

Being A Good Carer

An invaluable guide to
looking after others -
and yourself

Amanda Waring

SOUVENIR
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Foreword

Amanda Waring has done so much to raise awareness of the need for dignity, compassion and kindness in care services, drawing on her personal experiences and a gift for communication. It has now been many years since she published *The Heart of Care – Dignity in Action: A Guide to Person-Centred Compassionate Elder Care*. She is, without any doubt, well qualified to build on her immense knowledge and learning to share understanding of the role of caring in this new book, *Being A Good Carer*.

Carers are vital partners in our system of social care. But sadly this is rarely acknowledged and, as a consequence, their contribution is not always valued as it should be. A recent report on ‘The Human Rights of Carers in Northern Ireland’ published in 2014 by the Northern Ireland Human Rights Commission stated:

Caring can be rewarding and fulfilling as well as demanding. What is important is the need for recognition of the role being played and the support that should be available and easy to access. Too often, obtaining support can simply be a further additional struggle to overcome. Carers are not a homogenous group. Carers can be all ages from children to the very elderly who are looking after family members. Each carer is an

individual who has his or her own story to tell and particular needs.

Whilst there is much that is shared about the experience of caring for a family member it is helpful to be reminded that every caring situation is different. People and their circumstances vary and every caring situation is a personal journey. It is my sense that *Being A Good Carer* is part of the personal journey of Amanda Waring. The reason the words are conveyed so powerfully is because we know that they are drawn from a wealth of personal experience – she really knows what she is talking about! She is able to use her knowledge of what it is like to provide personal care and support to offer straightforward practical guidance for others.

Amanda's story is well known: the experience of witnessing a lack of dignity and compassion in the care received by her mother, actress Dame Dorothy Tutin, turned her into a reluctant, but strident, campaigner. As a campaigner she has turned a negative situation into a positive force to improve the quality of care of older people through her films, teaching and writing. She has used her own resources and networks, passion and charisma to make change. Her first film 'What Do You See?' which features Virginia McKenna makes use of the poem 'Look Closer' by Phyllis McCormack and manages to convey in just ten minutes so much about how important it is to always see the person in every caring interaction. To always see the person behind the presenting condition or frailty or confusion. I was proud to promote the film to innovative not-for-profit care providers within the membership of the National Care Forum and to encourage all registered home managers to make use of the film in training their staff. Keeping the individual at the heart of care is

absolutely fundamental to best practice. In fact, best practice in social care is not possible without it.

Carers do make an immense contribution to society by providing care and support to family members and for some it is a lifelong commitment. We know that at least 6 million people in the UK are providing care and without them the system of social care would probably collapse. However, too often carers feel neglected and undervalued. Getting information at the right time and in the right way can be difficult for many carers. *Being A Good Carer* therefore makes an important contribution to the need for information. It is important to remember that most care takes place in private by people who may not actually define themselves as 'carers'. It is, for the most part, a personal thing and for many carers the term 'care' probably doesn't adequately describe what they do, day in and day out. I believe that their contribution to personal well-being, quality of life and health is vital and deserves to be acknowledged as such.

Amanda's writing style makes it seem as though she is speaking directly to you. I have no doubt that *Being A Good Carer* will add significantly to our understanding about how best to offer emotional and spiritual support in practical ways. Her discussion of grief and loss is clearly informed by a depth of knowledge.

The book covers personal care and daily living, care planning, dementia and end of life care in a straightforward way. The fact that chapters are devoted to emotional and spiritual needs as well as caring for yourself is an added bonus. I was especially pleased to see that Amanda has included a chapter on creativity and activity in the book. Given her own background in the creative arts she is uniquely qualified to highlight the contribution that art, in all its many forms, can

make to personal well-being and quality of life. And this is true for both people receiving care and support as well as family carers.

Although the primary readership for the book is likely to be informal, or family, carers, the contents will be just as relevant to paid professional carers. The fact that it is written from the perspective of a carer accentuates its value, in my view, as a source of continued learning.

The delivery of 'compassionate dignified care' is a journey towards quality. A journey which has no end as our efforts to attain and maintain standards continue to develop. Our understanding of the importance of care and support to individual quality of life and well-being arguably is getting better all the time. This practical book is a valuable additional resource to the social care library. I hope it is widely read and its lessons used to make a positive difference to the lives of people in need of care and support.

Des Kelly OBE

Introduction

Welcome!

