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## INTRODUCTION

*Carol and Jack*

*“At least two kinds of courage are required in ageing and sickness.*

*The first is the courage to confront the reality of mortality—the courage to seek out the truth of what is to be feared and what is to be hoped. Such courage is difficult enough. We have reason to shrink from it. But even more daunting is the second kind of courage—the courage to act on the truth we find. The problem is that the wise course is so frequently unclear.”*

*—Atul Gawande*

This is the guide which we wish had been around when we were first taking on responsibility as carers. We were often uncertain of what to do, bewildered by the decisions that needed to be made, unfamiliar with the kinds of resources needed, looking for help and not always finding it.

The years during which we were carers were amongst the most daunting and disturbing in our lives. It was only afterwards that we realised that not only were our experiences made more difficult because we had been so unprepared and ignorant, but also that what we went through was typical of so many others’ experiences. Our individual legal and finance knowledge meant that we were more knowledgeable than most about some of the issues we had to negotiate. However as a carer you are called on to make decisions about medical, legal, financial, and personal matters, frequently in the same timeframe. Each of us found that on occasion our lack of specific knowledge

related to aged care issues caused frustration and wasting of time. At times it led to decisions we later regretted.

Most of us will only need to care for a small number of people in our lifetime. The caring role is not generally something we think about ahead of time, and it's not something that comes naturally or easily to many of us. Yet it can completely take over your own life. It is likely to leave you uncertain and unhappy. If you are like us you will feel that your life will never be the same again.

Our purpose in writing this book is to share our experiences—and those of the many others who were so eager and generous in relating their own—and the knowledge we have gained. Our hope is that we may be able to make caring a little easier for others who have to meet the same challenges and want desperately to do their best for the persons for whom they care. Because the worst feeling is when you feel that despite your best efforts and good intentions you have not done the right thing, or made the best choice

“Carer” is a sometimes confronting concept, and we were slow and somewhat reluctant to use it to describe ourselves. In these pages we use it to include both the person who loves and is concerned about someone close to them, and the one who does some of the work of physically looking after them or takes responsibility for managing their affairs or makes the arrangements which ensure that other people will do that.

The experience which changed our lives was caring for our long-time friend Kim. At an earlier time Kim had been a carer herself, when her comparatively young husband was diagnosed with multiple sclerosis. They had no children and no brothers or sisters so that after he died she was reliant on friends for support.

Kim was in her late seventies when she became one of the three hundred thousand Australians with dementia. She was not an obvious candidate; she took a long daily walk and her life was full of intellectual stimulation (so much for the idea that exercise or crosswords will immunise you)...This is what Carol had written about her (for another publication) not long before she began to show signs of memory loss and confusion:

*“Kim nursed her husband through a long illness and though she had no family at all after he died, her life since then has been rich and full. Kim gets involved with politics and in her local community, does courses, and goes to the latest films and theatre. She knows Sydney’s public transport system like the back of her hand, and can always tell you the best places to eat. She is widely read and always interesting. Many people would say that Kim has had a hard life, but we have never heard her complain. Our daughters describe her as their role model for when they reach her age.”*

Only a few years after that was written, it became clear to everyone who knew her (and she had a wide circle of friends at that time) that Kim was unable to continue safely living at home. She left the gas on, locked herself out, and forgot to look before crossing the road during her daily two-kilometre walk. The less said about the fact that she was still, apparently, driving her car without attracting attention (we did not know about this at the time), the better. She moved into residential aged care and for a time she was able to enjoy the view from her room looking out over her beloved Manly. She was still relatively sprightly and walked without assistance. However one day she fell and broke her hip, the surgeon “must have nicked a nerve” (as one of the staff euphemistically trivialised it) and she never recovered, physically or mentally. Her dementia deteriorated rapidly and visibly and she ended her days confined to a wheelchair in her nursing home.

How do we make the transition from independence to vulnerability? No-one ever says “I have done with managing my own life, I’ll give up mobility and dignity.” No-one volunteers suddenly to be denied the possessions and experiences they once thought were the most important parts of their life.

Yet thousands of carers spend up to ninety hours a week looking after the demented or helpless person they still love. We have met several in their eighties who are full-time carers, and who do their

job with stamina and seemingly limitless stores of patience. In fact most people who are aged and disabled or who have dementia are not cared for in institutions. They are looked after at home by their families.

However for many there comes a time when the only way that round-the-clock care can be provided is in residential aged care.

Nursing homes in Australia house tens of thousands of people whose life is marked by profound losses—of space, of choice, of companions, of stimulation, of enjoyment of food, of pleasure in music or reading. Sometimes those losses have occurred without warning and without acceptance. Many of those people have family or friends who grieve for them, feel guilty about them, and worry about them, every day.

Like a large number of nursing home residents, Kim suffered from disabling dementia. She opened her mouth, looked you in the eye and out came a stream of incoherent rambling which made not the slightest bit of sense. An exhortation to you to look out the window at something that wasn't there was followed by gibberish, delivered with grave intensity and seeming concentration. Yet she still recognised us when we arrived for a visit and never forgot that such social interactions begin and end with a hug or a kiss. And just when you thought she had lost track of the pattern of your visits, or did not notice what you did (or respond to it), she would ask, "Have you brought me the usual little something?" Amongst all the unconnected murmurings and lack of communication, it is those moments to which we clung. If we had abandoned her to her fate and felt that there was no longer any point in continuing to visit, we would have missed the time she said as Carol was leaving, "Be careful crossing the road", or the day she suddenly said her husband's name, twenty years after he had died and five years since she had herself last mentioned him. "Poor old Rolf", she said sadly and shockingly.

