADPKD often comes with other symptoms too. The type of pain you experience and the other symptoms you have will depend, in part, on the source of the problem:

- Urinary tract infections usually result in pain to one side of your abdomen or lower back that comes on reasonably quickly (e.g. over a few hours) [2]. You may feel feverish and have chills or shivers [2]. You may want to urinate often, although there might not be much urine when you do go and it might be painful to pee [10].
- Bursting and bleeding cysts usually cause severe, 'stabbing' pain in the side of your abdomen, often in one area. There is likely to be obvious blood in your urine [2]. However, about half of all patients with cyst bleeding do not have symptoms [2].
- Kidney stones can cause very severe pain that may begin and go away suddenly [11]. It affects the back, the side of the abdomen, and sometimes the groin [11]. You may also have blood in your urine and feel sick and feverish [11].

- Chronic pain caused by kidney cysts may be felt in your abdomen or loin [1,12]. People describe it as a nagging discomfort, dull ache, or severe stabbing pain [1]. It is often worse when standing or walking, and you may be able to point to the area quite specifically [9].
- Although liver cysts are very common in adults with ADPKD, most often they do not have any symptoms [1]. A very enlarged liver is often associated with a feeling of ‘fullness’ and nagging or stabbing abdominal pain. You may also get ‘referred’ pain in your shoulder [1]. If you have liver cysts or very large kidneys, you may get full quickly when eating, have acid reflux (heartburn), or get breathless [6].
- If your posture has changed due to the weight of your enlarged kidneys or liver, this can cause problems with your muscles and the spine, leading to problems such as chronic low back pain [1].

It can be difficult to find words to describe the pain you are experiencing to your doctor. There are questionnaires that are designed to help you with that, for example the ‘[McGill Pain Questionnaire](#)’, or the ‘[Brief Pain Inventory](#)’ [3]. Your doctor may have other questionnaires that you can use as well.

Diagnosing the causes of pain in patients with ADPKD

Your doctor will examine you physically, and ask about your pain (e.g. when it came on, what makes it worse or better, and how severe it is) [9]. Depending on the possible cause of your pain, you will have some tests, for example, checking your temperature, a urine test, blood tests, or a sample of fluid being taken from a cyst [9].

You may also have a scan (such as an ultrasound, CT or MRI scan) to check whether you have kidney stones or problem cysts in your kidneys or liver [5,7,12].

Ultrasound uses sound waves, CT (computed tomography) use X-rays, and MRI (magnetic resonance imaging) uses magnets to image the inside of your body.

In addition to a kidney specialist, you may see other specialists, such as a radiologist, physiotherapist, and pain specialist. This is to help find the cause of your pain [6].

Managing chronic or recurrent pain in patients with ADPKD



Doctors aim to treat or cure the cause of pain whenever possible. In most cases, acute pain can be adequately relieved within days [2]. However, if you have chronic pain, it usually means that a cure is not straightforward or possible [3]. Tailoring and combining approaches to managing pain that are suited to you becomes very important. This requires patience, time, and help from your GP, specialists, and other healthcare professionals [14]. This ‘multi-disciplinary approach’ has proven useful for people with severe chronic pain, regardless of the cause [3]. Managing chronic pain can involve a mixture of physiotherapy, medication, and psychological approaches to give you the best possible comfort, physical function, and quality of life.

Medications

You may need to use medications long term to help manage your chronic pain [6]. Different classes of drugs can be used. Your doctor knows about your medication and conditions, and can give you specific advice on which medications are safe for you, how often to take them, and when you might need to change medication.

Opioids and non-steroidal anti-inflammatory drugs (NSAIDs) are the two types of medicine often used to manage pain in ADPKD, although NSAIDs are not ideal for everyone with kidney problems. Other drugs might be useful too - these are called analgesic adjuvants. We explain these below. If these medications are not working for you, there may be other medicines you can try.

It is usual to review your pain medication from time to time with your doctor, to check it is still necessary and working well for you. If you or your doctor are unsure which medication can best help with your pain, you may want to ask for referral to a specialist pain management service (see below).

NSAIDs and paracetamol

NSAIDs can help to relieve pain that is caused by inflammation, for example, pain related to burst or bleeding cysts, an infection, or kidney stones [5]. Examples of NSAIDs are ibuprofen, diclofenac, and celecoxib. You can buy ibuprofen over the counter (without a prescription), but most other NSAIDs need a prescription.

