

WORKING WITH **FAMILY CARERS**

Valerie Gant



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WORKING WITH **FAMILY CARERS**



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First published in 2018 by Critical Publishing Ltd

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British Library Cataloguing in Publication Data

A CIP record for this book is available from the British Library

ISBN: 978-1-912096-97-8

This book is also available in the following e-book formats:

MOBI ISBN: 978-1-912096-96-1

EPUB ISBN: 978-1-912096-95-4

Adobe e-book ISBN: 978-1-912096-94-7

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Cover design by Out of House

Text design by Greensplash Limited

Project management by Out of House Publishing

Printed and bound in Great Britain by 4edge, Essex

Critical Publishing

3 Connaught Road

St Albans

AL3 5RX

www.criticalpublishing.com

Paper from responsible sources

Acknowledgments and dedication

In writing this book I would like to acknowledge the following:

My family and friends for listening to my ideas and encouraging me, most especially Paula and Steve.

Colleagues and students at the University of Chester, especially Eve Collins and Mandy Schofield.

Family carers everywhere – you can do this and you can do it well.

Lastly, I wish to dedicate this book to my youngest daughter who has taught me more about caring than any textbook in the world could ever do.

Isobel – this is for you.

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Meet the author and series editor

Dr Valerie Gant (author)

Dr Valerie Gant is an experienced social work practitioner and senior lecturer at the University of Chester. Val has written and published on a variety of subjects relating to health and social care. Her personal experience of having a child with severe learning difficulties has both inspired and informed her in-depth professional knowledge of this area. An active researcher, Val is interested in carers, disability issues and auto-ethnography, both as a process and as a method, and has recently published a paper on this method in the journal *Qualitative Social Work (QSW)*. She lives by the sea, and when she isn't writing and researching she enjoys walking her dog and spending time with her family.

Dr Steve J Hothersall (series editor)

Dr Steve J Hothersall is the Head of Social Work Education at Edge Hill University and both a registered social worker and a registered nurse. He has written on social work practice with children, young people and their families, mental health, need, social policy and philosophy, especially epistemology. Steve has also served on the Editorial Board of the *British Journal of Social Work* and reviews for a range of academic journals. His academic interests relate to methodology, the use of philosophy to inform both teaching and practice, and research focusing on the development and use of professional knowledge, drawing on underpinning epistemic principles and considering their role and application in knowledge communities. He is currently working on developing and implementing a model to support practice and research underpinned by reference to philosophical pragmatism. He is also passionate about the music of Ludwig van Beethoven, and the role of music in the promotion of wellbeing.

Series editor foreword

It is with great pleasure that I write this foreword for the first book in what is hoped will be a noteworthy and innovative series for Critical Publishing entitled 'Early Intervention, Prevention and Support'. Val Gant's 'Working with Family Carers' is perhaps a particularly noteworthy title, as its focus epitomises what this triad aims to focus upon. Family (and informal) carers are perhaps the frontline in terms of early intervention, prevention and support, so to launch this series with such a well-crafted text is apposite.

Val is a senior lecturer in social work at the University of Chester, based at the Warrington campus, and brings many years of practical, professional and *personal* experience to her writing. This topic is one very close to Val, both personally and professionally, as even a cursory glance at the text will reveal, and what is particularly revealing is the way in which the writing utilises both perspectives to the fullest extent.

The book sets out to explain the myriad complex realities of being a family/informal carer, juxtaposing these with the contemporary nature of professional social work practice. Within its pages, we are introduced to the contemporary nature of family and informal caring, with new statutory provisions being highlighted to contextualise the prevailing landscape. Definitions of core concepts are provided and the reader is introduced to the 'world' of family and informal caring, aided by the effective and creative use of case studies and exercises. Along the way there are chapters that focus on the background to informal care, revealing how and why things are the way they are today, highlighting the gendered nature of care and its economic implications, for the government, and for all of us. There is detailed commentary on the legal and policy content, and careful and empathetic consideration of what it is, and must be like, to be a family/informal carer, and the impact that can have on people, in both good and not-so-good ways. Chapters on the role of professionals in this domain are given equally effective treatment, thus allowing practitioners from a range of different professions and occupations the opportunity to reflect deeply on what they do and how they do it, for good, or for ill. The text also considers relevant research that has helped guide and inform the current care landscape, and a special focus is given to young carers, older parent-carers and those caring for those with dementia and similar conditions, before the final chapter asks us to reflect and look to the future.

This is a book that draws on the author's professional, personal and human experiences of care and care-giving, and as such offers what I perceive as a profoundly moral perspective. In its pages we can begin to understand that many people's lives

are dedicated to the wellbeing of others, often at the expense of their own wellbeing. That this happens all day, and every day for some is, quite frankly, not only revelatory, but shocking. The dilemmas inherent within such mundane, everyday tasks as helping someone to dress themselves are revealed in full technicolour, and challenge us all – as professionals, policy makers and the public, to rethink the role of family and informal carers in different ways, and re-evaluate how we manage and support, holistically and structurally, what is a truly herculean task.

