

Patient story: Paget's disease Sheila Varian

KILLING  cancer

PDT saved Sheila from more traumatic surgery

Surgery to remove a skin cancer may not be the most troubling event of your life. If it was on your back, for instance, you could probably live with any scar. You would know it was there, but the tissue removed is, in reality, quite small with rarely much psychological consequences.

Yes, you've had a cancer and are concerned that it might return.

But what if your cancer or pre-cancer was in an area of the body that was 'private' and was part of your perceived masculinity? Imagine telling a man that he would have the tip of his penis removed?

Well, that sort of surgery is taking place now. For the penis and also for women's vulva. The cancers or pre-cancers are often removed surgically that have a huge emotional impact.

Sheila Varian is one lady who had been through the surgical route before finding PDT, offered by Dr Ernest Allen and his colleagues at the Christie Hospital in Manchester.

What was the surgery like? "It was very difficult and stressful indeed. My GP supported my request to try PDT, but my Gynae Consultant and PCT were unhelpful to say the least.

"The Gynae offered conventional surgery to remove even more of the vulva after my first surgery in 2001 - that was in 2006. A dermatologist made a tentative suggestion of Imiquimoid Cream.

"Surgery involves staying in hospital for several nights at least with all the inherent risks involved from MRSA and C Diff. Risk of infection to wound. It is a very long healing process over several months. There is permanent scarring and disfigurement, causing long term physical and

psychological damage. Patients are generally left to cope alone with the consequences and also struggle to gain support or practical help," she says.

In 2001 when the pre-cancer was first diagnosed - known as Paget's disease - Sheila started with conventional laser treatment. She says it resulted in severe "agonisingly painful" scarring and did not remove all of the Paget's disease. What followed was a partial vulvectomy/clitorectomy November 2002 and February 2003 - removed remaining Paget's Disease but left with ongoing nerve pain.

For Sheila, the PDT was a far easier and less traumatising treatment. "I find it immoral that all women with VIN (pre-cancerous conditions) are not offered the choice of PDT or treatment with chemo-type cream (Imiquimoid/Cidofovir) as an alternative to surgery. It should also be offered to all appropriate patients.

"My case speaks for itself. The Paget's initially presented on the left and with a very small area on the clitoris. Conventional laser and surgery have left me unable to work as I cannot sit or stand for any length of time without excruciating nerve pain. The reoccurrence was on the right and following two PDT treatments the area is free of Paget's and the skin looks fresh and healthy."

One of the targets for the charity is to be able to extend this research and treatment, both for men and women.

