

spina bifida

UTIs: The effects on your life

Case studies

Poor management

My name is Carol. When I turned 16, I didn't want to attend the children's spina bifida clinic any more. When I was very little, I had the urinary diversion procedure, which means I have a continence bag. I thought my condition had really stabilised, and I didn't need endless checkups and tests. When I left the children's hospital, I didn't have a transfer plan to adult doctors and an adult clinic. I didn't think I needed to.

I didn't know that as an adult, I had to look after my health.

In my early twenties, I had a bad run of UTIs. They kept me off work quite a bit. I went to the local doctor who prescribed antibiotics and they seemed to work. I am now 32. About a year ago, I developed a lot of kidney pains. My GP finally sent me to a kidney specialist. The pain was the signal that I was entering the final stages of kidney failure. I am now starting kidney dialysis and going on the transplant list. One kidney works about 15% and the other not at all.

I am very depressed with not being able to work and having my life ruled by dialysis. I am angry. Apparently, the urinary tract infections in my 20s had damaged my kidneys and left a lot of scar tissue. The urinary diversion caused the wrong pressures, which further hurt my kidney function. I could have had the diversion reversed. This would have meant cathing and being kinder to my kidneys.

Why didn't someone tell me that I needed to carefully manage my urinary system? Look at the mess I'm in, all unnecessary.



Effective management

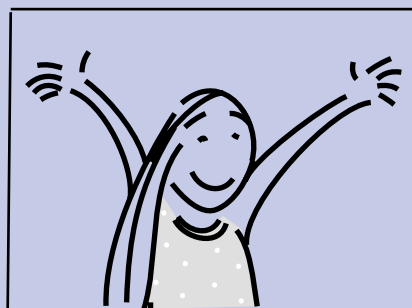
My name is Sarah. I have been self catheterising since early primary school and everything has been going well. Cathing and continence pads for the inbetween periods has been my routine. It took me a long time to actually leave the children's hospital but I had a transfer plan. My 'kids' doctors found me a good 'adult' spina bifida clinic, including a urologist who still looks after me now. The 'kids' continence nurse told me just before I left: 'If you do nothing else, make sure you watch your urinary system and have regular specialist check-ups.'

I had a good urologist in my early twenties. I needed my bladder sphincter tightened. This operation also had a lot of complications, including infection, but it didn't damage my kidneys.

I am now 32. I have had a good run of late, touch wood. I had my annual check-up last month. This involves a kidney scan and some other pressure tests. The results were good. Kidneys working well; bladder volume and pressures about the same. Some overall deterioration, but no cause for alarm.

The big news for me is getting married, and yes, planning a family! Been to see all the docs in my team, to make sure my body can cope with a pregnancy. Got the go-ahead. They have found me a specialist obstetrician with lots of experience with spina bifida.

Spina bifida does not go away, but with the prospect of my own child and a good life ahead, taking good care of myself in a partnership with my medicos has paid off.



You have just looked at two totally different **continence management** scenarios. Sarah, who has taken good care of herself and been regular in consulting her urologist and other members of the spina bifida treatment team. And Carol, whose tragic situation could have been avoided, if she had sought expert advice.