

# TAKE CARE

How to be a Great Employer for  
Working Carers

David has got his timing just right. With heightened awareness of ‘care’, this guide will be a landmark publication. It is an extraordinary combination of the personal, the reflective and the practical. I intend to make sure it is in the first red box of every new Minister charged with responsibility for Social Care for years to come! Look hard into this book – for somewhere inside it, is you.

— *Rt Hon Alistair Burt MP,  
Minister for Community and Social Care 2015-16,  
Co-Chair APPG Carers and President,  
Carers in Bedfordshire*

Caring matters to us all. We are cared for at birth, we care for our children, we care for our parents, and we end up being cared for. Our longer lives means many people need to keep working longer and not drop out because of caring responsibilities. This book bridges the moral case for why carers need support with the business case for doing so. Employers are going to face worsening skills and labour shortages and will need to make it possible for employees who are carers to keep working – just as we have done for women with children. I hope it will be widely read and acted on.

— *Geoffrey Filkin, Chair, Centre for Ageing Better*

While there are a plethora of resources available internationally to describe the role of carers; not all are written in the absorbing, down-to-earth and reader-friendly way that David has mastered.

— *Ara Cresswell, CEO, Carers Australia*

In this short & very readable book, David shows why and how employers should care for their working Carers. I hope it will also inspire more Carer associations around the world to create equivalents of Employers for Carers, which has had such an influence on policy for carers in the UK.

— *Baroness Jill Pitkeathley,*  
*Co-chair All-Party Parliamentary Group on Caring*

{Take Care} should become required reading for those wishing to understand, introduce and develop great policies and practice for working carers.

— *Ian Peters, Chairman Employers for Carers, UK*

David has been pushing forward the agenda on responsible business for many years. He is very much doing so again now with Take Care, challenging us to think about how employers can help their working care-givers - and crucially why it makes good business sense to do so.

— *Momo Mahadav|President & CEO,*  
*Maalal|Business for Social Responsibility, Israel*

We live in an ageing society, so it is critical that people are able to work for as long as they need and want to. Helping workers with caring commitments makes it possible for more of them to stay in work or return to work. David Grayson has produced a compelling case with plenty of practical and successful examples from around the world.

— *Andy Briggs, Chief executive officer of Aviva*  
*UK Life and Chairman of Global Life &*  
*Government Business Champion for Older Workers*

## ABOUT THE BOOK

*Employers large and small need to take care!*

They are at risk of losing some of their most valued and valuable employees. They will not lose these employees to competitors or to self-employment but to the employees' loved ones for whom the employees have significant caring responsibilities. The average UK workforce today will have at least one in every nine employees who are juggling their job with caring for a loved one. In Canada, this is 1:3. This may be a parent or elderly relative; a partner; a disabled son or daughter or a close friend.

Caring is a natural part of life — it is fundamental to the human condition. Many of us, when we start caring for someone, don't think of ourselves as a 'carer'. We are simply doing what comes naturally as a loving son or daughter, partner, parent. Sometimes, caring can be a short episodic burst — perhaps when a loved one needs help to recover after an operation or is suffering from severe depression. Other voluntary carers may be caring long-term and the amount of their caring progressively increases. Many working carers simply give up on juggling work, caring and personal life and quit their jobs. This can be bad for them (the negative caring nexus: greater financial pressures, greater social isolation, poor physical and mental health); bad for their employers (loss of institutional memory, productivity and of experienced and talented staff); and bad for society as employees with

caring responsibilities who feel forced to quit their jobs, will have lower pensions and fewer savings to fall back on in later life and will, therefore, be more dependent on the state.

Yet it need not be like this. Smart (as well as responsible) employers understand the business as well as the moral case for helping employees with caring responsibilities to stay in work. Such organisations identify their employee carers, offer flexible and home-working, carer-leave, support internal networks of employee carers, provide access to advice and information, and continuously learn and improve, through exchanges with other employers as well as regular feedback from employees.