Family and informal carers are not only at the frontline of caring for those who are vulnerable, but they are the frontline. Professional services, be they state-sponsored or part of the private, voluntary and independent sector would be decimated overnight if family and informal carers were provided with the support they require at the level they actually require it. It is perhaps not understating it to say that those professional support services, well-intentioned as they are, and its workers, well-motivated as they are, are only really touching the sides of something so pervasive and enormous, that to err in supporting this task is to risk many people and their communities imploding, with dire consequences for us all.

This text is pivotal – not only as the first in a new series, but as a text in its own right, on a topic given much less academic, professional and governmental attention than it truly deserves. I have been moved and inspired by some of the insights afforded to me by reading Val's work – and I believe that this book will do much to invigorate this topic – and focus necessary attention on an issue that is likely to affect most, if not all of us at some time in our lives. We owe it not only to family and informal carers, but to ourselves, to take seriously the issues this book raises, and to respond appropriately. And therein lies a challenge to the ways in which we currently configure our support of family and informal carers, a challenge that the government should heed.

Dr Steve J Hothersall, Series Editor

Head of Social Work Education, Edge Hill

Chapter 1 | Introduction: Why this book and why now?

Over the last three decades, the titles ‘care-giver’ and ‘carer’, as both a role and as socially recognised and (perhaps) accepted ‘entities’ have emerged. Changes in legislation which enshrine such recognition have now occurred, most recently in the Care Act (2014) which arrived with much promise and potential for optimism, with politicians going so far as to proclaim it *‘[T]he most significant reform of care and support for 60 years’* (Lamb, 2014).

Demographic changes in society, an increase in life expectancy – seen as a celebration in the twentieth century, and a challenge in the twenty-first century (Macnicol, 2015) – as well as policies aimed at supporting this group of people, many of whom have illnesses associated with age, all add to the realisation of the ubiquitous existence of carers and of them having a definable role. Although there has been a growth in total life expectancy, this has been outpaced by the issues associated with the number of older people who are frail and living with co-morbidities (Hulme et al, 2016). Due, therefore, to the increasing health and social care needs of an older population, the likelihood of people needing a high level of intensive support as they age has increased. The effect of the pressures on health and social care brought about by the current economic climate also has an impact on the likelihood of an individual needing ‘informal’ care. National health and social care services now only tend to work with those in crisis, and on a short-term basis, meaning friends and relatives support and assist with care that in decades past would more likely have been addressed within the ‘professional’ arena. According to the 2011 Census, 10.3 per cent of the UK population provided unpaid care (ONS, 2013), an increase of 600,000 since the 2001 Census, the first time a question on the provision of unpaid care was asked, and this number looks set to increase, with the most intense caring, that of over 50 hours a week, increasing most (Carers UK, 2015; Franklin, 2015; Robards et al, 2015).

As well as the issue of physical decline, there is a notable increase in the number of people recorded as having dementia and associated mental health impairments (Alzheimer’s Association, 2017; de Boer et al, 2015). Put simply, people are living longer, but the older one is, the more likely one is to be in poorer health and in receipt of care, most likely ‘informal’, ie unpaid care from friends or relatives. The emotional and psychological challenges of care-giving as well as the practical and physical impact need therefore to be recognised, understood, acknowledged, and supported. For practitioners working with and supporting carers, developing

their own understanding of what caring is, and means, may lead to an increase in the building and developing of crucial relationships and may be the key to finding a gateway into that unique situation, culminating in a deeper and more successful connection. I believe it is that connection and our possession of the capacity to empathise that separates us out as a species and offers hope for the future. As professionals, we are duty bound to do the best we can with what we have at our disposal. As human beings, we are morally bound to recognise the importance of caring and to accord it the status it deserves. This text will hopefully provide the basis for a more enlightened and engaged appreciation of one of the most significant roles and functions within society – caring. Offering a discussion and analysis of some of the key research areas related to caring and highlighting these through the use of case study examples, this book offers a way to begin to explore the impact of caring on the lives of family carers and the effectiveness of support, as well as exploring ways to acknowledging this crucial role.

The aim of this introductory chapter is to begin to explore definitions of care and care-giving, and identify the perspective from which it is being considered, as well as providing an overview of the structure of the chapters that follow. The chapter will introduce the reader to the format of the book, designed as it is to encourage interaction: each chapter is designed to be worked through using case study examples and reflective and practical tasks. Further reading is suggested at the end of each chapter and a list of resources will be included.