Those are the reasons we kept coming to visit her, and wanted to do so. Brain cells may have been destroyed, and yet it is as though the

necessary connections for memory and conversation can still at times be made, or re-made. Amidst all the demented behaviour, the dessert stirred into the main course, the inability to put on even a cardigan, she was still Kim. She still mattered. She deserved better than she sometimes received. How could we best look after her?

Life in the twenty first century is generally hurried and there is all too much encouragement for superficiality or self-focus. Many, in fact most of us, are isolated and ignorant of important aspects of the lives of others. We may, for a long time, remain protected from the harsher truths of existence. We had no knowledge of or acquaintance with dementia—indeed, with any of the hard issues connected with ageing, until we found ourselves looking after Kim. Our ignorance caused her harm on more than one occasion. This is not an unusual tale.

Yet in the course of writing this book (life being as it is, it took several years) we have come to believe that change is coming. As the population bulge of the Baby Boomers is increasingly called on to care for their parents' generation, the issues of caring are becoming more prominent. Several popular and successful novels which have been published while we have been reflecting on these issues, have dealt with the very same matters raised in its pages—Helen Garner's *"The Spare Room"*, Michelle de Kretser's *"The Lost Dog"*, Susan Duncan's *"The House at Salvation Creek"*, Debra Adelaide's *"The Householder's Guide to Dying"* are just a few. In the same time frame Caroline Jones published *"Through a Glass Darkly"*, a beautifully written account of grief and loss of her father, and Sue Pieters Hawke has written *"Hazel: My Mother's Story"* which focuses on Hazel Hawke's Alzheimer's disease. A whole slew of recent films look at the same issues. We once wrote a book on working parents, and at that time it seemed the whole world was pregnant or raising small children. Now, two generations later, so many seem preoccupied with old age. Then, we were made aware of the amused lack of interest on the part of those who were childless, or who had graduated from the ranks of young parents. None of us can have the same luxury in relation to issues of ageing and caring.

Sadly, the dislocation and conflict which are so frequently a part of modern family relationships, coupled with the trend to smaller families and childless couples, will mean that many ageing people will not be able to rely on family to provide companionship or management skills to steer them through the decision-making, and the nurturing that seem to us such an inevitable part of successful ageing. More awareness and engagement by the community in supporting its older members, and an emergence of more compassionate and hands-on service providers, seem to be the only possible answers.

### **A note on the resources detailed in this book**

The whole purpose of this book has been to assemble in one place information and resources which can help carers in the situations in which we found ourselves at sea. Much information can be found on the Internet from public and private sources, and there are many publications which provide detail to a degree which we cannot do here. In the main we found many government websites to contain so much “stuff” that it was difficult to find answers amidst what seems to the harassed enquirer to be too much information. Yet we were impressed and greatly assisted by some of the wonderful books that we found on specific subjects. Many of them, even if old, large, or out of print, can be bought inexpensively and fast (and frequently with no attendant postage costs) through the book finding resource: <http://www.bookfinder.com>.

### **A note about the terminology of aged care**

The changes made by the Federal Government to the aged care sector in 2014 are dramatic, and not yet complete. Particularly in the area of costs and charges (either for care at home or to enter residential care) there are profound differences which mean that if you had some prior knowledge you need to be very clear about the extent to which the situation is now different. Also, because the changes are quite dramatic, further changes continue to be made as the new system is bedded down. There is new terminology used at a fundamental level: for example “accommodation costs” and “accommodation bonds”

have been replaced by “accommodation payments”.

It is easy to become confused about the terms used to describe different modes of aged care living, because the terminology has been changing in recent years. You still hear consumers and professionals alike refer to “hostels” and “nursing homes”, although these are now more often called “low care” and “high care” residential aged care institutions. Typically, “hostels” or “low care facilities” provided separate rooms for residents, with optional cleaning and laundry services and meals in a communal dining room. More recently the term “nursing home” has frequently but not necessarily been replaced by “residential aged care facility” in legislation and industry usage. There is an equal amount of confusion about what was previously called “self-care” accommodation, that is, units within or adjacent to an aged care facility in which a resident could live without necessarily calling on help with daily living but was able also to access services such as cleaning, laundry and prepared meals. These are now more often called “independent living units” (“ILUs”). “Supported living” or “serviced apartments” are other terms sometimes used for accommodation units for those who routinely require assistance with daily living tasks such as cooking and washing, yet wish to remain as independent as possible.

As for the terminology we use for the principal characters in this book, we have hesitated to use the term “elderly” because it feels to us to be often used in a patronising or condescending way. We have used “ageing” more often because we are all indisputably getting older and because by definition the people this book is about are people who need care as they age.

We are aware that for most people it is their parents who need care but there are also many who are looking after other family members or friends. So we have used a variety of terms at different times (“your relative or friend”, “your family member”, “the older person”, or “the person you love”) and hope that you will understand the need for such expressions, and feel included within them.