# TAKE CARE

How to be a Great Employer for  
Working Carers

BY

**David Grayson**



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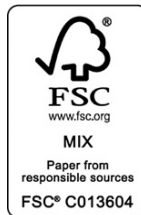
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INVESTOR IN PEOPLE

Dedicated to the memory of Patricia Grayson  
(1922–2015).



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*There are only four kinds of people in the world — those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.*

*— Rosalynn Carter,  
Former First Lady of the USA and  
founder of The Rosalynn Carter  
Institute for Caregiving*

## FOREWORD BY ARA CRESSWELL

While there are a plethora of resources available internationally to describe the role of family and friend carers, the pressures upon them, their contribution to both the people they care for and to the wider society and what supports they need to sustain them, not all are written in the absorbing, down-to-earth and reader-friendly way that David has mastered.

While David has canvassed a range of issues relating to the caring role, the focus on combining work and care has particular resonance for an Australian audience.

Several times throughout this publication Australia's good record in recognising both the value and needs of carers is cited. It is indeed true that carers have achieved a high profile accompanied by a more supportive policy environment in the last decade.

The national government and many states have introduced Carers Recognition Acts which formally recognise and value the role of carers, acknowledge that they have their own legitimate needs for support within and beyond their caring role, recognise that they should be regarded as partners in care by medical professions and other service providers which support those they provide care to, and embody charters for carers and place obligations on public service agencies to honour those charters. (Unfortunately the penalties for not observing the admonitions of the Acts are negligible.)

In 2014 changes were made to the national Fair Work Act 2009 (which sets national employment standards) to recognise an entitlement for unpaid carers of up to 10 days of paid personal/carer's leave which can be accumulated from year to year.

Very importantly, the social security system incorporates a Carer Payment for carers who cannot work because of the demands upon them as carers and who meet a means test. It is roughly the equivalent of the Age Pension and is indexed to average male weekly earnings. In addition, a fortnightly indexed Carer Allowance of AU \$124.75 is available to assist with the additional costs of caring for carers providing substantial care. Carers on the Carer Payment, Carer Allowance and Veteran's pensions are also eligible for a lump-sum annual payment of AU \$600. The Carer Allowance and the annual payment are available to carers even if they study or work.

Both the national and state and territory governments also contribute to the costs of providing carer support services. In particular, the focus on carers being able to combine work and care has assumed a very high profile in recent years. The reasons are varied, but for government a particularly compelling reason arises from a pre-occupation with the long-term economic cost of social security. The research shows clearly that the longer people stay out of employment because of their caring responsibilities, the less likely they will be able to return to employment when their caring role diminishes or ends. They will very likely simply transition to another, albeit less generous, social welfare payment and, in the absence of their capacity to accumulate superannuation benefits,

will be reliant on the aged pension when they are past working age.

Persuading employers of the value of recruiting or keeping carers in their employ is a more challenging task. David's book canvasses in detail the case for employers from the perspective of their business interests — including the benefits of keeping experienced employees, reducing the costs of recruitment, the value of a loyal workforce and the benefits of workforce diversity which has become a prominent theme in management and business literature.

Importantly, David highlights that a carer-friendly workplace is not just a matter of employers taking on carers or keeping them on where they acquire caring responsibilities or the caring role intensifies. As a number of carer stories in this book highlight, the understanding and support of managers and co-workers is particularly important. This means that a truly carer friendly workplace makes the effort to educate all its employees about the role of carers, not just the human resources parts of the enterprise.

A workplace which values carers and wishes to assist them to combine work and care will also make information available about where carers can get support and services outside the workplace.

David has identified a range of strategies, models and case studies for creating carer friendly workplaces which will be of great assistance in the campaign to capture the hearts, minds and hip pocket nerve of employers and foster a commitment to assist their employees to combine work and care.

Ara Cresswell  
*CEO Carers Australia*

## FOREWORD BY IAN PETERS

‘No one should need to care alone’. This rallying cry from Carers UK’s 50th anniversary campaign should equally apply to those who juggle work and caring responsibilities. However, employers’ attitudes towards working carers generally significantly lag that for parents with children.

