

## Case Example - Advocacy

**Provided by: East Cheshire Advocacy, October 2006**

“The person I am writing about died from cancer in September 2006. I have changed his name to respect his memory.

Stan was just 69 years old when he died of cancer 4 weeks ago. This is an account of some of the work I have done with him, as his advocate, over the last few years.

Stan had learning disabilities and obsessive compulsive disorder. His case was so extreme that the staff caring for him had a huge manual of policies to meet his needs.

Due to an injury sustained several years ago, Stan also had very severe swallowing problems and needed constant monitoring of his condition. He occasionally had to have his throat stretched to enable him to swallow. On one occasion when he was taken to the emergency dept of Macclesfield Hospital with this problem, he was put in a side room with his 2 support staff. This room contained shelves of needles, dressings and all other types of hospital equipment. To Stan it was a disaster area that needed sorting as his compulsion for putting everything in order came to the fore. They spent 8 tortuous hours in this room waiting for the consultant to come and see Stan.

In the end the staff could not handle the situation any longer, they were exhausted and so was Stan, and they left to return the next day. He was eventually seen and the throat problem was resolved, but what came out of it was a need to educate the emergency team to the needs of people like Stan. Through the PALS service at the hospital I put a complaint in on Stan's behalf, and the learning disability team set up special training for the emergency department, to enable them to meet the needs of patients like Stan in the future. Also, a fast track system was put in place for Stan, so that the next time he was taken to the emergency department he was put straight through to the consultant.

More recently I have attended hospital appointments with Stan and his carers because of the abnormal growth that appeared on his back. The consultant was unsure of my role, but I explained that as Stan's advocate I was there to listen, understand the situation, ask any questions on Stan's behalf, then with his staff make informed choices. Stan was deemed not to have capacity to make his own decisions.

As it was the consultant left us with more questions than answers, and I turned to a palliative care doctor friend to help me through the information I had received and to pass this on to the people supporting Stan.

The next stage for Stan was to be seen at The Christy Hospital in Manchester which is a specialist cancer hospital. I met Stan and his staff there and as planned we were immediately shown through to a quiet waiting area. Stan had been sedated for the journey and the appointment, otherwise he could not have tolerated it. For the first time, in all the years I had advocated for Stan, he showed some interest in me. He held my hand, and during his examination fastened all my jacket buttons. Little did I

realise this would be the last time I would ever see him alive. Three doctors came to look at Stan's cancer as it was a very rare form and one they might only see once a year.

I had made the decision, with the staff, that Stan would not tolerate Radiotherapy or Chemotherapy, as his OCD would not let him be still for long enough. He could not be given an anaesthetic every time he had radiotherapy treatment and he was unable to swallow for chemotherapy treatment. The doctors decided they would have a meeting about his case, but that surgery would have to be so radical that Stan would never tolerate it.

It is not very often an advocate has to make life or death decisions, but in Stan's case I definitely felt that he had suffered enough in his life, and that every effort should be made to make the time he had left as comfortable as possible. Stan only survived a few weeks after this last appointment. During that time he was cared for, in his supported home by the staff who knew and loved him. His GP came regularly to see him and kept the pain under control and the Macmillan Nurses gave the staff all the support they needed.

As an advocate I have supported quite a few people to hospital appointments and I am finding now that the medical profession are realising the benefits of having advocates to explain and support people through their treatments.

Maggie Harwood  
Manager, East Cheshire Advocacy”

---

Maggie Harwood  
Manager  
East Cheshire Advocacy  
The Moss  
4-6 Congleton Road  
Macclesfield  
SK11 7UE

[www.ecadvocacy.co.uk](http://www.ecadvocacy.co.uk)