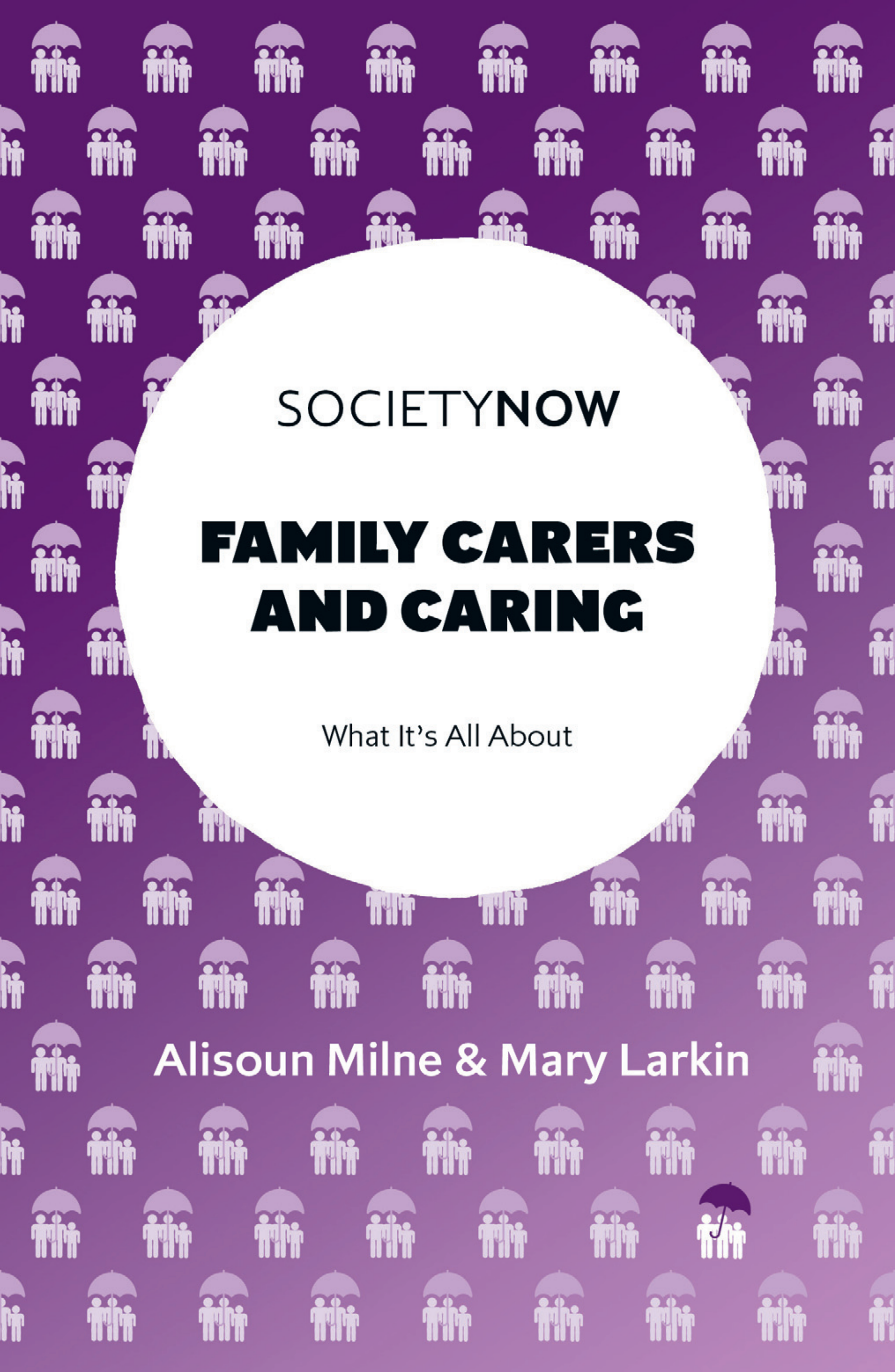

SOCIETYNOW

FAMILY CARERS AND CARING

What It's All About

Alisoun Milne & Mary Larkin

FAMILY CARERS AND CARING

Family Carers and Caring: What It's All About *makes a major contribution to the current debate about the future of social care in the UK and most importantly offers the basis for a new and evidenced narrative about how we identify, recognise and value the family carers who form the bedrock of our somewhat tired welfare state. Social care promised by Boris Johnson on the steps of 10 Downing Street was a historic moment to reconfigure our care system and thereby to formally recognise, support but not exploit the contributions of family cares. Delivery was delayed, but that delay creates opportunity and* ***Family Carers and Caring*** *offers the perfect brief for reforms to come, acknowledging and evidencing the critical role that family carers will play within a redesigned care system.*

Family carers, unpaid, often over-burdened and poorly understood, underpin both the UK health and the social care systems. The value of their care is estimated at £193 billion a year, but there is growing evidence of multiple health and financial inequalities as carers care for longer and many struggle to balance complex care at home with employment and wider family responsibilities. Family care of necessity has become a 21st-century issue for local and national government. 1 in every 5 of NHS staff now have family caring responsibilities. The UK workforce needs to reverse the early retirement of so many workers in middle age, many of whom have acquired new caring responsibilities. We are seeing *the rise of young carers whose own education and career prospects are at risk because they are neither recognised nor supported sufficiently. Additionally, and importantly, the NHS is also reconfiguring the role of hospitals and transferring health care and recovery back into family homes.*

The UK, of course, like its international counterparts, has seen multiple strategies and new legislation over the past two decades, intended to rebrand social care; to integrate health and care and to personalise support to meet individual needs. But family carers have not achieved the 'parity of esteem' envisaged by the Care Act and post-COVID financial challenges mean that fewer carers are now receiving support. An estimated 500,000 people await assessments or the delivery of agreed packages of support from their local authorities and families are still selling family homes to pay for care. But even allowing for the very real financial pressures on all public services, we can do better and ***Family Carers and Caring*** *offers strategic analysis; creative forward thinking and a new understanding of what 21st-century care and support could look like.*

