

The Hardest Thing About KLS

The hardest thing about KLS is accepting it. It sucks.... for us as parents and for our young people.

When a child is born - we already have dreams and aspirations about what they are going to be like, what they are going to achieve and how they are going to do x, y and z when a child is born with a disability - the parent grieves their dreams and learns to accept their child as who they are and begins to create new dreams... different dreams and accepts a different path and for their child this is "normal".

KLS just sucks - we have amazing children with everything going for them.. then BAM - life stops... they have a crippling and disabling condition, they can't do anything, they need 24 hours support, they are aware they are not their normal selves and they watch as their dreams, their friends, their adventures go on without them.... and no matter what as parents we cannot make it all OK

Then it's over - they are fine, life goes on - they struggle to catch up, they battle to fit to fit in, the problem goes away - it was just a nightmare....

Or was it - BAM - it hits again.... they had hoped the last episode was the last, actually we all hoped the last episode was the last, we live like it was ... we made no plans for tomorrow...

The BAMS keep coming - there is no rhyme or reason... the episodes are more frequent, or longer, you miss something that was important, your friends get fed up with you not being there for them (they forget your ill - they have other priorities). The Dr's can't help - your parents promise it will end, it will get better ... they have heard others do get better and they keep telling you, you will too.... but no one truly gets it... unless they have it too....

A carer's view is different from a patient's view.... the patient relies on you to fill in the blanks, to reassure them it will end, to explain what they missed and that is hard. A well healthy teenager does not want to rely on a parent to keep them safe, a well healthy teenager does not want to worry about tomorrow, does not want to talk about it let alone anything else and all the time they are being challenged... is it real, yeah I'd like to sleep all day, you're just lazy mate, etc....

So our children have to find a way that works for them, they have to learn how to accept that they have a chronic condition - they have to acknowledge that their path is different than their friends, and they have to find a way that works for them... the path to adulthood is challenging at 15 / 16 / 17 / 18 / 19 - we have to prepare them for it... it is even more challenging with KLS.

But for us there is a way... as a family we use to plan ahead - we then had plan's A, B or C cause of KLS, this changed as I realised my son never looked forward to anything - cause he said it was pointless, as he would miss it - so we changed and are now more last minute.... when his episodes were frequent we use to celebrate the ending with a special meal - he was sick of rich food, and being reminded of time he missed - I felt bad, but I never asked what he wanted.... after an episode I wanted to share "our news", he wanted time online to catch up with "his news".

We discovered that talking was essential, we had to understand what it is like to have KLS, ask him what he would like in place after an episode, how we could help keep his life happening. We had to let him know it is OK to be fed up with KLS, to hate it. We remember everything the Dr's have said, he doesn't - it was either too much to take in, or he was in episode and does not remember. We share that we wish it would end, that it is not his fault - that we all hate it - but we LOVE him....Talking does not happen overnight, but as carers and parents we are there at any time to listen it is OK to be pissed off and angry that KLS affects you - that is a major part of the grieving process.... grieving the you, you could have been....

Then you get to accept the new you - the one who appreciates time, who values the friends that stay, who communicates more as it helps keep them safe, the one who is more aware of others, who has amazing determination to be the best they can and who begins to discover that a lot of things are achievable - you just need a different approach and someone in their corner....

When my son is well - he is AMAZING... when he is in episode - his life is on hold, we hold it together for him... when he is struggling - we are all trending on egg shells and that is not a thing we can do, either KLS will take over or it won't - but we have to just accept him the way he is, and adapt our ways...

We have learnt to accept that KLS interrupts our lives, at times it sucks, it has changed him, it has changed us, but it does not define us.... it is just something we have to deal with... and some days if we want to be sad, angry or disheartened - that is OK!