

Managing ADPKD Pain

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

Chronic (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]. It is usually, but not always, related to an enlarged kidney or liver that presses on other organs or tissues [1].

Less commonly, ADPKD-related pain can be acute – that is, short lasting and coming on more suddenly [1,2]. This may be due to a kidney stone, a cyst bursting, or a urinary tract infection [1,2].

Any new and unexpected acute pain must be taken seriously, and you should approach your doctor or specialist to investigate the cause. With chronic pain, or recurrent pain, the focus is better pain management and reassurance once treatable causes are ruled out [3].

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 is 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 individually and your situation [1,2]. Occasionally, surgery to remove kidney or liver cysts can be performed for very persistent (intractable) chronic pain [3]. However, these are high-risk procedures and there is no guarantee that they will relieve pain satisfactorily in all patients

[5,6]. So, such operations are not usually recommended solely for the management of pain [7].

Causes of ADPKD-related pain

In people with ADPKD, acute (short-term) pain is most likely to be caused by [2]:

- A urinary tract infection
- A burst or bleeding cyst
- Kidney stones

These problems become more likely as your kidneys increase in size [8]. 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.

People with ADPKD can also get chronic pain, which is pain lasting at least 4 to 6 weeks, sometimes with recurrent episodes of acute pain in that time [1]. 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

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

Symptoms associated with ADPKD-related pain

The following are possible causes and symptoms of acute and often sudden pain in people with ADPKD:

- 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 also feel feverish, have chills, or shivers [2].

- Bursting and bleeding cysts can cause severe, ‘stabbing’ pain in the side of your abdomen that tends to be located in one area. There is likely to be obvious blood in your urine [2]. About half of all patients with cyst bleeding do not have symptoms though [2].
- Kidney stones can cause very severe pain that may begin and go away suddenly [9]. It affects the back, the side of the abdomen, and sometimes groin [9]. You may also have blood in your urine and feel sick and feverish [9].

You may be able to reduce your risk of acute pain caused by urinary tract infections or kidney stones by following some simple lifestyle and dietary advice [4,10,11]. This includes staying well hydrated [4,10,11]. See NHS Choices for more tips on preventing these conditions.

Chronic pain in people with ADPKD may be related to the location and size of cysts:

- Pain caused by kidney cysts tends to be felt in your abdomen rather than lower back [1]. 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 [8].
- Although liver cysts are very common in adults with ADPKD, most often they do not have any symptoms [1]. A severely 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, you may find you feel full quickly when eating, have acid reflux (heart burn), or get breathless [6].
- If your posture has changed as a result of 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](#)' [12]. 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) [8]. Depending on the possible cause of your pain, you will have some tests, for example, your temperature, a urine test, blood test, or a sample of fluid being taken from a cyst [8].

You may also have an ultrasound, CT or PET scan to check whether you have kidney stones or problem cysts in your kidneys or liver [5,7]. Ultrasound uses sound waves, CT (computed tomography) use x-rays, and PET (positron emission tomography) uses a radioactive dye 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 and check if it is not linked to something other than ADPKD [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 possible or straightforward [3]. Tailoring and combining approaches to managing pain that are suited to you becomes very important. This may require patience, time, and help from your GP, specialists, and other healthcare professionals [13]. This ‘multidisciplinary 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. 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 about medication that can 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 [14]. Also, using NSAIDs repeatedly or for a long time can damage the kidneys [14], so long term use of NSAIDs is generally not recommended for people with ADPKD, particularly when kidney function is already impaired [13].

Not all pain responds to NSAIDs, and pain relief from NSAIDs comes on within 1-2 days after taking it. So if you don't notice improvement in that time, it's probably not useful for you to take them. If NSAIDs do help your pain, then your doctor will recommend the lowest dose that is effective and for the shortest time possible [14]. For ibuprofen, the lower dose of 400 mg daily can be just as effective as 800 mg daily doses for acute pain relief. In other words, it may not be worth taking more than 400 mg for pain relief, because higher doses are not more effective for pain and have more side effects [15]. Your doctor will recommend the optimal dose for you.

The impairment of kidney function with NSAIDs is usually reversible once the medication is stopped. The 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 the benefit of pain relief against the risks of taking NSAIDs, and there are other medications and strategies for pain management that they can recommend.

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 in adults) [16,17]. It is not 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 different forms of opioid medications. They come in a range of doses and are taken in different ways. If you are prescribed an opioid, you should take the amount that is just sufficient to relieve your pain, to minimise side effects (see below) [1]. Codeine, dihydrocodeine, and tramadol are opioids that are often prescribed for pain. There are also more potent or 'stronger' opioids as such morphine, oxycodone, and fentanyl. 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, heart burn, problems thinking clearly, and sleep disturbances [1,13]. Not all patients benefit from long-term use of opioids. It is possible to become

physically dependent on them - this means it can be difficult to stop using opioids even if they're not working to reduce your pain, or are causing severe side effects [1,13]. 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 not any research studies on their effects on pain in patients with ADPKD [1]. If your doctor or pain specialist thinks these medications might help you, they will give you information to help you decide whether to try them.

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

- Anti-depressants, such as tricyclic antidepressants (e.g. amitriptyline or nortriptyline [1]) and serotonin-norepinephrine re-uptake inhibitors (e.g. duloxetine) [20]. Lower doses of tricyclic antidepressants can be used to treat chronic pain than depression [21].
- Anti-epileptics, such as gabapentin [1]. This medicine can have strong side effects such as feeling dizzy, drowsy, and having difficulty concentrating or balancing, so you may need to start taking it 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].

Tolvaptan is only recommended for some adults - for more information on tolvaptan, see our page on '[Treatments for ADPKD](#)'.

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 [13,27]. These include local heat treatments, transcutaneous electrical nerve stimulation (TENS), hydrotherapy, acupuncture, and massage [13,27]. These have not yet been adequately tested for pain in patients with ADPKD in particular, but are safe and have been shown to work for other patients, particularly those with musculoskeletal pain.

There are many types of 'hands-on' physiotherapy available. They do not work equally well for all people. 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.

There is specialised physiotherapy designed specifically to help manage chronic pain. This includes specific stretches, relaxation techniques and pacing, which form part of cognitive behavioural therapy (CBT) [13,27,28]. 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 minimize 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 is 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 has 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

Go to the [British Pain Society website](#) for information on managing pain.

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