

Book Review

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The Selfish Pig's Guide to Caring

H Marriott

Publisher: Polperro Heritage Press Price: £9.95 (£11.00 inc. P & P from Publisher), ISBN: 0954423313

There is, quite rightly, a wealth of information about *disability*. Disability itself has medical, social and legal definitions or models. The medical model uses the World Health Organisation definition and the simplified working definition is the International Classification of Impairments, Disabilities and Handicaps. The focus is on functional difficulties and the distinction is drawn between impairment (failure at the level of organs or systems), disability (which refers to reduction or loss of ability to perform an activity in the manner considered normal) and handicap (the social disadvantage resulting from an impairment or disability). The social definition draws a distinction between an individual's specific impairment and their disability so that a person with an *impairment* becomes *disabled* when they find themselves excluded from mainstream activities. The third definition is the legal definition and this includes the rights of the individual. In the United Kingdom, the Disability Discrimination Act states that a person has a disability (for the purposes of the Act) if the person has a 'physical or mental impairment which has a substantial and long term adverse effect on his ability to carry out normal day to day activities'. This is all very important particularly when it comes to questions about settlement of legal or industrial or insurance claims, etc, assessment for resources and state benefits, etc but this vast and intricate field of disability is of little help to the carer. If only as much intellectual effort had been applied to the dilemma and predicaments of those who are directly responsible for people with a disability.

The plight of carers is appalling. In the United Kingdom, according to Mencap, four out of five families with disabled children say that they are at breaking point. Although educational needs are covered by statute, the actual help from Health or Social Services departments is discretionary. For example, some local councils means test, others don't. In one part of the country, wheelchair users get the cheapest equipment whereas in another, they will get the best equipment for their particular mobility. Hugh Marriott gives some stark statistics: one in three carers has a problem paying the bills, one in five is cutting back on food, six out of 10

believe that the worry of caring has affected their health and more than half have had to give up paid work to care. I am quite sure that these bleak facts apply to all countries and not just the United Kingdom.

Hugh's wife Cathie developed Huntington's Disease. When the symptoms began to appear, Hugh and Cathie Marriott sold their house, bought a sailing boat and set off to sail around the world. When they returned, Hugh Marriott decided to write a book for carers. As he states 'I didn't write this book because I am a trained journalist. I wrote it because I am an *untrained carer*'.

The book is full of information. Much of it has been said before but never with so much vitality and wit, and not in one handy volume. The writing is clear and forthright (and, at times, blunt). The topics are illustrated throughout by David Lock with amusing and appropriate cartoons.

Marriott deals with topics that you don't usually find in medical text books such as thoughts of murder, coping with the responses of friends and the failure of understanding in official circles. The chapters on sex, coping with continence, trying to get information, etc are quite outstanding.

At a time when newspapers, Sunday supplements and books are full of boring and usually self-serving stories of how I coped with breast cancer or what my son's leukaemia meant to me, or how cancer of the testicles brought me to the knowledge of my inner self, this book stands out like a beacon in the miserable ocean of disability and chronic illness and *caring*.

One of the (many) strengths of this book is the section on 'Getting Information'. This deals with sources and categories. The sources include the medical profession, social services, occupational therapy, Citizens Advice Bureau, specialist support groups, carers support groups and the internet. This is an excellent guide and practical and it is a true guide: under headings such as Caring Techniques or Modifications To The Home or Respite Care or Toileting, the book gives a guide to the appropriate source.

There is very little to criticise. I would have liked to have seen a chapter dealing with the spectrum of human ability and the fact that people with disability would like society to focus on their *ability*. Most, if not all, disabled people want the focus to be on their social relationships and, as far as possible, medical intervention based on their capabilities. They wish to be accepted within

society on an equal footing and with equal rights. The only other criticism I have is with regard to information. In the United Kingdom, the *Disability Rights Handbook* is invaluable. Disabled people are disabled in many different ways and the Special Olympics and sporting organisations may be of great help to carers.

I have never come across a book like this and I recommend it wholeheartedly not only to people

who have the responsibility of caring (and that includes doctors, administrators, politicians as well as carers) but also to the people who actually suffer the disabilities.

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Editor *Spinal Cord*