



The Christie
PET-CT Academy



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PATIENT REPRESENTATIVE



Living with Lanreotide

Lanreotide and I have been living-in-sin for three years now. Before that, I spent a year with Sandostatin but we fell out when he messed with my blood sugar levels.

Lanreotide and I have a love / hate relationship.

I see him sitting in my fridge in the run up to injection day, every time I reach for the milk. He winks at me from his long white box and I know his silver foil wrapper which covers his sharp needle is waiting to be set free.

I love that he keeps me stable – together with 3 cycles of PRRT.

I love that he doesn't make me bald.

I love that he stopped my flushing in one fell swoop.

I love that he made me more aware of my diet and what my body needs. But he lied when he said I would lose weight.

And so we roll.

Every time he comes home on day twenty-eight, he gives me a 'bolts through the brain' headache, just for a day.



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He brings with him a laundry basket full of fatigue.

He makes my stomach bloat and gives me a rock hard abdomen.

At first, he completely stopped me visiting the loo.

But we've learnt to compromise.... I now have slim jeans and fat jeans.

I hate that he makes my hair shed and frizz.

He dries up my skin and makes me look weary.

But most of all, I hate it when he messes with my cognitive ability, the panicked search for the perfect word, the loss of train of thought, the befuddled fog.

On the other hand, things could be so much worse. I don't know the science behind the discovery that this drug could slow the growth of neuroendocrine tumours.

I don't understand the microbiology in our cells which drinks this drug to slow our cancer down and I certainly don't know the price to produce it.

But I do know that – together with our UK NET Centres of Excellence - it is a life saver for most Neuroendocrine Cancer patients and it can keep working for many years.

We are all different and we all respond differently. But if there is a choice between a somatostatin analogue (which Lanreotide is) or the relentless 'Red Devil' Doxorubicin chemotherapy, I'll take Lanreotide any day.