I have known David Grayson for over 20 years in various capacities, most recently as colleagues on the board of Carers UK. It is entirely consistent with David’s long held conviction that employers can be forces for good, that his personal experiences of caring so articulated in this book, have led him to what should become required reading for those wishing to understand, introduce and develop great policies and practice for working carers.

In his own words, this book is a cross between a ‘how to guide and a call to action’. David lays out a seven step approach from discovering the need through to monitoring the effectiveness of policies. I confess that as the former leader of a large organisation quoted by David as an exemplar in this field, we felt our way there by listening and acting. This blueprint would have been really helpful 10 years ago!

David brilliantly combines the power of individual stories with a deep insight into worldwide analysis of what has worked, what has failed, the challenges and opportunities. From Helen at Westpac in the preface, to

his own story, to Craig Hughes and James Melville-Ross as exemplar leaders, the stories drive home his insights in a compelling and memorable way.

Demographics in the developed world make it clear why this book should be read by multiple audiences from business leaders, to HR professionals, academics to policy makers. Caring is becoming a universal human experience. In the United Kingdom 1 in 9 employees are carers, with that rising to 1 in 6 for those aged 45–64. By 2030 that will be 1 in 6 and 1 in 3 — a figure already reached in Canada. Once an employee spends 5 hours per week caring, it impacts their work, health and often earnings potential. Without the necessary empathy, information, flexibility and support far too many leave the workplace.

Retaining that experience, returning former carers to the workplace, and recruiting young carers makes good business sense. It is not corporate philanthropy.

There is no single template on what will work for every organisation, but the book highlights three common pillars: leadership by example; supportive and empowered line management; flexibility to changing individual circumstances.

David lays out many examples of great practice, which are often set in a wider context of a commitment to diversity, inclusivity and corporate responsibility. He highlights the opportunities created by existing and emerging technologies to redefine both support for working carers and also new forms of self-employment and collaborative enterprise for those combining work and care.

He shows how non-UK countries now lead the way in carers leave, with France and Belgium using fiscal incentives to grow local support businesses.

The book is uplifting but also sobering. While much has been done by many enlightened companies and governments, much remains to be done. Adoption is hugely variable; SMEs are largely not yet engaged; employers cannot fully address the issue without high quality local care provision and supportive public policy; too many organisations have ‘hidden carers’ concerned about the perceived adverse impacts of declaring they are carers.

David admits to being an optimist and a campaigner. Encouragingly he has a track record of success. This book will increase the probability of success in this area.

In my capacity as Chair of Employers for Carers (EfC) in the United Kingdom, the only self-financing employer led carers group in the world, I share David’s aims and optimism. EfC has built a membership base representing over 1.25 million employees and an easily accessible compendium of best policy and practice. We have doubled our membership in 3 years as awareness grows, and we now sit at the table of government policy.

The provision of excellent workplace support for carers is a fourfold win: for the carer; for the employer; for the wider economy through higher tax and lower benefits; and importantly for the person being cared for.

David’s book should help accelerate the momentum and I commend him for his initiative and passion.

Ian Peters

*Chairman Employers For Carers*

## PREFACE

*Work: the chance to be me!*



*“It’s not just a question of the money. It’s the opportunity to use my experience and skills, to contribute to my workplace and community, and to enjoy some social life among a wonderful group of supportive colleagues. Very importantly, it gives me the chance to be just me, “Helen” the person, as well as the loving mother and carer of Ben.”*

Together with her husband Peter, Helen Johnson has cared for her profoundly disabled 24-year-old son Ben since his birth. Ben was diagnosed with Rubinstein-Taybi Syndrome (RTS) at birth and has a severe intellectual disability, medical, physical and sensory complications due to a further diagnosis of Autism Spectrum Disorder at 3 years of age.

Sadly, Ben also became a paraplegic in 2009 after an ‘unexplained’ postoperative complication causing an ‘incomplete spinal cord injury’. To date Ben has had to endure 54 surgical procedures all in Melbourne, 180 km from the family home in the Australian state of Victoria.