As the authors note in the introduction to Chapter 2 of their book, the profile of the population of family carers in the UK is dynamic, diverse and constantly shifting. We are beginning to see the 'big conversations' which have already taken place in a number of our European neighbours around how we define and therefore how we deliver social care and support and the role of family carers in a changing society. The House of Lords Adult Social Care Committee recently entitled a report on the state of

UK social care as 'A Gloriously Ordinary Life' *in recognition of powerful stories from family carers and those they support who wanted to reimagine care to actively support* 'ordinary lives' *and 21st-century preferences and ambitions. As a long-term personal carer myself, I can only hope that this book is read, discussed and shared across local and national government, the NHS and of course the UK's rich constellation of community organisations as we work together to define an 'ordinary life' for the extraordinary people who are family carers and* how *we can progressively and strategically work together to achieve it.*

Dame Philippa Russell DBE, Vice-President,
Carers UK

This excellent book presents a wide-ranging, informative and accessible discussion of what family care and carers are 'all about', with conceptual and theoretical material illustrated by case studies. Drawing on their extensive knowledge of the subject, Milne and Larkin argue for change in the place of family care within social care systems. This book will be a valuable resource for a range of students and researchers in social work, social policy and related subjects.

Professor Liz Lloyd, Senior Research Fellow,
School for Policy Studies, University of Bristol

FAMILY CARERS AND CARING

What It's All About

BY

ALISOUN MILNE
University of Kent, UK
And
MARY LARKIN
The Open University, UK

emerald
PUBLISHING

United Kingdom – North America – Japan – India
Malaysia – China

Emerald Publishing Limited
Howard House, Wagon Lane, Bingley BD16 1WA, UK

First edition 2023

Reprints and permissions service
Contact: www.copyright.com

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN: 978-1-80043-349-6 (Print)
ISBN: 978-1-80043-346-5 (Online)
ISBN: 978-1-80043-348-9 (Epub)

Alisoun dedicates the book to her husband Simon,

Mary dedicates the book to her eldest granddaughter Alice.

We would also both like to dedicate the book to those who do caring now and will become carers in the future.

