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“Psychosocial questions in inhibitor care”

with psychotherapist Ms Nicola Dunn, Royal Free Hospital, London, UK

PARENTING CHILDREN WITH INHIBITORS

When we think about psychological issues with children, generally they just want to be normal. And, of course, their parents just want to protect them because they think that the level of care should be as high as possible. What are your views on strategies that we can adapt to face this clash between parents who want to protect and children who want to be normal, just like anybody else?

Parents are hardwired to want to protect their children and we know that. I think what happens and is challenging, is that when haemophilia is discovered, often the parents first will feel that somehow, they must have done something wrong, they did not protect their son from getting haemophilia. And then, of course, an inhibitor is an additional element of that.

So, then they want to protect all the time and protect more, because somehow, they did not protect enough, even though that is not correct, but that can be the feeling.

But then what we know is that the word normal is very difficult. I don't even consider myself normal. I don't think I know anyone that is normal, but that is a word that we all use.

But there are other words that might be helpful, which are **resilient and being strong in your own way.** And I guess, resilience comes, often, from living not a closed down life. **Living a life where there may be an element of risk, a containable risk. Because out of risk comes growth.**

Whether that is an emotional risk, or whatever it may be called- the risk of being yourself and the risk of reaching out and rising to your potential. And I think that feels risky for anyone and it must feel even more challenging for the inhibitor community.

But there are certain people in the community whom I know who have lived a fulfilled life. **This is really what we want the parents to be thinking about, that their children, their sons growing up will have a fulfilled life in their own terms, whatever it will be.** And of course, that is very different from being protected or overprotected.

The other word is RESILIENCE!!!



Facebook is a very common place where the parents express their fears and their anguish about having a child with an inhibitor. Generally, the parents treat their children like heroes. Do you think it is a correct way to treat children – like heroes, and parents like warriors. As if there was a war going on against something all the time. Do you think when the child will reach their teenage years, this kind of exposure will have been very damaging for them?

Everything in moderation!

I think the answer is- everything in moderation. **On one hand there is overprotecting the children, on the other is saying to them that there is no risk.** Because actually what the teenagers are doing, they are learning to manage the risk. And sometimes teenagers get it wrong just because it is hard to gauge that. They are in a new body, a young adult's body, and everything is changing and sometimes they get the risk wrong. It is tricky line and tricky pathway. I think bravery is one of the elements, if you are talking about heroes, but it is about having a measured response to that.