The Johnson family has faced intense financial and emotional distress. In addition to Ben needing 24-hour care, his disabilities have come with enormous medical, specialised equipment and other associated costs. Helen says caring is a ‘tough job’.

‘It is financially restraining, emotionally stressful and complex... so much goes into organising your own life and someone else’s as well’.

When Helen gave birth to Ben, her employer — the Australian bank Westpac Banking Corporation — gave her as much ‘Carers Leave’ as required.

However, when Ben was 3 years of age, ‘I could not envisage my ability to return to work due to his chronic illness and the 24/7 care needs I was required to provide therefore, I sadly resigned from Westpac in 1996’.

In 2003 an ex bank manager opened her own Financial Broker Service and asked Helen to join her on a casual basis, even though Helen continued to need a great deal of time off due to Ben’s medical needs and health challenges.

‘However, after 12 months a particular Westpac Manager heard I had returned to work and approached me to return to Westpac on a casual or part-time basis. Of course I jumped at the chance, and returned as a casual employee with the agreement of 100% work flexibility, as Ben was, and continues to be, my number one priority. I continue to be employed with Westpac to this day but I have now obtained a permanent part-time position with an on-going agreement and permission to have work flexibility to support Ben whenever required’.

Helen has received the full support of her workplace managers and colleagues at Traralgon and now Morwell Westpac branches in Victoria, which has enabled her to work part-time while still attending to Ben’s immediate needs, countless visits to specialists and frequent surgeries

‘My wonderful Managers and work colleagues continually provide me with amazing flexibility and understanding with my arrival times in the morning as often I don’t know what to expect each morning when entering Ben’s room to help prepare and get him ready for the day.

Firstly, you would not believe the enormously long medical regime we have to go through for Ben, however when the ‘odd’ surprise is thrown in with the “everyday” stuff that’s when it is NOT a GOOD START TO THE DAY!

Some mornings (or in the late hours of the night or early hours of the morning) I would enter his room and it would be like a murder scene because he has put his fingers so far up his nose (he loves holes) that he would have a continual blood nose and he would smear blood everywhere!

However, it is a really bad morning (or night) when I enter his room and I discover he has managed to dislodge his continence pad and managed to smear faeces over every part of his body, in his mouth, in his ears, up his nose, in his hair and all over his bed. This is why I am required to do 2 to 3 hourly night checks on him every night and we also have to ensure his catheter is flowing and not blocked and that he is comfortable due to his minimal ability to move and re-position his body.

It is also not unusual for him to have a small vomit in the night and of course because he cannot call out to us, he just has his little “silent vomit” makes sure he can smear a majority of it over every part of bed and himself and then quietly lays his head straight back down and continues to snore! He truly is a placid young man’.

## THE IMPORTANCE OF WORK IN THE CARING JOURNEY

As Helen says: ‘It’s not just a question of the money. It’s the opportunity to use my experience and skills, to contribute to my workplace and community, and to enjoy some social life among a wonderful group of supportive colleagues. Very importantly, it gives me the chance to be just me, “Helen” the person, as well as the loving mother and carer of Ben’.

‘Although my job in the bank is demanding I continually say, I go to work for my sanity and for my “respite”. My work life helps me keep sane! I know I would not be the person I am today, without my employment. I also believe without my work, my own emotional mental

health and well-being would be challenged. It gives me the necessary social opportunities and connections. Working gives me a meaningful purpose, separate from my intense caring role. It gives me my own independence, enables me to contribute financially towards my family's needs and helps create financial sustainability for our future'.

What did it feel like when Helen gave up work to care full-time for Ben?

'I felt emotionally devastated, ripped off and extremely sad. I felt we were financially crippled because we had just built a house based on having two salaries. I felt very low, as if life had been pulled out from under me. Everything I had worked so hard for, I felt I had lost all my dreams. I had so many fears. What use will I be to my family, to both my sons but especially my son with severe and multiple disabilities? How will I manage to care for him when I know nothing?'

