

Crohn's Disease Caroline, Avon



Caroline, a mum with two teenage children, works as a part-time Administrative Assistant in a primary school and was diagnosed with Crohn's Disease in 1983 when she was 21 years old. Initially Caroline suffered with diarrhoea. Then she developed red patches on her legs with oedema followed by 'many ups and downs'. In 1995, Caroline required bowel surgery and then she collapsed in 1996 with a major haemorrhage. This was followed by a further operation in 1998 which was complicated by a blood clot. In the past two years due to narrowing of the bowel (stricture), Caroline has had three 'anal stretch' procedures as a day case. The alternative is a stoma (a 'bag'), but Caroline is not willing to accept this as an alternative. Today she considers herself to be relatively healthy, but she freely admits that she has 'felt better'.

Her disease has had a major impact on her family. She decided to take redundancy after one of her operations and a long period of sick leave. Caroline has needed anti-depressants to cope with the bad times, when she has felt angry and frustrated by her disease,

but is now more accepting of the restrictions on diet and activity that she faces. Caroline has not found it easy to find another job, because her sick record counts against her.

Caroline believes strongly that IBD sufferers often feel isolated because their disease is not a 'dinner table topic'. She feels that appearances can also be deceptive, because IBD sufferers put up with many invisible symptoms, including pain and fatigue. Caroline says she does not always look as ill as the serious inflammation in her small bowel feels. Caroline believes that hospital facilities must be improved and that the support of an IBD Specialist Nurse would make her life easier.

Currently, part of an extended drug trial, Caroline requires regular, two-weekly injections of certolizumab pegol, a new biological treatment (not yet licensed) which is administered at her hospital. She has been receiving this drug for over two years, but still has to take other drugs as well. Caroline considers that one of her biggest challenges is dealing with the tiredness which she says can make it hard to function. At the moment she feels she is 'holding her own', but is undergoing investigations for a possible stricture.

Messages:

- Symptoms of Crohn's Disease can include profound and debilitating fatigue
- Surgery is often necessary for Crohn's Disease and can provide significant periods of remission, but it is not curative
- New treatments for Crohn's Disease are being developed and are under trial. It is important patients have access to these
- Patients often suffer from other associated inflammatory symptoms in addition to their Crohn's Disease.