

I want to know more about...

# Diet and Lifestyle in ADPKD\*

\* Autosomal Dominant Polycystic Kidney Disease



**pkd**charity  
Polycystic Kidney Disease

together the answer

This booklet is for people living with autosomal dominant polycystic kidney disease (ADPKD) who have normal to moderately reduced kidney function (i.e. kidney function above 30%). It may also be useful to their family and friends. It gives general information and tips on a diet and lifestyle that can help to keep you healthier if you have ADPKD. It provides information on topics that our supporters ask us about most often, including salt, drinking fluids and exercise.

Your own diet and lifestyle needs might differ to those given in this booklet, depending on your health. If you have severely reduced kidney function, kidney failure, are currently on dialysis or have had a kidney transplant, the advice in this booklet may not be right for you.

Please always seek the personalised advice of a kidney specialist before making any changes to your own or your child's diet or lifestyle.

## Overview

No specific diet or lifestyle measures have been shown to prevent cysts developing in people with ADPKD. However, a healthy lifestyle may help to protect your kidney function and reduce your blood pressure and risk of cardiovascular problems, such as stroke. Keeping your blood pressure down is especially important, as high blood pressure can damage your kidneys if you have ADPKD.

Tips for a healthy diet and lifestyle include:

- ❖ Maintain a healthy weight
- ❖ Drink enough fluid to stay hydrated
- ❖ Aim for a balanced diet that is low in salt, sugar and fat
- ❖ Take regular exercise
- ❖ Limit how much alcohol you drink
- ❖ Stop smoking

## Stay a healthy weight

Being a healthy weight may reduce your risk of high blood pressure and cardiovascular problems. Your doctor can advise you on the weight that is healthy for you. A common way of checking your weight is to calculate your body mass index (BMI) and

compare this to the healthy range. To calculate your BMI, you'll need to know your height and weight. NHS Choices has a simple, online BMI calculator. A healthy BMI is between about 18.5–25.

Check with your doctor if:

- ❖ You have large polycystic kidneys or liver – you may need to take this into account when considering your healthy weight
- ❖ You're of South Asian, Black or minority ethnic origin, as your BMI may need to be slightly lower than the range listed above to help reduce your risk of diabetes and cardiovascular disease

To make a plan to lose weight and for more information and advice, see [NHS Choices](#). Talk with your doctor if you're struggling to lose weight.

## Drink enough fluid

You may hear that drinking extra fluid can be helpful if you have ADPKD. However, there haven't been any studies proving that drinking extra fluid slows the growth of kidney cysts. For the moment, kidney experts recommend that you drink when you're thirsty, but not excessively.

## Check the colour of your urine to see if you are hydrated



### Clear to light yellow

You're hydrated.  
Drink as you get thirsty.



### Dark yellow to dark amber

You're dehydrated.  
Have a drink of water.

## Why is my urine an odd colour?

Strange coloured urine can be caused by some foods or medicines. It can also signal a health problem. See your doctor if your pee has changed colour and you haven't had foods or medicines to explain this.



### Cloudy (milky)

You might have a urinary tract infection, especially if you have other symptoms, like a burning sensation when you pee, needing to pee more often or smelly pee. Kidney stones can also cause cloudy pee.



### Pink, red or light brown

This can be caused by some medicines or food (e.g.

beetroot, blackberries or rhubarb). If you're female, it could be vaginal blood. Sometimes, a urinary tract infection causes blood in pee. Or if you have ADPKD, it could signal a cyst infection, bleeding cyst or kidney stone.



### Dark brown

This can be caused by some medicines or food (e.g. broad beans, rhubarb or aloe). It might also signal a urinary tract infection or kidney or liver problem.



### Green or blue

This can be caused by some medicines or food colours. It can also be a sign of a urinary tract infection or a liver problem.



### Dark yellow or orange

You might be dehydrated. Orange pee can also be caused by some medicines, laxatives, B vitamins or carotene (found in carrots and some other fruit and veg) or a liver problem.

*These urine colours are for illustrative purposes only and may not match the colour of your urine.*

In the UK climate, drinking about 6–8 glasses of water (of about 200ml each) each day should be about right to keep you hydrated. If you've lost more fluid through sweating or diarrhoea for example, you may need to drink more.

There is nothing to suggest that people with ADPKD shouldn't drink caffeine. Although some researchers have put forward a theory that caffeine could affect cyst growth, this hasn't been proven in studies of people. Drinking a low amount of caffeine each day doesn't affect cardiovascular health either. While it seems sensible to avoid lots of caffeine, drinking up to 2 cups of coffee or 4 cups of tea a day is thought

to be okay.

## Have a healthy diet

If you have ADPKD, it can be confusing to know what to eat and drink. There is no recommended special diet that people with ADPKD should follow. But, a healthy diet can help control your weight, which helps to reduce your blood pressure and risk of cardiovascular disease.