My name is Amanda Waring and I am writing this book for you, the carer. Whether you are a professional carer or a relative caring for an elder loved one, I hope *Being A Good Carer* will be an invaluable and inspiring handbook to ensure that you give the best care that you can, whilst supporting yourself to do this. The year 2020 is bringing so many challenges for all of humanity with the arrival of the coronavirus/COVID-19. We all will have to care for each other, whether remotely or together, and maybe even support loved ones through end-of-life transitions. This book will guide you through and be a companion for you to turn to in times of great need. *Being A Good Carer* is easy to read and includes practical hints and tips, checklists, exercises, solutions to dilemmas, anecdotal advice, voices from the experts, and unique ways to deliver compassionate dignified care to older people right to the end of life, and after death. *Being A Good Carer* addresses spiritual and emotional needs and heartfelt ways to connect with those in your care.

If you are a professional carer my hope is that within these pages you find what you need to educate, motivate and reassure, whilst inspiring you to foster deeper relationships with

those you care for. Please ensure that you read the section on **How to Care for Yourself and Prevent Burnout** for you are as important as the ones you care for. If you are a relative caring for an elder loved one please ensure you read the section on **How to Care as Relatives for Loved Ones** where I hope to walk you through your caring journey, addressing fears and anxieties, providing solace and support, and to remind you that you are not alone. Each section in this book will provide you with more detailed and in-depth ways to provide care for your loved ones so please enjoy exploring the whole book.

How to use this book

I have grouped the material into eight sections that can be read in any order depending on your particular needs. Each section shares knowledge, ideas and best practices for your continued learning and understanding to best support those you care for and those you love. There is also an appendix with resources for professional home care workers.

You may notice that there is some cross-referencing and gentle repetition; this is to allow readers to dip into the sections most relevant to them, while ensuring that no important principles are missed. Furthermore, I think it is important to indicate where the same point applies in a different context.

How to Care for Relatives as Loved Ones

Guidance and tips on supporting a loved one with dementia and at end of life in their home or with you, taking positive steps, who cares for the carer, changing relationships, loneliness, when and how to get help. Understanding the

stages of death and ways to ensure the 'living' in the dying process, addressing regrets, end of life wishes, ways to provide solace and comfort, rituals and ceremonies to help grief and loss, transforming grief, helpful organisations, moving forward . . .

How to Care for Someone with Dementia

Guidance and tips on positive communication and engagement, understanding their world, solutions to common issues and behaviours, supporting sensory challenges, support for night-time issues . . . Please note that in **each** section as well as in the section on how to care for someone with dementia there are hints and tips on dementia care.

How to Support Personal Care and Daily Living

Guidance and tips on intimate care, bedpans, bathing someone with dementia, dressing, teeth brushing, hoisting, mealtimes, appetite solutions . . .

How to Care for Yourself and Prevent Burnout

Guidance and tips on ways to prevent burnout, recognising signs of compassion fatigue, reigniting compassion, self-care daily checklist, positive solutions to restore emotional and physical balance, how to keep motivated and sustain morale . . .

How to Support Creativity and Activity

Guidance and tips for promoting well-being, creative arts, music as medicine, sharing meaningful activities for those with dementia, thinking-outside-the-box ideas, keeping on moving, learning new things . . .

How to Support Emotional and Spiritual Needs

Guidance and tips on recognising and addressing emotional needs at times of transition, providing spiritual and faith support, making things better, helping others feel needed, gratitude, heartfelt listening . . .

How to Give Compassionate End of Life Care

Guidance and tips on how to be with someone who is dying, pacifying fears, pain management, words to uplift, comfort and inspire, letting go, creating a peaceful environment, end of life care in dementia, forgiveness, physical care, the dying process, post mortem care, honouring and remembrance, supporting different cultures . . .

How to Ensure Dignified Care

Guidance and tips on supporting the dignity of another, addressing thoughtless behaviour, understanding dignity breaches and dilemmas, protecting your dignity, whistleblowing, upholding the dignity of those from the LGBT community and different cultures . . .

**Appendix I: Being a Home Care Worker and Appendix II:
How to Write a Care Plan**

Guidance and tips on practicalities and documentation, the Mental Capacity Act, what to do and what to avoid.

A personal reflection on my own journey with care and how I came to write this book

I was delighted to be asked to write *Being A Good Carer* after the success of my last book *The Heart of Care* for Souvenir

Press. I realised that many of my roles and experiences in life have provided material and inspiration for me to draw on in the writing of this book. For this reason I have included here some personal material first introduced in *The Heart of Care* where I feel it is particularly appropriate.