CONTENTS

LIST OF FIGURES AND TABLES

Chapter 2

Chapter 3

Chapter 4

Chapter 5

Chapter 6

ABOUT THE AUTHORS

Alisoun Milne is Professor Emerita of Social Gerontology and Social Work at the University of Kent, UK. She has been involved in work on family caring for over twenty years; this included being a member of the independent advisory committee, the Standing Commission on Carers. Alisoun has written widely on care and caring issues and is embedded in national and international care-related research and practice networks. Up until 2021, Alisoun contributed to undergraduate and postgraduate social work programmes that included teaching on family care and carers.

https://www.kent.ac.uk/social-policy-sociology-social-research/people/1950/milne-alisoun-j

@alisounjm

Mary Larkin is Professor of Care, Carers and Caring at the Open University, UK. She has extensive experience of carer research and working with carers and carers organisations. Not only does she publish widely but her expertise in family caring has led to her membership of national and international bodies, committees and commissions. Mary's many years of teaching in higher education has included the development of courses about, and for, carers. Within the Open University she has spearheaded strategies to support students and staff who are carers.

https://www.open.ac.uk/people/mml5

1

INTRODUCTION

Family care is a prominent and universally challenging twenty-first century issue. At least 60% of UK adults will become a family carer at some point in their lives (Carers UK, 2019a; Organisation for Economic Co-operation & Development, 2021). Although it is now part of everyday discourse, the term ‘carer’ has been variously defined over time accommodating changes in the population as well as shifting understandings of issues such as age, culture, gender and what constitutes a ‘family’ (Larkin & Milne, 2014). This is reflected in its evolution from the focus solely on ‘single women caring for elderly parents’ to the contemporaneous widely accepted definition, that 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: https://carers.org/about-caring/about-caring)

As this book will demonstrate, the concept remains contested. For many of those who actually ‘do caring’ the word carer has limited meaning; indeed, as many as half of carers do not own the term (Bowlby et al., 2010). Whilst acknowledging these tensions, the above definition is the one we have adopted for this book. The rationale for this decision is three-fold. The exploration of any group of people requires (some) clarity of definition. The Carers Trust definition not only offers us this, but it also makes explicit a key conceptual dimension of family caring, namely that carers are unpaid. Paid carers will be referred to (mainly) as care workers or care staff to avoid confusion. Whilst some terrain is shared by carers and care workers, for example gender issues, definitional differentiation is essential in order for us to be confident about the academic and experiential territory we are exploring in our book.

A third issue relates to a distinction between caring that is normative or ‘usual’, for example looking after a healthy child, and caring for a person with specific support needs because of illness or disability. Parents who are caring for a chronically ill or disabled child would usually be defined as ‘carers’, whereas parents with dependent children who do not have a long-term health condition or disability would not. The boundary between ‘the family’ and a ‘family carer’ is a fourth issue. We acknowledge that support and care by families take a number of forms and that family relationships intersect with caring ones. The focus of our book is on ‘carers’ and ‘caring’; the wider impact of ill health and/or disability on relationships and families is addressed but not in any depth (Price & Walker, 2015).

The combination of cultural variation, contestation and definitional inconsistency means that the shape and profile of who is – and who is not – regarded as ‘a carer’ is dynamic and complex. Nonetheless, that the number of carers in the UK – and across the world – is increasing and is predicted to continue to increase is widely accepted. In 2021, it was estimated that there were 10.6 million carers in the UK and at least 647 million carers worldwide. 4.3 million people become carers every year in the UK; there are 12,000 ‘new’ carers each day (Carers UK, 2022a). In 2001, 2% of the UK population were carers; by 2011 this figure had risen to 12%, and by 2019 it was 15%. Predictions pre-COVID-19 (COVID) suggested that by 2037 the number of carers in the UK will have increased to over 11 million (Brimblecombe et al., 2018a; Larkin & Milne, 2014). COVID led to a dramatic rise from 15% to 26%, i.e. 13.6 million people; an *additional* 4.5 million people started caring during the pandemic (Carers UK, 2020c). It is not known how many of these 'new' carers will become carers in the longer term, but it seems very likely a significant proportion will, increasing numbers still further.