To follow a healthy balanced diet:

- ❖ eat 5 portions of fruit or vegetables a day
- ❖ base your meals on starchy foods, such as potatoes, bread, rice or



pasta

- ❖ eat some dairy (or dairy alternatives, such as soya drinks)
- ❖ have protein, such as beans, pulses, fish, eggs, or meat
- ❖ only have small amounts of food high in salt, sugar, and fat, and choose unsaturated fats

You'll find more information and advice about healthy eating at the [NHS Live Well hub](#) and [British Nutrition Foundation](#) websites.

### Eat less salt

If you have ADPKD, it's especially important to reduce your salt intake, because too much salt increases your blood pressure, which can damage your kidneys. If you're an adult, aim to keep your daily salt intake to no more than 5g or 6g - about 1 teaspoon - and preferably less. This includes not just salt added at the table or during cooking, but also 'hidden' salt in foods such as bread, breakfast cereals, bacon, ham, sausages, takeaways, and ready meals.

Salt may be listed on food packages as sodium, because salt is a chemical compound containing sodium (NaCl). If the label only shows the amount of sodium per 100ml or 100g, you will need to multiply this figure by 2.5 to find out how much salt this is equal to. Remember to adjust the figure by the number of grams of the food you

are eating. Adults should aim to eat no more than 2–2.4g of sodium a day, which is equal to 5–6g of salt.

**Children under 11 and babies** should eat less salt (and sodium) than adults.

The daily recommended maximum amount of salt that children and babies should eat depends on age:

- ❖ 1–3 years – 2g salt a day (0.8g sodium)
- ❖ 4–6 years – 3g salt a day (1.2g sodium)
- ❖ 7–10 years – 5g salt a day (2g sodium)
- ❖ 11 years and over – 5-6g salt a day (2-2.4g sodium)

Look at food package labels to check the amount of salt. Be aware that some manufacturers show salt content by portion size, which may be less or more than 100g.

Some packages use colour coding:

- ❖ **Red** = high salt (more than 1.5g salt per 100g)
- ❖ **Amber** = medium salt (between 0.3g and 1.5g of salt per 100g)
- ❖ **Green** = low salt (0.3g salt or less per 100g)

Watch out for products that say 'low salt' or 'low sodium' on the label. In these products, the manufacturer has replaced the sodium with potassium. This can

be a problem for people with ADPKD. Before switching to these products, check with your doctor. If you have low kidney function or are taking certain medications, you might need to eat less potassium so that potassium levels in your body don't become harmful.

The **CASH (Consensus Action on Salt & Health)** website has lots of information and reference papers if you want to campaign for less salty foods at your local restaurants or shops.

### **Eat a moderate amount of protein**

Protein provides energy, is needed for growth and repair of the body and to maintain good health. Protein-rich foods include meat, fish, eggs, pulses and beans.

There is not enough proof that a low protein diet can protect your kidneys from damage for experts to be able to recommend this – some actually recommend against a low protein diet. Importantly there is some evidence that too little protein could stop your

body getting all the nutrition it needs.

The amount of protein you need depends on your age and body size. Provided your kidney function is not severely decreased (CKD [chronic kidney disease] stage 4 or 5, or eGFR [estimated glomerular filtration rate] below 30 ml/min/1.73 m<sup>2</sup>), experts recommend that adults with ADPKD eat a moderate amount of protein. This is about 0.75–1.0 g of protein for each kg of your own body weight each day. So for example, if you weigh 65kg you should eat about 56– 65g of protein each day.

The amount of protein found in foods is variable. The table below provides a rough guide to the protein content of some common foods.

### **Tips to help you select healthy foods**

#### **Try a free app to help you make better food choices**

It can be hard to select the healthiest packaged foods, especially when you're in a hurry. Some products are surpris-

*Table. Protein content of common foods*

Portion	Average protein content
<b>Animal protein</b>	
Cooked red meat or chicken breast (100g)	30g
Cooked fish fillet (140g)	30g
Milk – ½ pint	9g
Cheese (40g)	10g
Yoghurt – 1 pot	7g
2 eggs	12g
<b>Vegetable protein</b>	
Cooked pulses e.g. beans, lentils 80g – 3 heaped tablespoons)	7g
Nuts (30g - handful)	6g

ingly high in salt, added sugar, saturated fat and calories. Labels can also be misleading. The free FoodSwitch app developed for UK shoppers might help. The app can scan barcodes on labels, show you what is in the product and suggest simple, healthier switches for you and your family. The app contains a SaltSwitch section. See links below to download for IOS and Android devices.

### Look out for the traffic light system on foods

Many food packages – especially supermarket brands - now have a colour-coded summary on the front. This helps you to tell, at a glance, whether the food is high in fat, saturated fat, sugar and salt:

- ❖ **Red** = high
- ❖ **Amber** = medium
- ❖ **Green** = low

The more 'green' on your foods, the better!

