

Psychological effects of Pyruvate Kinase Deficiency (PKD), and other chronic haemolytic anaemia's

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Pyruvate Kinase Deficiency (PKD) is a rare hereditary disease causing severe haemolytic anemia. Having PKD, is not just about the physical effects. Often doctors look mainly at the blood results and other measurable effects of the disease, but there is another side that is also very important; the psychological effect for the patient and their families. I am a mother of 2 beautiful boys and beside that I am lots of other things, but I am also a patient with PKD. During some phases of life, this order wasn't so clear and I felt more a patient than anything else.

Insecurity

Young parents who first step into a world of blood, hospitals and medical terms, experience a lot of fear and uncertainty. Most of the time they will trust the doctor to give them good information, but with very rare diseases like PKD a lot of doctors have no idea what they are doing. The knowledge about PKD is not great and most of the parents are not well informed at all. This gives an even more insecure feeling because knowledge is very important. A child with a severe haemolytic anemia like PKD is not a normal child but it is not disabled or very sick either. However they can be very sick very fast. Because of the lack of information and the lack of references on what you can and can't do, life can get quite challenging. A child with PKD is in many ways no different from a normal child but their body will slow them down. For parents it is hard to find the way to motivate their children because of that. They need to get to know the child and try to read their body and then teach the child to do the same which is not an easy task.

Discrimination

The Yellow Skin-colour affects a lot of people with haemolytic anemia's like PKD in childhood and in later life. People get stared at, bullied and are asked what is wrong with them all the time. Going out every day in a world where people confront you with something that is completely out of your control, can have a damaging effect on everything. Some get so traumatised by their skin colour; it is a real burden in later life. They feel so ugly that they are afraid of having their picture taken and some people really have doubts if they will ever find a partner in life .

Building up a life

Young adults with PKD just starting their adult life often feel that they can do anything. But then when they start a job, they feel this is too challenging. Or they question if they can start a family or not. And for a lot of people with PKD their bodies then slowly turn against them and they feel more tired than ever. Suddenly they are challenged again with new questions that a lot of doctors have no answer to.

Not only blood, but also knowledge and guidance

So the main thing that people with PKD and other severe haemolytic anemia's need is knowledge. And then after that they need guidance. They need to have people around them that know their story. But also people that can help them deal with ordinary daily things. Specialised psychological help, specialised physiotherapy all kinds of disciplines that can help parents and patients to build up a life and deal with the everyday challenges living with a severe haemolytic anemia is giving them.