There are a range of intersecting factors which have contributed to the increased demand for family care. The ageing profile of the UK – and worldwide – population is a key driver. There has also been a reduced use of institutional care; improvements in the lifespan of children and adults with lifelong disabilities; a continuing demographic shift to smaller more dispersed families; and cuts to support services for the carer *and* the cared-for person. The relatives that carers support now tend to be older and/or are much more dependent than they were 20 years ago; care tasks are also more demanding, time consuming and complex (Larkin et al., 2019). The policy context in which these socio-demographic changes have occurred is an additional key influence. Over the last 30 years social care policies have been underpinned by an assumption that people with dependency needs are best cared for by their relatives in the community and that reliance on public services is to be avoided except in the most extreme of circumstances. This is an issue to which we return in Chapter 4.

The carer population is not only changing in size but also in nature. It is estimated, for example, that the numbers of people taking on a caring role each year (pandemics excluded) is very similar to the number whose caring responsibilities come to an end. More carers are also undertaking serial caring roles; an increasing number are caring for an elderly parent, for example, and then later on in their life course, are caring for their spouse (Carers UK, 2021a).

In terms of who carers support, the most frequently identified conditions – in descending order of likelihood – are age-related health problems such as frailty and dementia; mental illness; people at the end of life and cancer (Larkin et al., 2019). Most carers support just one person (83%), although 14% care for two people and 3% are caring for three people or more (Carers UK, 2019a). This issue is explored in Chapter 2.

Caring roles and tasks range from the relatively moderate to the very intensive. Tasks include shopping, preparing meals, collecting medication, cleaning, doing the laundry, taking someone to medical appointments, administering medication, offering personal care (such as bathing and dressing), physical help (such as getting in and out of bed), social and emotional support, helping with financial matters and/or benefits, keeping an eye on the person, taking them out and organising formal services and/or professional care (Carers UK, 2019a; Larkin & Milne, 2014; Petrie & Kirkup, 2018). What carers do with, and for, the cared-for person varies depending on their level of need, their condition, what other kinds of support they receive (from other relatives or formal care services) and the nature of the care relationship.

The number of tasks and amount of care carers provide also varies; as might be expected, it reflects the nature and intensity of the care tasks. A carer might provide a few hours of care a week – shopping, collecting medication and taking someone to medical appointments – or may care 24/7. Those providing more intensive care such as personal and physical care tend to provide more hours of care per week (Carers UK, 2019a). More intensive carers tend to live with the person they support i.e. they are co-resident. Research from 2019 shows that on average carers in the UK provide 19.5 hours of care per week; just under half (48%) provide care for 20 or more hours; and a fifth (21%) care for more than 50 hours per week. Some carers care for many years; recent evidence suggests that over two-thirds of carers (65%) had been carers for over 5 years whilst almost a quarter (23.5%) had been caring for 20 years or more (NHS Digital, 2019).

In most middle- and high-income countries care of those with dependency needs would be unsustainable without the provision of family care. It represents 9% of global GDP (International Alliance of Carer Organisations, 2021). In the UK the economic value[1] of family care has been estimated to be £193 billion per year, outstripping the total cost of the National Health Service (NHS) (Carers UK, 2020a). In 2017 it was estimated that 149 million hours of care a week were being provided by family carers in the UK. At least an extra 4 million full-time care workers would be required if family carers ceased providing care tomorrow (Petrie & Kirkup, 2018).

WHY WRITE THIS BOOK?

Our intention in writing this book is to bring key dimensions of the carers discourse together – for the first time – into a single critical narrative presented in an accessible and yet academically informed way. Whilst there is a plethora of material on care and carers, it tends to be disparate, fragmented and located in a number of disciplinary spheres:

---

[1] This is the cost of replacement care provided by unpaid carers based on an official estimate of the actual cost per hour of providing home care to an adult.

academic research, policy and service related material, carer generated evidence, theoretical analysis, public health, social care and social work, and work relating to rights, social justice and inequalities.

