

Primary Biliary Cholangitis (PBC) & ursodeoxycholic acid (UDCA)

Getting the most from your treatment

PBC is a lifelong autoimmune disease which affects the liver. With autoimmune diseases, your immune system attacks healthy cells in your body. In PBC, the body's immune system begins to treat the bile ducts as a foreign body and so attacks the lining of the bile ducts. Over time, the damaged lining leaks bile acid out to the surrounding liver cells, causing inflammation and scarring.

Symptoms that you may experience with PBC include fatigue, itching (pruritis) and dry eyes and mouth (sicca syndrome). There are different treatments that can be prescribed to help manage these and other symptoms, so it is important that you explain all your symptoms to your healthcare professional, including how they are affecting your day-to-day life.

Although PBC is a lifelong condition, there are effective drug treatments which can slow down the disease progression and improve liver function. One such treatment is UDCA which successfully treats around 70% of people with PBC.

Provided PBC has been diagnosed at a reasonably early stage and you receive UDCA at the correct dosage for your weight, your PBC can be well managed.



Liver experts all agree that it is vitally important that UDCA should be prescribed according to your weight, to make sure you are getting the full benefit from your treatment. Studies show UDCA is most effective at a dose of 13-15 mg/day for every kilo that you weigh. Because your

weight can fluctuate your doctor should be weighing you regularly and adjusting your dose accordingly. You can also keep a record of your own weight and inform your doctor if this changes. UDCA comes in a range of tablet sizes and suspensions.

Because PBC is a lifelong condition, it is extremely important that you continue to take UDCA, even though your condition may improve. Any improvement in your PBC will be due to the UDCA and if you stop taking it your condition will worsen.

Many people find that it is easier to take one 500 mg tablet per day than several smaller ones, especially if they are taking medication for other conditions. However, everyone has individual needs so do discuss the different options with your healthcare professional.

There are a few medications which can affect how well your UDCA works. These include some indigestion remedies containing aluminium hydroxide, as well as cholestyramine and cyclosporine. Your pharmacist will be happy to help you.



It is really useful to get into the habit of attending regular appointments with your doctor or liver nurse. As well checking on your weight, you will also have blood tests, and possibly an ultra sound or 'fibro' scan to monitor your condition.

The symptoms of your condition may fluctuate over time. In addition, you may also experience side effects from your UDCA, although bear in mind that not every symptom you experience may be because of your PBC.

Keep talking to your doctor or liver nurse about how your symptoms can be investigated, minimised and managed and make them aware of any changes in side effects if you change your brand of UDCA.

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For UDCA dosage recommendations at your fingertips and to check if you are on the correct dose, search for the 'UDCA Dosing App for Patients' in the App Store or Google Play.



You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard

By reporting side effects you can help provide more information on the safety of medicines.

If you have been diagnosed with Primary Biliary Cholangitis you may want to visit the following:

PBC Foundation (UK)

www.pbcfoundation.org.uk

or download their patient information leaflet from:

www.pbcfoundation.org.uk/newly-diagnosed/leaflets

Patient

www.patient.info/health/primary-biliary-cholangitis-leaflet