Aims of the book

There is an ever-increasing reliance on family carers in everyday life (Carers UK, 2015; Hulme et al, 2016; Smith et al, 2015) with reports regarding the issue regularly appearing in the media; for example: “*Undercover carers’ save the taxpayer £40 billion a year*” (Daily Express 15 Dec 2016). “*I became my mother-in-law’s carer – but I just couldn’t handle the stress of the job*” (Daily Telegraph 5 May 2017) and “*The crisis of young carers: ‘Going to school is a break’*” (The Guardian 26 Jan 2017). It is a topic also covered widely by radio; for example: Radio 2 ‘Carers Week’ 6 Jun 2016; Radio 4 ‘The Secret Lives of Carers’ 1 Dec 2015, and yet there is surprisingly little clarity regarding what ‘caring’ and ‘care-giving’ really means in real, practical terms. From a relatively simple word comes a vague, ambiguous and invariably complex phenomenon, and yet one which many people accept without question and believe they understand. For many, including those who are providing a significant amount of unpaid care to friends and/or relatives, carers are still seen as ‘other people’, generally provided by social care agencies and importantly ‘the ones who are paid’. The implications for (a lack of) identity of carers has significant consequences, and some of the reasons behind this,

including the gendered nature of caring, the fact that caring takes place in the private sphere, and that the work undertaken by carers can be messy, unpleasant and hard, is discussed and explored in [Chapter 4](#).

It is important to make the point here that this book is about those 6.5 million *unpaid* 'informal' carers, 1.6 million of whom provide 50 or more hours of care per week (Carers UK, 2015), with no pay, and often little support in managing their day-to-day activities. In the UK it has been estimated that the demand for care brought about by an ageing population will soon outstrip supply (McNeil and Hunter, 2014), and the ways in which carers or care-givers (I will use the terms interchangeably throughout the book) are supported by the state has an impact that goes beyond any individual situation. This book then is about care and care-givers, is intended as a text book for students of social work, social care, those in health care (nurses, occupational therapists, physiotherapists) and other cognate disciplines and as noted above, is written about those whom I call 'family' care-givers: those for whom caring is not a term of specific employment, and for whom there is little recompense. I debated about using the term 'informal' as opposed to 'family' carers; however, for me the term 'informal' does carers something of a disservice, as that term implies that caring is an activity undertaken casually, with some degree of choice in taking on the role, and a lack of responsibility for outcomes associated with the tasks of caring. Such is not the case for many. This book therefore, is for both students and practitioners, designed as a way of helping to work through and make sense of a very complex terrain. While paid carers will also find information of use in this book, the primary focus is on those who provide care for a family member, friend or neighbour in an unpaid capacity.

Recent legislative changes in the UK brought about by the Care Act (2014) have now altered the profile of carers, and as such a text of this nature is timely. The changing demographics of society mentioned above: people living longer and many more living with life-limiting illnesses brought about by the diagnosis and recognition of previously unrecognised disabilities, has increased the need for an up-to-date text that may be used by students and practitioners across the range of health and social care professions.

A professional and a personal perspective

This book was brought about following several research projects I have carried out exploring the lives of parent-carers of adults with learning disabilities. As a social worker, working in what was at the time a specialised adults with learning disability team, I noted and recognised the impact of care-giving and receiving care on people's lives. It is never a straightforward one-way process, and throughout my career I have

observed many examples of reciprocal care. As an educator, working with social work and health and social care undergraduates and post-graduates, I have noted how the involvement of carers is threaded through all the modules and programmes I teach. For example, 'interprofessional working', 'critical social work practice', 'safeguarding vulnerable groups', 'social work law and ethics', as well as research and dissertation modules all engage with carers and the issues they face. Students also bring their own unique experiences of being carers (and in some instances, of receiving care) to the classroom and I have been privileged to listen to the many examples that care-giving students draw on to begin to make sense of their own place within this terrain. Likewise, several colleagues are involved in complex caring scenarios and I have noted and heard anecdotally that some employers are becoming aware of and are seeking ways of supporting staff members with caring responsibilities, beyond those of raising children.

Although this book is written primarily from a professional perspective, it is also my personal experience of being a parent-carer that has had a significant influence and impact on my values, my focus and the overall perspective provided here. My youngest daughter has what is currently referred to as a 'severe learning disability' and at the time of writing this book she is undergoing the transition between children and adult services. The personal experiences I have gained shape and frame my reference point when exploring issues relating to carers and it would be disingenuous of me not to acknowledge this here.

Definitions

As with many topics and social issues, understanding exactly what it is you are talking and thinking about is quite useful – hence the need to consider definitions. Notions of caring, care and care-giving are, as you might expect, fraught with ambiguity, confusion and misunderstanding. Here we will consider some of these in order that you can begin to appreciate some of the dimensions and complexities of this area and engage more critically with the issues.

Care – [Noun]: 'The provision of what is necessary for the health, welfare, maintenance, and protection of someone or something' (Oxford Dictionary online, Oxford, 2015).

Care-giver – [Noun] 'The person who provides the majority of care or guardianship, especially to a child or an infirm person' (Oxford Dictionary online, Oxford, 2015).