Helen is very honest about the mental health issues she encountered and how much she benefitted from a counsellor whose own son had been severely injured in a driveway accident from a car. 'She showed me that my feelings were ok and normal and that I can and will get through this'.

## HOW EMPLOYER SUPPORT MAKES A DIFFERENCE

'I am so proud to have Westpac as my employer as it truly is supportive to its employees and especially to those who are carers. Another example is when an employee is applying for Annual Leave; on the electronic leave request

it has a question, ‘Are you applying for annual leave to care for someone or for medical reasons?’ Also some of the Westpac Employee Perspective Surveys asks the Question: Are you a Carer? Do you Care for somebody? I think these questions are an example of a sincere, carer-focussed company who truly cares about its employees and their overall health and wellbeing. My managers, work colleagues & Westpac (as an employer) have been SO supportive to me as an unpaid family carer and to my family situation with regular reminders that ‘family comes first’ and ‘family life work balance’. I am forever grateful for their amazing on-going support’.

Twenty plus years on and you don’t need to speak to Helen for very long, before realising she is a great example of the old adage that ‘if you want something doing, ask a busy person!’ Besides caring for Ben and working for Westpac, Helen also works two days a week at a State-wide Disability Support Service in Melbourne as a Parent Support Worker and an NDIS Education Facilitator. This workplace is 360 km round trip from home requiring an early start and would not be possible without the support of her husband (Ben’s father) Peter, as he also engages in flexible Carer work hours to enable Helen to leave early in the mornings.

Helen is also a National Carer Ambassador for Carers Australia and in 2015 received a Nomination for ‘Australian of the Year’ and although she did not win she said it was an absolute honour to have received this National recognition for her passion and dedication in advocating for and on behalf of Carers across Australia. She also sits on a number of federal government consultative committees for carers and disability, which meet in

Canberra. Helen is also a Volunteer Board Member for a local Gippsland Disability Service Provider — Interchange Gippsland and a Volunteer Board Director for Carers Victoria which is a State-wide Carer Service. She has served on both Boards for over 10 years and she is currently the Vice President of both organisations. Also, Helen recently received a Life Membership to Carers Victoria for her passion and ongoing commitment to creating positive change for Carers throughout Victoria and Australia.

Her advice to other carers? ‘Never say never! I thought it would be impossible to return to work after Ben was born. Be honest with your employer: I know some people choose not to talk about home life and their personal caring situation – especially men – but if possible, it is important to do so, because employers can’t assist and support you if they don’t know of your caring responsibilities. Many more employers are attempting to support their employees who are family Carers but it has to be a two-way street and I believe good communication with your Manager’s and Work Colleagues is the key. If possible, whilst on Carers Leave, keep connected with your employer: sometimes it is hard to think beyond your caring role but it is important to ensure a smooth transition back to work when it is possible to do so!’

Despite being an intensive, long-term carer, Helen can also work because she has an employer that strives to be a great employer for working carers, she has supportive line-managers, understanding co-workers, customers who want to be served by Helen because of her empathy and vitality, employer policies for flexible working, carer leave, a relevant EAP (Employee Assistance Programme)

and above all — a co-determination to make the arrangement work.

*Take Care* is about how to ensure that many more people juggling work and looking after a loved one, can do so successfully and positively.

# INTRODUCTION

WORKING AND CARING: THIS IS PERSONAL

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**Photo courtesy of Michael Holt.**

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This book is dedicated to my mother Patricia Grayson (1922–2015).

She is the reason why I have written this book.

Mum was a primary-school teacher for almost 40 years. She graduated with distinction from Edgehill Teaching College in 1942. Apart from one term teaching in York, all the schools she taught at were in Sheffield and subsequently in North East Derbyshire. Her early classes in the Darnall and Attercliffe areas of Sheffield in the later years of World War II and immediately

afterwards had more than 60 pupils. On a very conservative estimate, given the much larger class sizes she faced in the early years of her career, there were more than 1500 people whose early years of schooling were at the hands of mum.

