FOCAL AND SEGMENTAL GLOMERULO-SCLEROSIS (FSGS)

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This is a type of kidney disease, also called ‘focal and segmental glomerulosclerosis’ or just ‘focal sclerosis.’

What is FSGS?

FSGS is scarring within the kidney that can only be seen clearly under the microscope. Therefore it is normally only diagnosed after a biopsy test of the kidney. What you see under the microscope is that the “glomeruli”, which are the tiny structures which filter the blood to make urine, are scarred (or “sclerosed”).

What are the symptoms of FSGS?

These are variable from case to case. In many cases there are no symptoms, but the damage to the glomeruli causes some protein to appear in the urine. Therefore a routine medical check may pick this up. In some cases the level of protein loss can be very high and fluid retention with ankle swelling may occur: this is called Nephrotic Syndrome. In other cases kidney failure can develop which may give tiredness or sickness if kidney failure is very advanced.

What causes FSGS?

Basically doctors do not know fully. There may even be several different diseases that cause the same appearance in the kidney. It seems that the general cause of FSGS is immunological. That is, the antibodies and white blood cells we have to fight off infection cause some damage to our own bodies by mistake. In FSGS any damage is usually only in the kidneys, so the rest of you should be alright. In a few cases the condition seems to run in families, but this is uncommon.

What will happen if I have FSGS?

The outcome is very variable, and you will need to ask your specialist how things are likely to be in your case. The possibilities are:

1. It may continue unchanged for many years, requiring only regular check-ups with blood tests.
2. It may go away on its own in some cases.
3. If there is fluid retention with ankle swelling, this may get worse.
4. In some cases kidney failure develops, leading to the question of dialysis or transplantation.

What are the complications of FSGS?

1. High blood pressure may develop. This damages the kidneys and puts a strain on the heart and the rest of the circulation. Therefore high blood pressure should be treated vigorously.
2. If there is a lot of protein in the urine, the cholesterol level may be very high, requiring a special diet and sometimes cholesterol lowering drugs as well.
3. As noted above, kidney failure may sometimes occur. If so, it develops slowly, so you need not be concerned about a sudden change in your condition overnight.

Is there any Treatment?

This is not an easy condition to treat and sometimes doctors rely on treatment of the blood pressure and cholesterol. However, in some cases a course of steroids (prednisolone) produces a marked benefit, especially if there is heavy protein loss in the urine. If steroids fail, more powerful drugs that affect the immune system may be effective. Doctors have used drugs called cyclosporin and tacrolimus which can be helpful. Some people have tried using mycophenolate, but this has been less successful. These drugs suppress the immune system so can have side effects and need to be monitored carefully.

It is important to discuss the risks and benefits of any treatment with your doctor before starting such drugs. However, it may be worth a trial of such treatment if there is a chance of preventing the need for dialysis treatment.

Can I lead a normal life with FSGS?

The condition itself does not cause any specific symptoms or pain. Fluid retention or kidney failure may affect day-to-day life. Most patients with this disease, however, lead normal lives and go to work, have children and so on.