HCPC definition *Carer* – ‘Anyone who looks after, or provides support to, a family member, partner or friend’ (HCPC, 2015).

So what exactly is ‘care’? Attempting to unpick the definitions above can bring with it more confusion. As a word, it was not until relatively recently that it began to be explored and debated as representing a phenomenon in its own right. Often seen as an identity or characteristic over which people have little control, the discrimination of a swathe of people brought care to the attention of theorists and academics in the latter part of the twentieth century (Larkin and Milne, 2014). The associated implications of dependency (of the person in receipt of care) and autonomy have been, and continue to be, critiqued by scholars and disability rights groups. This and the diversity of carers and that of the people whom they support is discussed in [Chapter 2](#).

Leaving aside for the moment what could be crudely summed up as the disability rights vs carers’ rights debate (Fine, 2014), if we then start to unpick terminology just by taking the ‘*provision of what is necessary for health, welfare, maintenance, and protection*’ as a starting point, this covers a huge spectrum. There are many differences to consider, including geographical: for instance, for those living in the North of Scotland, the provision of heating is more necessary for health, welfare and maintenance than for those people living in Southern Spain, where electricity for air-conditioning may be seen as a necessity. Cultural differences, including expectations of filial responsibility also differ between a culture where there is greater emphasis on respect and family care for older people than is generally seen in the UK (Solé-Auró and Crimmins, 2014). Older age, as an example, is seen either as a time when one has achieved status and wisdom or as something undesirable, depending on the cultural expectations of the society in which it is perceived and experienced. The value that different cultures place on old age has associations with how caring for older adults is seen and practised, and these values can become internalised by both the recipient and the giver of care. Caring or care-giving is rarely delivered by one individual, given in one direction. It is not linear: for example, older adults may have more than one child who is providing care, a child more than one parent, and a spouse may have children and siblings to assist with care provision.

So, if we go back to the Oxford Dictionary definition, ‘*the provision of what is necessary...*’ and this time examine the aspect of health, presumably this incorporates both emotional and physical health? If it is self-defined, then what I deem necessary for my own physical health – a long walk with my dog on a regular basis – and my emotional health – to relax and listen to music (preferably Bruce Springsteen) on a daily basis – may not be recognised as important by others. For those others, the ability to smoke cigarettes may be seen as necessary by them for their personal welfare and emotional

health, and yet there is an inherent tension between this and the physical health implications that lead to this activity being condemned by others. Here again, this raises the question of who is actually responsible for deciding and/or recording '*what is necessary*' and how does the subjective nature of the assessor make a difference?

Timing is also significant in any discussion regarding '*what is necessary*'. To use the example of a parent-carer for a child with disabilities, the need for support to enable time to be spent with any other children in the family, perhaps in a practical way – taking them to school or attending parent nights – is likely to be limited by time, and is not likely to be seen as a 'need' in a practical sense for more than a few years. Likewise, the effect of some disabilities and some illnesses fluctuates. Provision of care for a partner who has multiple sclerosis, for example, is likely to be more intense at some times than at others, such is the nature of the physical effects of such a condition. Others may see the provision of '*what is necessary*' as being more about those needs proposed by Maslow (1943). He described these as relating to physiological, safety, emotional (social), esteem and self-actualising needs.

Few would doubt the centrality of such basic needs as food and water, warmth and shelter. However, if you see my point above about the variability in these needs depending on one's individual circumstances, the question is posed about how and where these are obtained; are they provided for, and if so, by whom? Should they be provided for? Is there a distinction to be made between needs being met by someone 'giving' or of someone 'receiving'? Are they obtained or achieved? When we start to explore who, and what, is a priority for these 'basic needs' and how they are met,

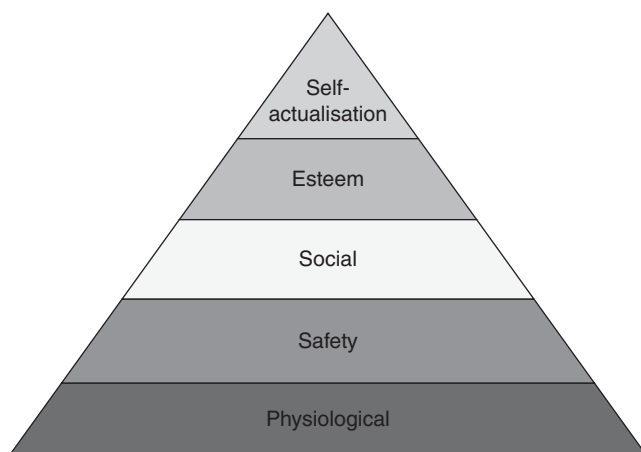


Figure 1.1 Maslow's Hierarchy of Needs

(provided, or funded) both contextually and globally this exploration becomes even more complex.