A couple of days before mum died, Louise — the student nurse who accompanied the district nurse for much of mum's final, palliative care at home — arrived with some additional medication. She had collected it from a local pharmacy and was keen to report the exchange she had just had with the lady handing over the medication:

'It is for Mrs Grayson? She taught me. She was the best teacher I ever had!'

As mum's neighbour Pauline also discovered over the years, that was not an unusual experience. In doctors' waiting rooms, at bus-stops, in shops and restaurants, there would be a familiar routine. Someone would look over, nervously smile and finally approach mum with a similar message of gratitude and appreciation.

As Dame Julia Cleverdon wrote after mum's death:

'Your mother influenced generations to step up to their responsibilities — to give more and get more from their lives.'

Mum's gift for engaging young children never left her. Penny Hawley described bringing her two young sons Hew and Eddy on several Christmas visits to South Ridge towards the end of mum's life:

'As you might have gathered from my questions at the time, I was worried about bringing the boys along to meet her, because most of us age more in our ideas and attitudes than our bodies and struggle to remember why small children are curious and inconvenient. Not the

marvellous Mrs Grayson who welcomed us all and clearly delighted in chatting with Hew about iPads and the other things he was interested in. She had such warmth and enthusiasm that she captivated us all. The inspiration she must have been to the hundreds of children who passed through her classroom shone through’.

Shortly before her 90th birthday, I encouraged mum to write down a list of some of her happiest moments. As might be anticipated, many of the moments involved the family but several of the happiest memories that she had listed first were about things in her teaching career. I believe mum was a great teacher because she genuinely cared for and was always interested in people. As her great-nephew Sam wrote on her 90th birthday poster: ‘she lit up the room’ and as he wrote on hearing of her death: ‘she made you feel so loved whenever she saw you’.

In similar vein, her great-niece Caroline wrote: ‘she always remembered every detail of what I was up to! She was a fantastic lady ... and like a fifth grandparent’.

Mum and I always enjoyed a close and loving relationship, as only children in particular usually do with their parents. On my 11th birthday, she and my late father had to rush me into Sheffield Children’s Hospital. What the local GP had days earlier diagnosed as a sprained knee was actually a rare and life-threatening bone disease in the hip: osteomyelitis, complicated by septicaemia. I was critically ill. For several days, it was touch and go whether I would live or die. Subsequently, the specialists suggested that if I lived, my parents might have to face the prospect that I would not walk again. Happily, the medics exaggerated. It was, however, to be a year before

I did walk again — on crutches and several years before I could walk unaided. Meantime, I had my left hip removed and I spent many months in a hip-spiker (a plaster of Paris casing from my upper chest to my toes — with strategically placed holes) whilst my leg, minus hip, fused in the hip-socket. Throughout this time, my mum never missed a day's hospital visiting. Whenever it was possible, mum nursed me at home, giving up her teaching job to do so. At the age when children are learning to grow more independent of their parents, I became entirely dependent again on mine — and especially my mother — to take care of my bodily functions, feed me, keep me distracted, reassure me. Mum didn't just care for me physically. She also helped me to deal with the 'why is this happening to me? If there is a God, why is He doing this to me?' despair and anger. Mum subsequently returned to teaching, in substantial part to pay for me to go to a good school and then to Cambridge — the first person in my family to go to university. Mum subsequently took early retirement from teaching to care for her mother at home. In time, she also cared for her best friend and then became carer for my father in his final years.

### Becoming Mum's Carer

So, decades after mum nursed me through the osteomyelitis, when first dad and then my mum started to need more help, it just seemed the natural thing to try and do my very imperfect best to help them and support them. Caring for loved ones after all is part of the human condition, part of what it is to be fully human, part of the

natural rhythm of life, as the quotation from Rosalynn Carter reminds us. I certainly didn't think of myself as a 'carer' — just a son helping his parents and looking after them. In all likelihood, I would have continued as a 'hidden' or non-self-identifying carer, but for Helena Herklots. Helena and I had previously served together for 5 years, on the board of a major social enterprise providing sheltered housing and domiciliary paid care for older people. Helena had often heard me at board meetings, ask whether I would accept something being proposed for clients, if it was for my own parents, in evaluating proposals. Shortly after she became CEO of the charity *Carers UK*, Helena got in touch again and invited me for a coffee. When we met, she quietly explained that at any one time in the United Kingdom, 6.5 million Britons are caring unpaid for a loved one — and that Carers UK is there to help and support these carers. Then she dropped the bait! 'Many people don't think of themselves or identify as a carer'. She paused. I smiled. I took the bait! Three months later I joined the board of Carers UK. Fast-forward another year and I became chairman as the charity was gearing up for its fiftieth anniversary.

