

Susan and Alex

Background

Married couple Susan and Alex live in Adelaide's north-eastern suburbs. Susan lives with Multiple Sclerosis and related psychiatric disability, and her husband Alex lives with incomplete paraplegia acquired when he was shot in the back while out rabbit shooting with a schoolmate in 1959.

Volunteer work

Both Susan and Alex volunteer to support others living with disability. They currently support an artist living with cerebral palsy to exhibit his art and provide assistance, through CARA, to people living with disability to cook and paint. Alex has also volunteered with the MS Society (where he met Susan) for 11 years. "Volunteering is absolutely wonderful," Susan says, "it gives me grounding in the realities of many people's lives." She says Alex has always been generous with his time because he believes what comes around goes around.

Employment

Alex describes himself as a proactive person. He drives a modified car with hand controls and has worked with the Highways Department for 15 years. Before that he worked in wrecking.

Susan is no longer able to work, but she ran her own business in art and telecommunications, and was a university lecturer before acquiring disability.

Re-assessing life and abilities

Living with chronic illness has changed the way Susan lives. “I can't do the art I used to do because of my physical limitations. I can't weld, pot or draw anymore ... I had to reassess my entire life. Now I'm studying a doctorate in Art and Disability, and plan to do some consulting work when I finish.” Susan had to work with the university to arrange a lecturer in Art and Disability.

As well as physical changes, Susan had to re-assess her life after developing psychosis. “I'm in the one per cent [of people living with MS] that gets psychosis because of frontal lobe lesions. That really affected my work. I lost my business because I couldn't realistically foresee what was happening and I was paranoid.” Now, Susan sees a psychiatrist and takes medication to manage her symptoms.

Alex has also had to reassess his life. “I've never worked with anybody in a wheelchair except one person living with quadriplegia,” he says. “I've never seen myself as having a disability; the way I look at it I've got ability to do things. I would advise people to think about what you can do, not what you can't do.”

Susan and Alex both have a positive view of the future: “Our disability doesn’t hold us back a lot. If we didn’t have each other, I think it would be a different world ... a very isolated world.”

Financial strategies

Susan and Alex receive the Disability Support Pension and have implemented strategies to manage financially, such as avoiding credit cards and socialising within their means. “We manage by not doing a lot socially because it costs money to go to pubs, clubs and theatres. We go to galleries because they're free.” Susan also enjoys the Adelaide Fringe Festival and goes to one show each year. “Last year I went to see a woman living with cerebral palsy who was a very good comedian. We try to support people living with disability with their art.”

Pride

Susan is proud of overcoming disability and finding new ways in life, yet Alex has rarely felt proud. “I've never considered myself to be proud of anything. Some people have chips on their shoulders, I had a forest, but I got over it. My Dad taught me to stand on my own two feet. He taught me the right things in life, taught me not get into trouble, not to break the law and we never hit one another.”

Friends, family and loneliness

Susan was always very independent and has a supportive family. When she was younger she moved to Sydney, and later managed her own business. When she became ill, she didn't know what to do for a while. "I was alone and I didn't have any support whatsoever. I remember I woke up one morning and couldn't walk. So I crawled to the bathroom, took the bathroom stuff off the bathroom stand and used it as a support to walk down the hill to Centrelink. That was the only place I knew where I could get help." From there, she sought assistance from the police who referred her to a nurse who organised a walking frame and introduced her to the Return Services League (RSL).

"The way I came out of it was finding friends. If you're afraid of going out, I would suggest joining a group. I learned that having people in your life is very important and disability can be a very isolating thing."

Suggestions for others

Susan says she's learnt to accept living with disability. "It took me two years to learn to accept it and appreciate the impact it has on my life. The mental reassessment is much harder than the physical reassessment." She says it was also important to be in charge of her health, "My advice would be never accept when a doctor says they can't do anything for you. Always get a second opinion and find a new direction". And her final piece of advice is to never give up. "Don't take

no for an answer. Find the right organisations to help you and reach out for assistance when you need it.”

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.

© Susan and Alex 2014. (Copyright resides with the original authors) 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.