When needs have been identified – which may differ depending upon whether it is by self-identification/assessment, or by meeting some pre-determined criteria, which itself brings into question the subjectivity of any pre-determined category of need, how and by whom it is measured (Bradshaw, 1972) – the response to the needs of carers in any society is once again fraught with complexities.

So, the definitions are superficially complex, but lack sophistication. When searching the literature for others' definitions, the most common definition of carer and care-giving comes from the carers organisation, The Carers Trust: '*A carer is anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction cannot cope without their support*' (Carers Trust, 2017). Again, this is a very broad definition and makes no distinction between physical, emotional and financial caring. If, for example, I am worried about my 80-year-old grandmother and telephone her every day, she looks forward to the call and says it 'keeps her going'. To me, this is obviously 'caring' and yet it is quite different from an individual who may be providing 24-hours-a-day, hands-on physical care for their partner who has suffered a stroke and is unable to self-care, and who may require feeding, mobility and personal care. Clearly the individual circumstances and preferences, along with so many other variables, impacts upon the experience of carers and those in receipt of such differing forms of care. The internalisation of moral and social norms, access to resources, as well as the prevailing political ideology are just a few of the ways in which care and caring is identified, intensified and shaped by external and internal factors. If, as McNeil and Hunter (2014) suggest, the number of family carers reduces, this will be in direct contradiction to the demands placed on formal services, again at a time of cuts and budget reductions.

Vital elements in the Carers Trust definition above: the first is 'cares for' and the second 'cannot cope without their support' – both elements as we shall see in subsequent chapters are open to debate and discussion. For example, is 'cares for' taken to mean in a practical or an emotional sense? Might they be separated out? Likewise, on whose definition is the decision made that the family member or friend 'cannot cope without their support'?

The words care, caring and care-giving carry with them similar connotations, and yet there are differences, most notably between caring *for* and caring *about*. Care is itself an emotionally laden term. For example, I care *about* the current situation in Syria and the catastrophic impact the fighting has on children and young people, however

do little in any practical sense about that. I care *for* my children in a practical and emotional sense, making sure their school uniform is clean, they have the train fare each morning, as well as whether they are happy, and have friends. I care *about* my students in that I want them to enjoy their programme of study, achieve a qualification, as well as learning and reflecting on that learning. I also care *for* my students in a practical sense, making sure they are offered an opportunity for a private conversation, and a coffee if they are distressed, and support them in their studies if life becomes problematic. In essence then it may appear that the difference between caring *for* and caring *about* are to do with practical elements, with caring *for* implying physical or emotional tending, and caring *about* a more abstract and temporal concept. An interesting question is whether one might exist without the other – can you care *for*, without caring *about* for example? As a family carer, one may go through the practical motions of caring *for*, without any thought of caring *about*. A wife who has experienced a lifetime of abuse from her husband who now has dementia may care *for* him in a practical sense, for example making sure he is fed and has clean clothes to wear, but does not in any sense care *about* him, and on more than one occasion may actually wish he would die. In another caring relationship, the geographical separation between a son and his father who has a terminal illness means caring *for* in a physical sense does not happen: however the son may be able to think of little else apart from his father’s illness and may spend many hours each day searching for cures on the internet – is this caring *for* or caring *about*? I contend that both caring *for* and caring *about* take place along a continuum.

The emphasis on care, whether *for* or *about*, takes place along a continuum moving from no choice/moral duty on the left-hand side, to full choice and emotional wish to care on the right-hand side, and these may meet somewhere in the middle, reminding us that each caring situation is unique, and that care may be reciprocated.

No choice/moral duty→→→→→→→←←←←←←←wish and choice to care

When you begin to explore the dynamics of care and care-giving – how it is understood by society, how it is arranged, managed and financed – you will see just what

Table 1.1 Caring for and caring about

	My children	Wife of man with dementia	Son of man with terminal illness
Caring For	Yes	Yes	No
Caring About	Yes	No	Yes

an abstract, political, social and ideological subject it is. Care giving and receiving is a fact of life and *'...not one of us can truly expect to look after ourselves through the whole course of our life without help from others.'* (Beresford, 2016, p 18). Care, therefore, is an essential part of human life and whether it is seen as a private or public concept, or a little of both, remains a moot point. Care (and care-giving) is both fascinating and replete with contradictions, dilemmas and debates, and a topic that requires a level of critical engagement in order to fully explore all its dimensions, and reveal others.

There is surely something ironic or paradoxical about writing a book purporting to inform, educate and offer a perspective on 'care' that is aimed at carers and the caring professions. You might imagine that anyone entering these professions does so out of altruism, out of a desire to help, to make other people's lives better and perhaps to empower.

In over ten years of interviewing prospective students for undergraduate and post-graduate social work study, I have found that one of the most common responses when questioned why they want to enter the profession is, *'Because I want to help people'*.

(*Note to potential students – you do need to expand upon that answer!)