### Drink alcohol in moderation

Your liver, not your kidneys, is primarily responsible for breaking down alcohol in your body. Unless you prefer to do so, there is no need to give up alcohol completely if you have ADPKD and are otherwise healthy. But, alcohol does increase people's risk of accidents and diseases including cancer, stroke and heart and liver disease. So, follow advice on low-risk drinking:

- ❖ Drink no more than 14 units a week regularly (whether you're a man or a woman)
- ❖ Have 2–3 alcohol-free days a week
- ❖ Spread your drinking out over a few days, rather than drinking a lot of alcohol in one session

The [Drink Aware website](#) has lots of information on reducing your alcohol

intake. It also explains the amount of alcohol in common drinks and the effects of alcohol.

### Take regular exercise

Regular exercise is an important part of a healthy lifestyle because it helps to control your weight and blood pressure. Reducing your blood pressure means you're less likely to have cardiovascular disease and it can help protect your kidneys from damage.

There are no special guidelines for people with ADPKD on the amount of exercise to do, but you can follow general guidelines set for everyone:

- ❖ If you're 19–64 years old aim for 2.5 hours of moderate or vigorous physical activity a week
- ❖ Children and young people (5–18 year olds) should aim for at least 60 minutes of moderate to vigorous physical activity every day
- ❖ Whatever your age, try not to spend long periods of time sitting or lying down

Moderate physical activity is enough to get you slightly out of breath, raise your heart rate, and make you warmer. You can split your exercise into sessions of 10 minutes of more throughout the week. So for example, you could do 5 exercise sessions of 30 minutes on 5 days of the week.

### Suggestions include:

- ❖ Brisk walking
- ❖ Swimming
- ❖ Dancing
- ❖ Cycling
- ❖ Vigorous gardening and housework

Simple changes can add up, for example, walking or cycling part of



the way to work and choosing the stairs instead of the lift. If you have enlarged kidneys, there's a risk you could damage a kidney by taking part in riskier sports (e.g. horse riding) or contact sport (e.g. rugby, hockey, or martial arts). However, in a large study of young athletes, injuries to a kidney during sport happened very infrequently, and were less common than many other sporting injuries. It's your choice which sports you do, but take into account any advice your doctor gives, especially if your kidneys are very enlarged. If you do damage your kidneys playing sport, it could cause a cyst to burst, bleeding and pain.

People with ADPKD can be at higher risk of having an aneurysm (a ballooning out of a blood vessel). If you know you have an aneurysm, ask your doctor for advice on physical activity. For ideas of activities and tips on how to get and stay active, see [NHS Choices](#).

## Stop smoking

Smoking is bad for anyone, but it is especially important to give up if you have any type of kidney disease. Smoking can increase the speed at which your ADPKD progresses and leads to kidney damage. Smoking is also a known cause of cardiovascular disease.

It's never too late to stop smoking, but it can be difficult if you have been smoking for many years. You can find out about ways to quit at [Smokefree](#). Or ask your doctor to refer you for free, expert support from your local NHS Stop Smoking Services.

## More information

### From the PKD Charity:

- ❖ About blood pressure  
[www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd/high-](http://www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd/high-blood-pressure)

### blood-pressure

- ❖ About controlling pain  
[www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd/controlling-pain](http://www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd/controlling-pain)
- ❖ About blood in the urine  
[www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd/blood-in-the-urine](http://www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd/blood-in-the-urine)

### From other organisations:

- ❖ British Nutrition Foundation  
[www.nutrition.org.uk](http://www.nutrition.org.uk)
- ❖ NHS Live Well Hub  
[www.nhs.uk/livewell/Pages/Livewellhub.aspx](http://www.nhs.uk/livewell/Pages/Livewellhub.aspx)
- ❖ CASH (Consensus Action on Salt & Health)  
[www.actiononsalt.org.uk/less/Health/index.html](http://www.actiononsalt.org.uk/less/Health/index.html)
- ❖ British Heart Foundation  
[www.bhf.org.uk](http://www.bhf.org.uk)
- ❖ NHS Choices BMI calculator  
[www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx](http://www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx)
- ❖ Drink Aware - new alcohol guidelines  
[www.drinkaware.co.uk/check-the-facts/what-is-alcohol/new-government-alcohol-unit-guidelines](http://www.drinkaware.co.uk/check-the-facts/what-is-alcohol/new-government-alcohol-unit-guidelines)
- ❖ Smokefree  
[smokefree.nhs.uk](http://smokefree.nhs.uk)
- ❖ US Nutrient Database - find out what is in all foods and ingredients  
[ndb.nal.usda.gov](http://ndb.nal.usda.gov)

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The PKD Charity Helpline offers confidential support and information to anyone affected by PKD, including family, friends, carers, newly diagnosed or those who have lived with the condition for many years.

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For the latest version including version with references, please visit <http://www.pkdcharity.org.uk/about-adpkd/just-diagnosed/adpkd-in-children>



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