Our aim is to help readers make sense of the complexities of carers and caring and offer a 'way through' the carer terrain. Given carers' contemporary and global significance and the fact that family care is of growing public and policy concern, the book is both timely and relevant to a wide target population.

Carers are uniquely situated on the intersection of population ageing, social policy, the family, gender issues and the role of the welfare state. Carers are both a public and a policy issue and a private family matter (Phillips, 2007). They are the focus of academic analysis and research and are of increasing concern to services and care practice. Carers are enmeshed with the concepts of care and caring, both conceptually and in the language of the everyday. The very nature of care itself is under scrutiny; questions about the boundary between the informal sector and formal services, how far care is a 'task', how far a 'duty' and how far 'a dimension' of all human relationships infuses literature in both the academic and non-academic spheres (Barnes, 2012).

How carers and caring are conceptualised is an important issue as it shapes the nature and direction of policy. In turn, policy shapes how care is arranged and organised and the role of support services. In a context of welfare constraint, the primacy of neo-liberal principles, and a strong emphasis on 'evidence of effectiveness' of services, carers tend to be conceptualised as unpaid members of the care workforce. Some commentators – and carers – would say that carers are exploited, expected to do the work of paid carers on an unpaid and unsupported basis and there is well-documented evidence about the negative implications of long-term intensive caring for the physical and mental health of carers, their income and quality of life (Larkin et al., 2019: see Chapter 3).

The book's content and tone is informed by the lens of social and health related inequalities, offering a conceptual analysis that both extends understanding and challenges existing thinking in relationship to care and caring (Barnes, 2006; Larkin, 2011; Milne, 2020). It also makes visible issues of social justice. If we are to protect the well-being and rights of the growing number of carers and engage meaningfully with developing models of sustainable care for people with support needs, reframing 'carers issues' is an essential pre-requisite. Caring is explicitly a political issue as well as a personal, family and societal one.

Our book is made up of 7 chapters, including this one. Chapter 2 outlines the *Profile of Family Caring in the UK: Patterns and Trends*; the key dimensions of 'what we know' about carers (mainly) in the UK and what they do. Chapter 3 reviews the *Impact and Consequences of Caring on Carers*, including the range of negative emotional, financial and physical consequences linked to caring and also benefits associated with caring. Chapter 4 – *Supporting Carers* – outlines care-related policy and what is known about the role and effectiveness of services for carers. *Conceptualising and Understanding Care and Caring* is the focus of Chapter 5; it explores two key blocks of material, conceptual lenses on care and caring, and understanding the nature of care and caring. Chapter 6 – *Social Justice, Social Citizenship and Rights for Carers* – reviews the intersection between carers, social justice and rights and ways that these inform a fairer more egalitarian model of care and support for carers. In Chapter 7 – *Final Reflections: Looking Forward* – we offer a brief overview of the book's contribution to the public understanding of care, caring and carers and offer the reader some key 'takeaway' messages. Particular attention is paid to caring and inequalities. Whilst the book's chapters build on one another, they can stand alone; links between issues and chapters are made where useful. As COVID is a global issue of some significance, we have woven material relating to its implications for carers where relevant. We offer a number of case examples; for reasons of brevity we have been obliged to be mindfully selective.

We intend to achieve a balance between breadth and depth in the book. Whilst we identify different caring challenges and populations of carers, there are some groups we have not had room to include, e.g. carers of those with HIV/AIDS. We have said little about the role of friends or communities, not because we do not consider them to be important but because it is relatives who provide the majority of unpaid care. Our focus is primarily adult carers supporting another adult although we do refer to young (aged under 18 years) carers and parent carers of disabled children. As those carers who do more intensive levels and types of care are the most challenged, we pay particular attention to them. We also discuss policy and the law, but we are not addressing specific legal issues here; that is the role of more specialised texts. Whilst we acknowledge that care and caring are global issues, space does not permit country-specific analysis beyond the jurisdictions of the UK. With theories too we have inevitably engaged with those that have had the greatest influence on carer-related discourse, research and on contemporary understanding of care and caring.