For practitioners, a book to inform, educate and offer another perspective on the topic of care may appear to be self-evident. One would imagine that those in, or entering, such professions should have a clear understanding of the key issues and concepts relating to care-giving and will hold dear the values and skills needed to support a variety of people in a diverse range of situations.

This is not a 'How to...' book: the skills needed for working with, supporting and empowering carers should be part of every professional's training and education. Valuing people, treating people with dignity and respect, using open and honest communication and ensuring transparent actions, are the bedrock on which work within health and social care is (or should be) based.

This book is about trying to go deeper than those basic skills. In part it is about exploring the assumptions and prejudices that we all hold, and encouraging reflection and deeper exploration of one's own actions and those of others. I hope by reading this book you will question, discuss and reflect on the nature of caring in the twenty-first century, whether this applies to you from a professional or personal perspective, or both.

Being a practitioner in health and social care can offer a unique insight into what is, on many occasions, the ‘hidden’ world of care. I believe it is a privileged position. Care is, by and large, invisible; it takes place in the private sphere, generally behind closed doors. It can be messy, undignified, and extremely hard work, and yet it is a situation in which more and more of us are coming into contact, whether that be on a professional or private level (or both). Care is a great leveller; whether you are in receipt of it, provide it, or are in a relationship where both situations occur. The likelihood is at some point in our lives we will both provide and receive this slippery notion that is care. Surely, like death and taxes, if this is unavoidable it needs to be recognised as such, unpicked and articulated, and perhaps even celebrated?

Life is fragile, inestimable and unpredictable; unexpected events can and do occur. No one can predict exactly if and when they will be a carer, or if and when they will need care. We all have a limited time on this planet and need to begin to recognise and articulate that and, as suggested above, celebrate it for what it is, even though at times it may seem too short, too messy, and too complicated. This book will offer a discussion regarding the way society is organised, the (what I believe is a false) dichotomy between ‘carer’ and ‘cared-for’. By so doing I hope it will introduce you to, or even expand your understanding of, discourses of care – including ethical debates – and will therefore, in some small way, help to inform and equip you with some of the underpinning knowledge and theories that provide the foundations for this most basic of acts – that of ‘care’.

Terminology

Language, the terms we use on a daily basis, and the meanings associated with these change rapidly (I still associate ‘wicked’ and ‘sic’ as negative things to be avoided). New definitions are included in the dictionary each year to reflect everyday vocabulary; for example, ‘hangry’ (bad tempered or angry as a result of hunger), ‘mansplain’ (the explanation of something by a man, typically to a woman, in a condescending or patronising manner), and ‘me-time’ (time spent relaxing on one’s own) are all examples of words that appeared for the first time in January 2018 in the Oxford English Dictionary (see <http://public.oed.com/the-oed-today/recent-updates-to-the-oed/january-2018-update/new-words-list-january-2018/>).

In terms of this book it is important to set parameters and to explain what I mean by the different terms in use. For clarity, the following terms and their use are as follows:

- » ‘People in receipt of care’ or ‘care-receiver’ interchangeably. This is in preference to ‘service-user’, ‘client’ or ‘patient’, although I recognise neither

of these are universally accepted and that there may be alternative terms in use.

- » I have used the term 'local authority' to refer to councils with social services responsibilities.
- » The terms 'carer' and 'care-giver' are also used interchangeably to indicate a family member or friend who provides care to someone known to them, *without pay*.
- » 'Health and social care practitioners' is, I recognise, a somewhat cumbersome term, therefore 'practitioner(s)' is used in this book to indicate anyone working with carers in a professional capacity. This includes students from a variety of disciplines, including social work, nursing, occupational and physiotherapy.
- » By referring to the readership as 'practitioner(s)' as a shorthand, is in no way meant to imply that this book is solely for that audience as commonly perceived.

In addition, the text takes a broad view regarding care and caring as this would apply across all jurisdictions of the UK. However, where there are country-specific legislative/policy requirements, these are made explicit, as will be seen in [Chapter 3](#).

Practitioners will often discuss the impact of knowledge, skills and values as these relate to caring and such considerations are often seen as a shorthand for notions of professionalism. It is therefore important to define how these terms refer to and impact on carers:

