

## Family and Friends

I was diagnosed on the 31st May, I never told my family until early July. I knew the diagnosis and I told my best friend followed by a select few of my closest friends - and that was because they had been live with me whilst I was in A&E and were there at the point of diagnosis so I could not avoid it. I guess I was trying to deal with myself first and all the thoughts that I personally had that came with KFS. There was so much I didn't know and the ifs & buts of KFS is not something I wanted my family to stress about too - that's just the way I am. I waited purposefully until I had the results of my cervical MRI - until I had a better picture of what was going on personally for me as opposed to the generic stuff.

I used the time to in between to research my way forward. I am glad I made that choice, as it gave me the time I needed to adjust, and if I could go back I still wouldn't change it. When I did start telling my friends and wider family - I was mostly met my silence, it took a while for them to let it settle in.

My theory is nobody knows what else to say after 'you will be fine soon' etc. because degenerative conditions don't get that fortunate outcome. It is a bit hard to offer platitudes when the outcome has no cure and is unknown so I didn't mind the silence. By the time I told them though I was truly fine with the diagnosis, I had already bypassed the feeling sorry for myself stage, denial and breakdowns so I was honestly able to tell them I was fine and that I planned to take it as it comes and keep on going, and adapting as much as possible. I didn't want pity, I didn't want fear, I just wanted their support and I am very lucky that I got it.

In the end my family had to see me at the height to pain, irrational and looking like absolute crap (sorry for the language) to realise the extent and reality of what I have to face on this see-saw. What I would find amusing was by the time they registered the pain I had already been in it for hours and when they would start pointing out I look really rough (that's the polite version) I was usually on the way to better hours/days.

The biggest thing I needed my friends to grip is that there may be times when I need to crash, cancel or postpone. It never means I don't care, just that I cannot predict when a day is going to take a turn for the worse. Long walks and extensive outings involving carrying shopping or such a like have to be changed into moderation, but those adjustments can be made when there is understanding.

One of my closest friends was the latest to check in on her take after she talked to my sister, and all she said to me was 'if you ever need a wheelchair you better let me ride in it'. Prepping, accepting and planning for possible outcomes is something I've always done, never did I expect to have to plan out KFS but with the help of my family and friends I have alternate outcomes now. Plans that make the pain and bad days bearable and plans that still allow me to dream and live life as much as I can, whilst I can, to the MAX!!!