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## “Psychosocial questions in inhibitor care”

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# IMPORTANCE OF SOCIAL LIFE

In my country a survey was done about quality of life in people with haemophilia. And there was one interesting finding – that there is always a positive correlation between quality of life and feeling of satisfaction about life, enjoyment of life. I talk about the social components of life – communication with friends, communication with family and wider environment. Would you agree with this finding? Should we try to have a more active social life to increase the quality of life? This is more challenging for people in their 40's and 50's, because they usually have small children, but they also have lot of joint pain that they are dealing with, so their satisfaction with life is really low. One of the most important things that is positive in their life is their social life.

When you have a family with young children, it is indeed a challenging time.

**But belonging to communities that understand something about what you are going through, is really important.**

People in the haemophilia and inhibitor communities are balancing two things – attending to their families and extended families and being in contact with other people where they feel some level of (I am using this word again!) normality, which is very important. It is important that they feel, they are with people that understand something about them. I know it is a tricky time for parents with young children to be able to socialise very much, but some element of it is important.

**If we are thinking about couples, it is a blend of socialising separately and preferably in your gender groups (men with men and women with women) and having enough of couple time.**

The latter is very important but can be also very challenging depending on how you earn your living or whether you have a young family when they are all demanding your attention.

The time of life between 40 and 50, it is midlife. Not the midlife crisis, but a midlife opportunity. **People are looking at what they want their lives to look like in the new portion of life they have.**

**There is a lot that is gained by coming together in a community, either it is small groups or larger groups. I really would not underestimate that.**

It is a challenging time, therefore reassessing the priorities of what actually would make an increased quality of life for that group is really important. Because a lot of them are actually managing chronic pain and not talking about it, and that is very tough on the quality of life. There is a lot to do when you are managing haemophilia with an inhibitor – you know you have to swim, you have to make the social contact and so on – but it is all about trying to work out what is possible for each individual. **There is a lot that is gained by coming together in a community, either it is small groups or larger groups. I really would not underestimate that.**

