KHA-CARI Patient and Caregiver Guideline for Autosomal Dominant Polycystic Kidney Disease - Management of Polycystic Liver Disease

1. My doctor says I have cysts in my liver also. What does this mean for me?
   Cysts occur commonly in the liver, especially in women who have had children. This is because the hormone levels during pregnancy trigger cysts growing in the liver. Usually people are not affected by them. However sometimes they have a feeling of abdominal fullness or dragging. Polycystic liver disease can be detected with an abdominal ultrasound.

   Women with polycystic liver disease should have counselling about the risks of pregnancy and about the use of hormone replacement therapy.

2. What other parts of the body can have cysts? How likely is the disease to spread to other organs?
   Polycystic kidney disease affects many different organs, but the kidneys are affected most often and most severely. People with disease in other organs are often not even aware of it. The liver is the second most commonly affected organ after the kidneys and may cause symptoms. The spleen and pancreas can be affected with cysts too, but usually do not cause symptoms. Sometimes people with polycystic kidney disease may develop a heart murmur, or an abdominal hernia which are also linked to the disease.

3. How do liver cysts contribute to my feeling of ill-health?
   Liver cysts rarely if ever cause significant liver damage in people with polycystic kidney disease. However liver cysts may cause liver enlargement and a feeling of abdominal fullness or dragging.
   If there is too much discomfort, you should discuss treatment options with your doctor.
   Some of these treatments include:
   a) Pain relief with other methods such as massage, acupuncture should be used first. Panadol should only be used if absolutely necessary. Talk about strategies with your kidney specialist, family doctor and pharmacist.
   b) Medications to stop the cysts from growing are still being tested.
   c) Surgery to remove large cysts or decrease the size of the liver may be an option. There are risks involved. This should be considered after careful discussion with your specialist, surgeon and other health professionals involved in your care.