NSAIDs have some side effects, for example, they can cause stomach problems and may make asthma worse in some patients [15]. Also, using NSAIDs repeatedly or for a long time can damage the kidneys [15], so long-term use of NSAIDs is generally not recommended for people with ADPKD, particularly when kidney function is already impaired [14].

Your kidney specialist and other professionals can help you to explore the risks and benefits of using NSAIDs and can advise on the best type, dose, and length of time to use them. They will recommend the lowest dose that is effective and for the shortest time possible [9]. For example, taking 200 mg ibuprofen twice a day can

be just as effective as 400 mg of ibuprofen twice a day for acute pain relief, but may have fewer side effects [5].

The impairment of kidney function with NSAIDs is usually reversible once the medication is stopped. NSAIDs that you can get over the counter (ibuprofen and aspirin) are the safest because they are short acting and so any adverse effects on the kidneys wear off more quickly. However, if you find that ibuprofen or aspirin are really effective for you, and you need to use NSAIDs for longer than a week, you must let your doctor know so that your kidney function can be monitored, particularly if you already have impaired kidney function. Your doctor can help you weigh up the benefit of pain relief against the risks of taking NSAIDs, and there may well be other medications and strategies for pain management that they can recommend.

Not all pain responds to NSAIDs, and pain relief from NSAIDs comes on within 1-2 days after starting them. If you don't notice improvement in that time, you might need to try a different NSAID or other treatment.

Paracetamol is a common medication that can be bought over the counter. It does not cause many of the side effects associated with NSAIDs. Paracetamol is generally safe as long as you don't take more than the maximum recommended dose (4 g daily for adults, which is equivalent to two tablets four times daily) [16,17], but it may not be a particularly effective medication for pain relief on its own. Hence, your doctor may recommend that you use it together with an NSAID or opioid.

Opioids

There are various opioid medications. Examples are codeine, dihydrocodeine, and tramadol, and the more potent or 'stronger' opioids morphine, oxycodone, and fentanyl. If your doctor prescribes an opioid for you, he or she should recommend the dose that is just sufficient to relieve your pain, but that minimises side effects (see below) [1]. Stronger or more potent opioids are not necessarily better. It simply means that a smaller amount can be taken to achieve the same effect. For example, 5 mg of morphine gives the same effect as 50 mg of tramadol [5].

Opioids have many side effects when taken in continual high doses, including constipation, nausea, heartburn, problems thinking clearly, and sleep disturbances [1,14]. Not all patients benefit from long-term use of opioids. People can also become physically dependent on opioids - this means it can be difficult to stop taking them even if they're not working to reduce your pain or are causing severe side effects [1,14]. So, it's important to try other approaches to managing chronic pain if possible.

Analgesic adjuvants

These medications are licensed mostly to treat other health conditions, for example, epilepsy or depression, but can help to manage chronic pain too.

Studies show that analgesic adjuvants can help with nerve pain [18] and pain associated with a condition called fibromyalgia [19]. However, there are no research studies on their effects on pain in patients with ADPKD [1]. If your doctor or pain specialist thinks these medications might help you, he or she will give you information to help you decide whether to try them.

Examples of analgesic adjuvants that might be useful for ADPKD-related chronic pain include:

- Antidepressants, such as tricyclic antidepressants (e.g. amitriptyline or nortriptyline [1]) and SNRIs (serotonin-norepinephrine reuptake inhibitors, e.g. duloxetine) [20]. Lower doses of tricyclic antidepressants can be used to treat chronic pain than are used in depression [21].
- Anti-epileptics, such as gabapentin [1]. These medicines can have strong side effects such as feeling dizzy, drowsy, and having difficulty concentrating or balancing, so you may need to start at a low dose that is increased over a few days [22]. Gabapentin may not be suitable for you if you have kidney failure, in which case, pregabalin might be an option [23].

Tolvaptan (Jinarc®)

Kidney and liver cysts can be a source of chronic pain in ADPKD, but it is not currently possible to prevent them from forming [6]. However, a new medication called tolvaptan (Jinarc®) can slow the growth of kidney cysts, and this may reduce pain related to the cysts themselves or more general kidney pain [24-26]. However, tolvaptan is not currently licensed as a pain treatment - it can only be prescribed to eligible patients to try and slow ADPKD progression. For more information on tolvaptan, see our page on '[Treatments for ADPKD](#)'.