- » Knowledge – Practitioners from a variety of health and social care specialisms working with and supporting carers need a certain degree of practical, technical and theoretical knowledge. This includes knowledge of legislation and its application, knowledge of benefits and the often complex financial arrangements that attend the caring role, and knowledge of services and support structures, all of which need to be located within the context of the condition or diagnosis of the person for whom care is provided, and effectively integrated (Hothersall, [2016](#)).
- » Skills – Working with carers, as working with those people in receipt of care, requires practical skills to make best use of the knowledge referred to above. Skills include communication: (Koprowska, [2014](#)) actually listening to and *hearing* what is being said, and being able to interpret this meaningfully. For example, if I asked a carer about their typical day, and the response was '*Well I have good and bad days*', on a practical level it may be important

to question this – a ‘good day’ might mean only being woken up twice in the night and having to change the bed once as opposed to several times, or it might mean that you were able to watch your favourite programme on television with only one interruption, whereas for people who are not caring this could be seen as a ‘(very?) bad day’. Clearly, therefore, skills of listening and picking up on nuances and subtleties are at the forefront of working with carers. Other skills include the ability to work across professional boundaries and disciplines in order to get the best possible support from a variety of professionals/service providers. The skill of being able to advocate effectively on behalf of carers should not be underestimated, as there can be real challenges here, particularly if a practitioner’s assessment places what the organisation might feel are ‘excessive’ demands on its resources.

- » Values – These act as a reference point for our decision-making and mediate both cognitive and emotional responses. It is important to appreciate that there may be instances where *professional* and *personal* values are challenged, and even compromised if these run counter to the values of the organisation or those of the carer or cared-for person (Akhtar, 2012; Martin, 2010). It is also important for you to maintain awareness as to the nature of the partnership between you, as the professional, and the carer. Do you afford them the same level of courtesy and respect for their views as you would another professional?

Practical task

Take a moment to look at the professional standards and practice of the career you are in, or one in which you hope to join. As an example, for social work this is (currently) the Health Care Professions Council (HCPC, 2015), and for nurses, the Nursing and Midwifery Council (NMC, 2015). Read through the professional standards that entrants to these professions are expected to attain.

Do these conflict in any way with your own personal values?

Can you identify any instances where you think the requirements within the standards would likely conflict with those of an organisation?

As well as knowledge, skills and values, other attributes such as experience, wisdom, cultural understanding and a recognition of the importance of social and economic

conditions (not least of these being access to resources) are essential when working with carers.

Looking again at basic definitions of the word ‘care’, consider for example the HCPC term ‘*look after*’. That too is fraught with contradictions and has different meanings applied to it by professionals and those involved in caring situations. Is it just about semantics though? Clearly it is difficult to narrow the focus of what is understood about care, although that does not, and should not, make it an invalid operation. Rather, through such processes, a consideration of these issues opens up broader debates regarding understanding and the use of terminology which, as we know, may be fluid and contextual. Regardless of the intricacies of the definition(s) applied to the action, we know, according to Carers UK and others (Dahlberg et al, 2007; Kudra et al, 2017) that ‘care’ is a situation that will touch the lives of millions of us at some point. Even if trying to capture the exactness and minutiae of the term is as impossible as plaiting water. The broader concepts and areas of understanding need to be discussed, reflected upon and broken down into component parts relevant to each unique situation. This text is designed to assist you in those processes.

Structure of the book

Chapter 2 Background to informal care

This chapter introduces you to the history of care-giving and it will consider what practitioners might learn from the past. Looking at the context for the carers movement, from the early action of one woman, to the politically active and nationally acknowledged organisations we see today, the chapter will trace the background to the ways that carers have emerged as a distinct social group in UK society in the twenty-first century.

Developing issues referred to in the introductory chapter, this chapter will set the scene for future discussions regarding the role of carers. The impact of legislation, social policy and the ‘rhetoric’ of community care on services will be considered in relation to the emergence of ‘the carer’ as will the impact of deinstitutionalisation and the move to ‘care in the community’. Caring occurs within a relationship and this chapter will explore the reciprocity of care as well as looking at a range of ideas regarding the balance between the potentially competing needs of carers and those people in receipt of care. The chapter concludes with a discussion regarding the gendered imbalance of care-giving, and examines how caring is constructed as an identity as well as the significance or otherwise of this (Grimwood, 2016).

Chapter 3 Law, policy, politics and people

Care has both an ethical and a political dimension (Tronto, 1993), and few would deny the moral, social and political significance of care-giving. This chapter will explore carers and law and policy, given that the current backdrop to care in the twenty-first century in the UK is set against a political ideology that emphasises independence, and values financial, material and career achievements. We know that carers are unlikely to have accrued savings of any significance and are unlikely to have access to private pensions. Carers are also more likely to live in low quality, privately rented accommodation. They are unlikely to have worked full-time and tend to be in low-paid, often temporary, employment. This chapter will draw on legislation and social policy to inform practice with carers. It is noteworthy that some of the problems carers experience may not necessarily be explicitly linked to their caring role. The implications of care-giving, set against a backdrop of austerity and financial prudence, will be introduced before being discussed in greater depth. The implications for practitioners will be highlighted.

