

## Patient Perspectives: *Getting a 'PEG'*

“When I was first told about the possibility of a PEG I wasn't too thrilled by the prospect. I had a strong desire to keep life as normal as possible for as long as possible. Several times along the way I was asked how I was coping, and although things had got harder, I wasn't ready for something I saw as a fairly drastic change.

I had a lot of concerns about how to manage the thing. Does it hurt? Does it leak? Will it get in the way? Will it show? How long is it? Can I use it for medicines? Will I still be able to eat normally? Can I still use the bath, and our spa? Does it cause problems with sex? Does it mean that somehow I am no longer fully human? So I wasn't about to rush in. But my philosophy about MND has been to stay as healthy as I can for as long as I can, because who knows when there might be a medical breakthrough, right? And the problem was that I was starting to lose weight.

Eating my main course was taking between 30 and 45 minutes. Even food that had been pureed was becoming a problem. And every meal I would end up coughing and spluttering and embarrassing myself in front of family and friends. I knew I would be OK, but they didn't and it was stressful for them to watch and see me struggle. And despite labouring over each meal for so long I was still losing weight. I just couldn't sustain my health any more. So in the end I just grew tired of the constant battle and decided I would talk again about the PEG. My health care team quickly agreed to it and we set the date. From the time I asked to the date of the operation was only about three weeks, but I was so ready to go in! I couldn't wait!

On the day of the operation I was admitted to hospital and waited in the ward until it was time. Then they wheeled me over to the endoscopy unit on the bed and I waited there a while until they took me in. The Gastroenterologist I had met several times before and we got on well. I chatted (with my mumble) until I went unconscious and awoke with it all over. I was wheeled back to the ward and began recovery. I was in hospital for four days, although it was over a weekend so it might have been faster if done during the week. I felt a bit of a fraud in there because I was quite well really after the first two nights. I was a bit sore from the operation and found it hard to roll over. I joked and said that it felt like I had been shot! The pain settled down after two or three days and when I went home I think I only took Panadol at night just to help me get to sleep the first two nights. After that I was fine.

Using the PEG is easy. They teach you how to do it in hospital and the Dietitians come too and work out your diet with you. They also arrange for the PEG feeds to be delivered to your home, and you are sent home with more than enough to keep you going. The PEG feeds are then ordered each time by phone or email about a week or so before you run out and again they are delivered to your door.

I am now having 75% of my food through the PEG. I still eat some pureed main meals, and lots of soft food like yoghurt, ice cream, custard and thickened drinks. I eat really as much to taste things as anything else and just to have something in front of me at mealtimes.

So how about all those questions I had? What is it like living with a piece of plastic tubing coming out of you? Well, it's surprisingly easy really. After a while you get very used to it, although sometimes in the bathroom mirror I look at myself a bit strangely! But it hides well under your clothes. Even though it has to come out of you at ninety degrees and then curl over against you, it only sticks up about 2 centimetres and is easily hidden by the folds in your shirt.

When I first got it I thought, "Wow, this is way too long!" I was tempted to cut it shorter, but I didn't and I am very glad. If it was shorter it would stick up more and it would not be so easy to use. You have to reach into your clothing and pull it out, so the extra length is important and helps you to manage your feeds. I have mine coming up towards my neck and I tuck the end of it around the shoulder strap of my singlet. Then when I need it I just reach under my shirt at my shoulder and it's there. I untwist it and I'm ready to go. I do my feeds by gravity and that is easier with the tube higher up.

It doesn't hurt. It doesn't leak. Each morning I clean around it in the shower and rotate it to keep it free and clear. That feels strange when you first do it but it's fine. There is a tiny amount of brownish discharge to clean away but it is easy and any that gets on your clothes washes out without trouble. The tube doesn't get in the way (even during sex!) and is very resilient when slept on. In other words, you learn to live with it very quickly. And people don't notice and are surprised when you tell them!

Since having my PEG I have been to Arnhem Land to visit my son (he's a pilot up there) and to Brisbane for a wedding. The additional weight of all the food in your luggage takes some thinking about, but it's possible. You might need to tell the airline and gain a special baggage allowance. Right now I am planning a trip to Sweden for my niece's wedding!

Best of all is that meals are now so much easier. I have my meal, as much as I feel like, and then I have the PEG feed afterward, three times a day. I also use it for my Rilutek and for other medicines. There is an app for the iPad called MedeCrush and it gives detailed instructions about how to put your various medicines down the PEG. Just look up the name and it says what to do. I think it cost about \$10.

I hope all this helps you. If you are like me, then you are wary of 'intervention' in medicine, and so I was determined to cope without the PEG as long as I could. I am pleased that I did, but now that I have mine life is much more comfortable. And if they find a cure for MND they can take it out and stitch up the hole!"

**Patient G. V**



## Jodies Experience

“My name is Jodie and I have been diagnosed with Motor Neurone Disease for a little over two years now.

I decided early in my diagnosis that I wanted to have the PEG, but because I could eat and drink well I put off having the procedure. Earlier this year, I got sick and tired from being sick. I ended up getting dehydrated and was admitted to hospital. I decided that It was time to get the PEG.

I then started to feel anxious about having the PEG and several things started going through my head; 'How would I have a shower? What if I had a bad reaction to the anaesthetic (like I had previously for a different operation)?'. Someone also told me that their relative had it and they had to have it removed because it kept falling out. I was then trying to find experiences online, but there was not much out there. I remembered my friend's grandma had Motor Neurone Disease, so I asked her about it. She told me that unfortunately her grandma had left it too late to get the PEG, and couldn't have it done.

I decided to go ahead with the PEG. It was stressful waiting to have the operation because of the things going through my head, but the operation itself was quick and easy. The first few days were hard and painful and I remember regretting having the operation. Within a week all the pain had gone. Now after six weeks, I forget it's there and I even wish I had done it earlier when I was stronger and able to get in and out of the hospital bed on my own.

I hope my experience helps others make their decision to have the PEG easier."