

Z

ALZHEIMER'S
.....
A SHARED JOURNEY

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by
BERNARD GOSSCHALK

Expenses arising from the production and distribution of this book will not accrue to Dementia SA

The total proceeds from its sale will go to Dementia SA to assist in its work across all communities in South Africa

Bernard Gosschalk
Cape Town, SA and Manchester, UK
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ACKNOWLEDGEMENTS

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I could not have survived these last few years without massive and concerned help from our close friends. In particular, two friends and doctors, Shirley and David; Jim and Jean; Helle, Pippa and Sonia, Leonard and Vera, Gersh and Lys, George and Sonia; Mark and Muriel and many others too numerous to mention. Some of them are unfortunately no longer with us, but all gave me unstinting support, warmth and encouragement. I can never ask for more. Also carers, nurses and workers in mental health and in care homes in Manchester. and Cape Town. Finally to Debbie who talked me through a first draft, no easy task for her.

In the latter city, two inspired and inspiring workers in the field: Karen Borochowitz and Harris Burman, both of whom changed my mood from one of utter darkness and despair to one of “hope”. The inverted commas will occur frequently in this story. I have learnt that the English language does not cater adequately for the full range of meaning and emotions when discussing dementia.

Inevitably, children are among those who suffer most from a role reversal in which a father or mother becomes the person who requires total support.

Z’s family have had to make an adjustment to their lives to cope with an illness in one person which effects all. No one outside a family can really appreciate just what this entails.

My own four children, their spouses and twelve grandchildren, have all in, their own way, tried to lift me from the valley of despair. They could not have done more.

Barbara Mueller and New Voices Publishing in Cape Town have had the difficult task of assembling a mix of emotion and reality – logic and Alzheimer’s never march hand-in-hand.

I do not know which is worse: “living” through Alzheimer’s or the agony of writing about the experience. It is deeply etched

into the hard drive of the mind. However, all the inaccuracies, inconsistencies and contradictions are my own. Do not believe those siren voices which suggest that it is therapeutic. “Normality” is unattainable.

Finally, this is for Z who has not got from life all that she so richly deserved. It is her story. I hope that I can do it justice.

*Bernard Gosschalk – Manchester and Cape Town
August 2008*

FOREWORD - THE CARER

The Carer is pivotal in the multi-dimensional partnerships that surround their charge; among them domestics, nurses, allied health professionals, Non-Profit Organisations, law-makers, doctors, researchers and the pharmaceutical industry. The harmonious co-ordination of these vectors (or more often, lack of) poses many problems, some of which are more easily corrected than many others. A root-cause as expected is the issue of money and the fact that mental health remains the Cinderella of the National Health budget.

This book provides a timely insight into some of the complexities and stresses that surround caregivers. Caregivers are afflicted by a 50% depression rate compared with 18% in their non-carer counterparts, and have twice the hospital admission rates. Then too, they not infrequently pre-decease their loved ones. Bernard Gosschalk conveys the reasons for this poignantly.

For those who thought the grass to be greener in the United Kingdom, Gosschalks' exposé makes one think again. If he achieves one objective in his journey, it is the re-awakening and appreciation of the support available to us, especially from those dynamic, selfless volunteers that form the heartbeat of support organizations such as Dementia SA. It is they that provide us with that curious mix of emotional support tempered by reflective reality.

Dr. Felix CV Potocnik

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April 2009

INTRODUCTION

This shared journey into the strange and tragic world of Alzheimer's began in 2002 and covers some of the history of our lives in Manchester and Cape Town.

I say some, because at the best of the times, memory is so flawed. Under the pressures and stresses of the illness, not only the mind of the sufferer is impaired.

The partner too, enters this tragic world and suffers in a different sense: the grief at seeing a loved one decline is almost beyond belief, physically and mentally, not to mention one's inability to affect the process or perhaps, worst of all, the experience of a "living" bereavement. One bereavement is enough. Even writing these few words is to reopen all the agonies. Why write them?

Karen Borochowitz, a worker in the field of dementia, suggests:

"You are so right about the English language and especially the difficulty we experience when trying to convey emotion. One way is to try to find words that accurately convey the emotion and the context so that the reader can understand the profound experience ... it is easier said than done. The bond you and Z share is special. There will be plenty of tears, Bernard, - we never give up mourning ...

Perhaps your courage and acceptance to explore all this in writing might in turn help and inspire others when dealing with this cruel and insidious disease".

I hope that she is right.

YOU'RE MY WORLD, MY EVERYTHING

THE WORLD OF THE MIND ...

THE WORLD OF THE SENSES ...

THE WORLD OF LOVE ...

MANY SOFT KISSES

... and we found each other!

in a wry smile
curved lips
and one soft kiss

All love, my darling

Z.

FOREWORD

“There are paradoxes in life we cannot explain”
– George Steiner

Stories do not necessarily have beginnings and endings. This one too has neither. But one has to start somehow and, in my own case, with someone. My father, Morris, was very badly gassed in France near Bethune in 1916. So badly wounded was he that the medics floated him on a hospital barge across the Channel to England where he spent two years in hospital. In 1918 he was discharged, a white, walking skeleton and officially given six months to live in the English climate. He bought a ten-pound, single ticket, steerage, to Cape Town on the *Walmer Castle* and was admitted to Somerset hospital.

There, he lay on his back on the beach in the sun for two years until his lungs were sufficiently healed for him to consider rebuilding his life. He lived to age 85. Today, when I pass that anonymous beach, I always pause to remember him. It is far more moving than any gravestone.

I grew up on his story of life in the army where he served in an artillery regiment. He had the gift of inspiring me with tales of that inhuman and unbelievable war when mankind took leave of its senses. Cousin Kaiser against Cousin King, Christian against Christian, “the war to end war”. Perhaps his courage and tenacity in life would inspire me in different fields later.

o o o o o

The second person also did not survive to know this story. We had forty wonderful years together, a dream marriage. She too taught me about survival against the odds.