



FSH-MD Support Group UK

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Leanne's story

Diagnosed with FSH-MD in her early teens, Leanne (29) has had scapular fixation surgery on both shoulders; the right in 2008 and the left early 2009. Undertaken by Professor Levy at the Royal Berkshire Hospital in Reading, Leanne says the decision to go ahead with the surgery was a tough one after a previous surgeon left her despondent after her negativity about the procedure. Professor Levy had a more positive approach so Leanne decided on the surgery hoping it would reduce the discomfort she was feeling.

Leanne is delighted with her surgery; "I used to be tired anchy by Friday night, but now I can go out and enjoy myself like others my age. I have less movement but the shoulder looks much better. I wish I'd had it done sooner. I feel I now have a fighting chance to live my life the way I want to."

Leanne says the toughest part of the procedure was coping with the 12-week post-operative period in the shoulder brace. The helps keep the shoulder elevated and cannot be taken off, even at night or to bathe. The brace causes difficulty performing basic tasks such as dressing, Leanne was able to overcome the bra scenario by hooking it over her bed posts to allow her to put it on. Sleeping was another issue as getting comfortable was difficult. Leanne relied upon pillows to help support the weight of the brace as well as creams to prevent chafing and the occasional sleeping tablet, "you always find a way of coping but I did have some bad days when I would cry with frustration". Leanne also had to rely on a wheelchair when she went out as the weight of the brace but pressure on her back when walking.

In hindsight, Leanne wishes she had access to occupational therapy prior to her surgery to help solve some of the many practical problems which she had to solve herself. Leanne feels that having both shoulders done within a year was probably not ideal as it "hit harder the second time". She would also advise people to think about the financial burden of being unable to work for several months. Finally Leanne suggests thinking about how you will spend your time, as there is only so much daytime TV you will want to watch!!

Taken from Target MD Autumn/Winter Issue 2009. With thanks to Jane Stein from the Muscular Dystrophy Campaign and Leanne for allowing this article to be reproduced.



wearing sling!



Before op!