Chapter 4 Carers: caring and care-giving

Chapter 4 takes a practical focus, examining what it is that carers actually *do*. Through the use of case studies we will be looking at some of the practical activities undertaken by carers. This chapter offers opportunities to understand where and how support may be useful and asks questions like what are carers' workloads? What is the nature of the caring task? For many carers the experience of supporting and caring for a loved one, a family member or friend brings with it an enormous sense of satisfaction – of a job well done. What could be more important than seeing people you love and care about grow, thrive and survive, and know that in some (small?) part that is directly down to your involvement? For many other carers however care-giving brings about stress and physical, emotional and financial hardship alongside battles with professionals. This, and the adjustment to a change in the identity for many carers, is explored.

This chapter concludes by discussing matters relating to caring for children and babies, beyond that of the expected norm for parents, and a brief exploration of issues related to accessing short breaks and/or respite services, and what practitioners may learn from this.

Chapter 5 Professionals and caring

This chapter draws on research that focuses on working with carers collaboratively in an interprofessional context. Who are the professionals and whether carers are professionals are just some of the areas considered in the chapter. Drawing on the work

of Twigg and Atkin (1994) this chapter looks at the ways in which carers are viewed by professionals, and considers how they are seen; as a resource, a co-worker, a co-client, a professional or an expert? Are carers superfluous, and is their involvement viewed as tokenistic by professionals? Noting the feelings associated with 'imposter syndrome' by some carers (and practitioners) this chapter then turns its attention to matters of assessment of needs. The chapter concludes with an exploration of assessment, both carers' needs assessments and combined assessments under the Care Act (2014), and recognises the importance of multi-agency and collaborative work.

Chapter 6 Research and practice

Continuing the debates begun in earlier chapters, this chapter looks at what research is and what it tells us about care and the effects of care-giving. Developing research-mindedness and intellectual curiosity are key skills for practitioners particularly in relation to care and care-giving (and receiving) scenarios in order to recognise the impact and experiences of such. The relevance of social media is also noted. The chapter will highlight the fact that care-giving is part of being human and the relational aspects of caring. The 'ethics of care' debate (Adhariani et al, 2017; Barnes, 2012) will be introduced and discussed.

As noted in previous chapters, carers are not a homogenous group and, as such, the emotional impact of caring will vary and be dependent upon a number of different factors. For many carers their situation is not seen as stressful or at all negative, and this chapter recognises some of the positive characteristics associated with caring. Concluding with a discussion of the importance of resilience both for practitioners and for carers, this chapter makes suggestions for further reading and inquiry.

Chapter 7 Young carers, older parent-carers and carers of people with dementia

This chapter introduces you to the concept of 'care' as it relates specifically to three groups of carers: young carers, older parent-carers and carers of adults with dementia. While recognising that every caring situation is unique, there are however many similarities as well as specific characteristics that differentiate each 'group'. Using case study examples to highlight key points, this chapter also considers issues relating to students as carers and ways of supporting them to achieve their potential. This chapter emphasises the importance of clear and detailed recording by practitioners, and of agencies working together in order to enhance and support the work undertaken by family carers.

Chapter 8 Reflections and conclusion

Safeguarding vulnerable people is everyone's business and this chapter will look at safeguarding inquiries, safeguarding adults boards and safeguarding adults reviews and offers a discussion of issues relating to post-caring, and matters of grief and loss.

The preceding chapters have been wide ranging, both conceptually and practically, in an attempt to furnish the reader with an outline of a multitude of issues relevant for carers, those in receipt of care, and practitioners alike. This concluding chapter summarises concepts, raised in earlier chapters to allow us to consider and discuss what the future may hold for carers, caring, and those in receipt of care.

Through an exploration of the 'metaphysics' of caring, a way through, or a gateway, into someone's world may be facilitated. Understanding caring is complex and nigh on impossible to appreciate fully. However, no matter how complex the situation is, and how many variables are involved, it is still a subject that needs to be pursued within the broader professional canon. Achieving a level of understanding regarding the lives of carers enhances what it is to be human, as well as enhancing practice and this final chapter attempts to synthesise some of the information and help support practitioners in the context of practice with carers.

In conclusion, care-giving and care-receiving are likely to touch us all personally at some point, and for those working in the health and social care professions, our professional involvement and engagement with care-giving will increase. As Kleinman (2012) so eloquently states:

Care-giving is one of the foundational moral meanings and practices in human experience everywhere: it defines human value and resists crude reduction to counting and costing.

(2012, p 1550)

For practitioners working with and supporting carers, developing their own insights and understanding leads to an increase in the building and developing of crucial relationships and may be the key to finding a gateway into that unique situation culminating in a deeper and more successful connection (Griffiths, 2017). I believe it is that connection and our possession of the capacity to empathise that separates us out as a species and offers hope for the future. As professionals, we are duty bound to do the best we can with what we have at our disposal. As human beings, we are morally bound to recognise the importance of caring and to accord it the status it deserves. As social workers, we must recognise the philosophical components of our work and try to understand the applications of such a perspective (Grimwood, 2016). This text will hopefully provide the basis for a more enlightened and engaged appreciation of one of the most significant roles and functions within society – caring.

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