Manual therapies and specialised pain physiotherapy

A range of manual therapies, or 'hands-on' treatment, can help to manage flare-ups of pain, particularly when it affects just one area of the body [14,27]. These include heat or cold pads, wearing corsets, transcutaneous electrical nerve stimulation (TENS), hydrotherapy, acupuncture, and massage [14,27]. These have not yet been adequately tested for pain in patients with ADPKD in particular but have been shown to be safe in other chronic pain conditions, particularly back pain. There are many other types of 'hands-on' physiotherapy available. They do not work equally well for everyone. It is worth finding out a bit more about each type and deciding if it is likely to suit you. You may need to try different treatments to find one that works best for your pain.

Specialised physiotherapy is designed specifically to help manage chronic pain. This includes specific stretches, relaxation techniques, and pacing, which form part of cognitive behavioural therapy (CBT) [14,27,28]. You can learn some of these techniques through self-help guides - ask a healthcare specialist to recommend a good-quality guide for you. If you need help with these techniques, there are also specialist pain physiotherapists within the NHS who can train or coach you. Their focus is to minimise the impact pain has on the physical activities you do. In other words, they can help you to optimise the way you plan and go about your daily life.

Psychological approaches

Successful management of chronic pain can be demanding and you might find it taxes your already limited resources [5]. The impact of pain needs to be effectively communicated to loved ones, colleagues, and employers, and this is not an easy skill to learn. You may struggle with a sense of helplessness, isolation, and loss of identity and self-worth, particularly if your pain restricts your physical freedom [29].

Finding different ways of doing the same thing or adapting by prioritising the things that truly matter to you is key to pain management, but can be very challenging. Psychological education and training can help you with this [30]. There are a range of resources available, from self-help guides to formal therapy by specialist pain psychologists to help you to manage your pain. Pain specialists may use a range of different approaches, for example, cognitive behavioural therapy (CBT), mindfulness, and acceptance commitment therapy, depending again on your individual needs [5,30]. These advanced psychological skills can help you to gain a sense of control over your pain, which can in turn reduce your anxiety and improve your pain [5]. If you are interested in self-help guides, ask your doctor or a pain specialist to recommend one to you.

Invasive treatments

Invasive procedures aim to either remove diseased tissue (e.g. a cyst) or an organ, or disrupt the nerves that send pain signals to the brain [3]. These are called 'invasive' because they involve needles or surgery.

Invasive procedures come with risks. Technically complex operations usually have greater risks. These include nephrectomy (removal of a whole kidney), which is more challenging than draining or removing a cyst. A range of surgical procedures have been tried in small numbers of selected patients with limited success [6]. However, more research is needed before we can be sure how well they work, and whether the potential benefits outweigh the risks [5,6].

Options and expertise for invasive treatments are evolving, and now include radiofrequency ablation (which uses radiation to damage the nerves in the kidney to stop them sending pain signals) and spinal cord stimulation (which uses mild electric pulses on the spinal cord to mask pain signals) [6]. Provided that other aspects of your pain management are optimised first, some forms of invasive treatment may be helpful [6]. These procedures often require joint working and assessments from your doctor, kidney specialist, transplant surgeon and, ideally, inpatient and outpatients pain services too [5].

Specialist pain management services

Chronic pain management often requires input from specialist doctors, nurses, physiotherapists, occupational therapists, and psychologists [5]. This is particularly true when the best efforts of general practitioners or kidney specialists are not giving you pain relief, or to optimise your pain management before higher-risk or invasive treatments.

Specialist pain services are widely available in the UK, but differ in the type and extent of support they can offer [31]. Referrals can usually be made by your doctor or kidney specialist [5]. Generally, it is better to be referred to a specialist pain service that is easy to travel to, because appointments can be frequent [5]. But, you may be referred to other pain services in UK depending on your specific treatment needs [5].

Learn more from the PKD Charity

- [About pain signals in ADPKD](#)
- [About urinary tract infections](#)
- [About kidney stones](#)
- [About blood in the urine](#)
- [About liver cysts and polycystic liver disease](#)

More information from others

- The [British Pain Society website](#) has information on managing pain.

- The [Arthritis UK Website](#) has information on back pain, including its management.

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