

Immunoglobulins and me: Cheryl's story

The condition I have is called Common Variable Immune Deficiency which is a deficiency of the immune system. I was diagnosed 11 years ago after suffering from repeated pneumonias. I commenced on the immunoglobulin therapy 11 years ago with the intravenous version that you have in a hospital setting. For an intravenous infusion of immunoglobulin you must visit

a hospital usually just for the day in either an infusion centre or a day unit. In order to give the infusion we have to give it straight into the vein and so we put a tube like a canula into your vein you're monitored closely throughout the infusion by nursing staff and we give a large volume all at once and then usually repeat that 3 or 4 weeks later. So when I was having

immunoglobulin therapy through an infusion in the hospital setting, it really didn't agree with my body. I would suffer from extremely bad headaches for 3 days after that and they would have to infuse me very- very slowly so my body tolerated the product. Then I'd heard about the

subcutaneous therapy that's the treatment that you do at home and I've been on subcutaneous therapy now for 2 years and I love it. Subcut Ig or subcutaneous immunoglobulin is usually self-administered at home. it's one of the big benefits of having a product that you can give safely at home and that's given with a very-very tiny needle into maybe an area like the abdomen or the upper leg. The frequency will depend on the volume that needs to be given, but approximately weekly. So before you go home to give your own subcut Ig usually you will spend some time with a nurse specialist and that can be perhaps two or three sessions it could be 10 sessions and that really depends on your needs. So you should feel really comfortable before you go home to do it independently. You should have the same amount of care and contact with the health specialists or nurse specialist that you need as you would if you were in hospital.

So you shouldn't feel that you're doing that at alone you should feel very well supported in the community. It's so much easier to do in your own home setting at the time of day that suits you and it's an easy process. I infuse the subcutaneous therapy once a week and it takes about 2 hours. I don't have any side effects with this method. I do take two antihistamines as a premedication because I was at one stage getting headaches. I'm aware that immunoglobulin therapy is a very-very precious product. we are monitored every 6 months by our immunologists to see if we're still eligible for the product and also to see if we need a reduction or an increase in our amount that we take.

I've recently had the amount of immunoglobulin I received lowered because I guess I wasn't getting infection so they lowered it. I'm really grateful that I have this product. it's the best thing. We call it liquid gold and when I can get a chance to go to the Red Cross I do go and I thank the blood donors and they just get such a buzz that they've actually met someone who's received their products. I feel really well at the moment it does have its plateaus and I do get stages where I struggle but since I've had the immunoglobulin therapy it has improved life has improved out of

sight. We have a motor home and we travel Australia quite a lot. Which has been a God's end. With having the subcutaneous infusions because as we've been traveling I've been able to actually receive that product up in Queensland and I have been in London several times and had infusions there. I hope for the future to continue to have good health be able to play with my grandkids and still to travel. I just love that to be able to be fit and healthy that's all I want.