As a carer

I cared for both my parents till the end of their lives. I moved from London to West Sussex to be near them. I tried to give them the support that they needed but it was not always smooth sailing! My time with them was full of moments of love, frustration, laughter, despair, grief and healing. I learnt so much during that time, about them, myself, my limitations, my resilience, my fears and my capacity for love. My personal experiences help provide emotional, spiritual and practical support for you throughout this book.

As an elder care campaigner, filmmaker, author and trainer

After witnessing the lack of dignified care my mother, the actress Dame Dorothy Tutin, endured in hospital I sold my flat to make my short film 'What Do You See?' to train care staff about dignity and compassion in elder care. I was invited by the government to initiate the Dignity in Care campaign and since 2005 I have spoken and trained around the world on elder care and in the media on improving elder care. Throughout this book I am delighted to share quotes and frontline knowledge from the thousands I have trained. I have also been able to utilise the experience of dear colleagues that I have met throughout my campaigning and teaching to add to all sections. I hope you will feel inspired to place compassion and dignity at the heart of your caring and to read the important chapter on dignity often.

As a soul midwife and carer to the dying

I have sat with the dying since I was eight years old, when I used to be taken by my granny to sing at the bedside of those who were terminally ill in the hospitals where she volunteered. Even at such a young age I seemed to have an understanding of what was needed through sound and songs, or holding that person's hand. It was as if I had done this before. I was not frightened. As a teenager I continued to sing regularly to those in care homes and hospices to help bring comfort and ease to elders in their final days.

From my twenties onwards I have undertaken many trainings and initiations and spiritual rites of passage. I have worked with different traditions and faiths, which has enhanced my knowledge and understanding of working with the frail and dying. When working in my role as a death doula, or soul midwife, I feel it is an absolute privilege to do this work. In the caring for a loved one and end of life care sections I share some of the ways I use to help support a dying person and those who are left behind. I hope you will read often the section on **How to Support Emotional and Spiritual Needs** to enhance your end of life care too.

As a celebrant

I have always wanted to change society's attitude to death and dying, to see if we could change the emphasis from the morbid aspects of death into a celebration of the transformational aspects of one's passing. From the time when I took my first funeral at the age of nineteen, becoming a celebrant provided me with that opportunity. As a celebrant I write and conduct funerals (and weddings and other rites of passages). In the caring for a loved one section I share celebration of life ceremonies, funeral wishes and grieving rites and

rituals to support you as you support others.

I can see how, even from the trauma of my mother's undignified care, much positive good has come. I have found ways to improve elder care through my film, books, celebrant work or by just 'being' with the dying. I can see the threads that have woven through my life bringing me to this point of writing *Being A Good Carer*. My wish is that *Being A Good Carer* be a practical source of comfort, connection and friendship to sustain you on your caring journey.

For info on my dignity, films and campaigning work please go to www.amandawaring.com and for information on my masterclasses and training go to www.theheartofcare.co.uk. For info on my work as a celebrant and soul midwife please see www.amandawaringcelebrant.com.

And last but not least

Thank you.

For all the care that you have given, and all the care that you will give.

On behalf of all those who may not be able to thank you due to dementia, ill health, incapacity, I want to give my heartfelt thanks for all that you have done, and all that you will do. To care for another human being is sacred and important work. They need you and this country needs you!

With gratitude,
Amanda Waring

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How to Care as Relatives for Loved Ones

‘The pain now is part of the happiness then.’

C. S. Lewis

This chapter is especially for you who are caring at home for a member of the family, to hold your hand, to be a friend, to provide emotional and practical support with extra hints and tips to assist your caring role, whether your loved one has dementia or they are being cared for by you at the end of their lives.

I cared for both my parents till the end of their lives. I moved from London to West Sussex to be near them. I tried to give them the support that they needed but it was not always smooth sailing! I was a single mother and, having moved from London, did not have a support network of friends and family, so I understand the emotional rollercoaster, physical exhaustion, and deep aloneness that can be overwhelming at times when you are caring for elder loved ones.

My time with them was full of moments of love, frustration, laughter, despair, grief and healing. I learnt so much

during that time – about them, myself, my limitations, my resilience, my fears and my capacity for love.

As our parents become older, more frail and less able we may see this as an opportunity to care for them at the end stages of their lives, with love and gratitude for the care and support they gave us at the beginning of our own. However, this reversal of child and parent roles can be difficult and unsettling.

