Ariella's Story

Ariella wrote her own story.

My name is Ariella and I am 29 years old. I live with my husband of 3 years and I have a rare form of dwarfism that I was born with called Ellis Van Creveled syndrome. This means I have short arms and legs but my torso is that of an average height person. My husband also has dwarfism but a different type called Achondroplasia.

My parents did not know I was going to be short statured—which is the politically correct name for this condition—as there were no tests done back in the 1980’s. When I was born I was premature and very tiny with severe heart problems and I was in the incubator for months.

When I was two-and-a-half I was taken to Melbourne to have open heart surgery to fix my heart. My parents were told I was lucky to be alive and even with the surgery my life will be complicated. They were also told that I would need another open heart operation later on in life probably when I would be about 20.

I overcame the odds and finally had my second surgery at the age of 25 as I was becoming very sick and I was lucky to survive the operation. I am now currently on two different forms of medications to prevent another operation, however the doctors are certain that I will be having another operation either this year or next year.

When I was a child I also had severe knocked knees which were surgically altered from the age of 14 over two years, using Elizeroth frames done by a surgeon in Melbourne. My whole life has been one surgery after another and although I am used to constantly being at doctor’s appointments or visiting hospitals for different procedures, I do get very fed up with this and often wish life was a little bit simpler.

Throughout my childhood I never saw myself as different from anyone else, I was just me. I did everything all the other children did, I just did things differently. I played sport, did ballet and tap dancing, enjoyed gymnastics and had lots of fun doing all of these activities.

When I got to primary school, I began to notice the difference in myself especially when the other children in my class would try to pick me up thinking I was a ‘doll’. I asked my parents why I was different from all my friends and they said “because God made you this way and you are special”.

So I accepted this answer and that was that. All of my primary school years were great—I had lots of friends and because I stood out everyone knew me so it was great because everyone at school looked out for me and if someone teased me then they would jump in and defend me. I was rarely teased and I if I was then I never noticed. Even now when I’m in public I don’t notice when people stare.

When I got to high school it was a similar situation; everyone knew me because I stood out and I also was involved in the Rock Eisteddfod where funnily enough I was the lead character in the production. The whole group of students who were involved were really great and supportive towards me and helped me with whatever I needed.

The impact of my disability on all aspects of my life is nothing too difficult. I am a qualified Child Care Professional and work with the 2-5 age groups in my centre. I am also 5 months away from finishing a Bachelor of Early Childhood Education where I will be able to teach 4-8 year-olds in kindergartens and schools.

This is the best profession for me as I love working with children and I especially can relate to them due to my size. The children love the fact that I can actually get in and 'play' with them on the playground or with the dress ups. I also love the honestly children give you.

I remember last week one of the children in the preschool room asked me why I was so little, so I replied: "I was born little and there are different sized teachers, little teachers like me and big teachers like the other staff in the room." The child sat there and had a think then replied to me by saying: "No Ariella, it is because you don't drink enough milk." I had to laugh at how innocent they are at that age and how serious he was that I was incorrect and that it was me not having enough milk that is making me short.

The staff at my work are great and very supportive of my 'disability'. I have a fold-up step which I carry with me so I can easily reach items in the room and I have often joked when one of the staff is unable to reach something by saying, "would you like my step?" Unlike some people who have dwarfism, I can laugh at myself and point out my difference without having a sense of shame or embarrassment.

My personal goals at the moment are to start a family, because I love children and I especially would love some of my own. However, at this point in time I cannot have any children until my heart is fixed because the pressure of a baby would cause a lot of complications to my heart and both of us would not survive.

The next goal is to finish my degree and get out and teach so I can finally do what I love, which is teaching children.

The factors that have enabled me to achieve my goals are support from my husband, family and friends. The only barrier towards my goal of starting a family is my health. As I mentioned earlier in my story, I currently need another operation on my heart in order to maintain a level of health that will be safe enough for me to live a better life. So once this operation has been done and I am recovered and back to 'normal' as they say, I can begin to achieve the goal of starting a family.

The main tip or hint I can give to anyone who has dwarfism is to make sure you have a close circuit of people who can support and help you. This especially applies to people who may feel scared about being this way or alone. Believe me, you are not alone, there are people who can give you advice and support.

One of those places is Short Statured People of Australia (SSPA). This is an organisation which provides support and information for people or families who have someone who is short statured. I have been a member since I was three, and I know it has helped my parents immensely with support from families in the same situation, and adults who are short statured who can provide and insight into what will come.

They also have conferences you can attend to meet other people and families in relation to short statured people and their needs. It is also a way for younger children to the mid-teens to be able to meet other children who are 'just like them', and they can discuss any problems they may have with someone who actually knows what it is like to be in their shoes. I have many friends who I have met at these conferences, and funnily enough I met my husband from one of these conferences.

Overall, I am proud to be who I am and although my life is difficult some days I would not change it for anything. Finally, I have never taken anything for granted because I know how precious life can be, considering I am lucky to be still standing here today telling my story.

Disclaimer

This website has been developed by Purple Orange (the shopfront of the Julia Farr Association) to provide public access to information that may be helpful in respect of disability issues.

While our goal is that all the information on this website is accurate and verifiable, we cannot accept responsibility for the accuracy, completeness, or relevance of the information to the purpose of anyone visiting the website.

We give no warranty that the information is free of infection by computer viruses or other contamination, nor that access to the website or any part of it will not suffer from interruption from time to time, without notice.

We have included links to other websites as a convenience to visitors wishing to find out more information about disability issues. Julia Farr Association does not accept any responsibility for the accuracy, availability or appropriateness to the user's purpose of any information or services on any other website.

The views expressed in these stories are those of the authors and not necessarily those of the Julia Farr Association Inc. or In Control Australia. We do not accept liability however arising, including liability for negligence, for any loss resulting from the use of, or reliance upon, the information expressed in these stories.

In some instances, stories may have been edited for practical purposes, but care has been taken not to change the author's 'voice' or the integrity or purpose of the narrative.

© Ariella Tairea 2011. Except as provided by the Copyright Act 1968, no part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means without the prior written permission of the publisher.