‘It is difficult for me to relate to this vulnerable and frail person, where is the capable and caring mother I once knew? I know it must be especially confusing and at times frightening for her, but I miss my Mum.’

Anna, carer

Looking after elder relatives and loved ones can prove satisfying but also challenging as it will generally follow a sudden change, crisis, or deterioration in their health. You may also be struggling with caring for your own family and pursuing a career. Perhaps your relationship with your elder relatives is strained and fraught and this too can require delicate navigation so that resentments and bitterness do not build up.

‘Can we still have a relationship or only that of carer/patient?’

Dee, carer

Caring for yourself

However much care we give our elderly loved ones, a decline in health and strength, despite our best efforts, is so painful to watch. When caring for a loved one our life revolves

around that person, our world can shrink and it can feel like an overwhelming or impossible task. Add to this the complicated family dynamics as well as your own fear of losing someone that you love, either to dementia, a care home, or through death, and stress levels can become very high. Fifty-two per cent of carers have been treated for stress because of their caring role. So it is important that you find good coping mechanisms and strategies to help yourself.

Please read the **How to Care for Yourself and Prevent Burnout** section but also consider the following tips.

- Consult other family members to share responsibility. Co-ordinate times when family or friends could care for your loved one to give you a weekend break to rest and recharge.
- Delegate. Find ways to outsource some tasks to lighten your load.
- Consider using daycare to give you a break in the day. Could someone do your ironing or housework? Perhaps you could think about using meals on wheels.
- Join a support group. Spending time with others who understand can alleviate some of the loneliness and provide positive sharing of suggestions.
- Try meditation or yoga. There are lots of mobile phone apps that you can follow if you can't get out of the house. Headspace is a good meditation app.
- Keep physically active as it will strengthen your immune system and increase your production of endorphins and this will make you feel better.
- Build some **you** time into your day. Have a massage, go for a swim or a walk, visit a church, have tea with a friend.

Try to bear in mind your family and personal values when caring for a relative: our values are what we draw on to cope with the ups and downs of family life and can play an important part in how we care for them in later life.

Below are the details of some organisations you could approach for help and to lighten your load.

Royal Voluntary Service

Find out where your nearest local one is. They offer a range of services, including visiting schemes, home-delivered meals and volunteer drivers.

www.royalvoluntaryservice.org.uk

Revitalise

It offers special Alzheimer's holidays for people with dementia and their carers, which are subsidised by the Alzheimer's Society.

www.revitalise.org.uk

Tel. 0303 303 0145

Carers Trust

This is Britain's leading provider of support for carers and the people they care for.

www.carers.org

Age UK

Provides information, support and grants for all aspects of elder care and support for those looking after someone with dementia.

www.ageuk.org.uk

Advice line 0800 678 1602

Alzheimer's Society

It has information about caring for someone with dementia and offers an online forum.

www.alzheimers.org.uk

Advice line 0300 222 1122

Emotional crisis

It is quite normal to feel lonely, misunderstood, unappreciated and angry about what is happening to the people we love. Sometimes it becomes necessary to make unpopular decisions about 'what is best' for our loved ones and this can make us feel as if we are letting them down or even betraying them, which means decisions get delayed until a crisis forces our hand.

'The emotional fallout of anger, frustration, fear and anxiety overwhelms me.'

Trish, carer

'Guilt comes with the territory, always I felt I should be somewhere else, everyone got short shrift. Let alone taking time for myself.'

Elizabeth, carer

Guilt is a common emotion when caring for an elderly relative. How do you juggle your other responsibilities, like work and children, while caring for your elder parent? Feeling torn between the demands of adult children, grandchildren, our career and ageing parents can result in feeling overwhelmed, resentful, and ashamed at not coping. All kinds of complex reactions to problems and difficult relationships within

families can get triggered at these times. The situation can be even worse if you live a long way from your parents and you want to do your best for them but you also need to live your own life.

'I am worried. Can I cope? Where is the person I love in all this?'

Toby, carer

'It feels like he's leaving me and there is nothing I can do about it.'

Hannah, carer

This emotional turmoil can lead to stress, anxiety and depression. Do not suffer alone, reach out to friends, support groups, your GP and helpful organisations like the ones below.

Depression Alliance

Now merged with Mind, it helps people suffering from depression, offering information and advice as well as a network of support groups.

www.depressionalliance.org

Mind

Offers support to people in mental distress and their families.

www.mind.org.uk

Free advice line 0300 123 3393