## LEARNING HOW EMPLOYERS HELP CARERS JUGGLING JOBS AND CARING

I quickly discovered that many care-givers are juggling their job and their caring responsibilities; and that one of the initiatives of Carers UK is *Employers for Carers* — an alliance of employers including British Gas, BT, KPMG, Sainsbury, the Metropolitan Police and others — who

aspire to be great employers of care-givers. I am passionate about the work of Carers UK. Like the rest of my board and staff colleagues, I want to see a society which respects, values and supports carers. I want an end to carer isolation. No one should have to care alone. Given how many people are working and caring, reaching carers through their employers is one very important channel of communication. Supportive employers can help many carers to stay in work. Where that is possible, it is good for the employer, for the carer — and for the person being cared for and the rest of their family — both short term and for the future. I have a particular interest in this. I went half-time in my own job at Cranfield University School of Management, with a consequent 50% drop in salary and knock-on impact on pension pot, in order to help look after mum in her final couple of years. I don't regret that for a single moment.

### Becoming Mum's Carer

Despite all my previous experience and networks, I still struggled as a carer. My fitness routine was gradually abandoned. Progressively, I stopped accepting invitations to functions that weren't immediately necessary to my current work. Socialising declined. Anecdotal conversations with other carers, as well as research carried out by and for several of the carers' associations around the world, suggest my experience is very common. As one very successful executive with a top global company, who had quit her job to care for her mother, said to me: 'if you and I were struggling, as well-connected, reasonably

well-off people, how much tougher is it for anyone with fewer friends and contacts or in a less fortunate material situation?’ Her question has driven me on to complete this book.

*I want to see a society which respects, values and supports carers. I want an end to carer isolation. No one should have to care alone.*

More and more of us will be juggling work and looking after a loved one. I vividly recall walking through Oxford one Spring evening, several years ago. I was attending the Skoll World Forum on Social Enterprise. I was walking between events with an old friend and mentor Prof Kirk Hanson from California. Kirk is one of the world’s leading business ethicists. I interrupted our conversation in order to make my nightly phone call to mum. I tried to make it the same time, 6 p.m., each night no matter where in the world I was. Kirk patiently waited for me to finish the call and then quietly commented: ‘that is part of my next book!’ I was confused. ‘I thought your next book was about ethical dilemmas every manager will face?’ I replied. ‘It is’, Kirk explained, ‘and looking after elderly parents alongside your work is very much one of those!’

I was very fortunate. I could afford to take a 50% salary cut. Mum had wonderful neighbours: Jim and Pauline Harling, who popped across to see her every day and would alert me if anything untoward had happened when I was not there. I drastically reduced my overseas travel for work. When I did go abroad, we started to experiment with different respite care homes. Invariably, when I returned and collected mum, the home — unprompted — would say what a delight mum had been

to look after; and they would be very pleased if she would like to stay. Mum, whilst unfailingly polite and appreciative to the care home staff, was always keen to get home. Although we did discuss different care options, I knew mum wanted to stay in her own home, if she possibly could — so that was my mission.

Eventually, mum needed 24/7 live-in care. Thanks to a chance introduction from a work colleague, I was connected to a small business *Miracle Workers* specialising in placing live-in professional care workers with clients. We were incredibly fortunate in meeting Ann Luff who looked after mum for most of her final 13 months. Ann's loving and calm presence lifted a great deal of the stress from me. I still made the 520 km round-trip from my home in London to Sheffield and back most weeks, but instead of food shopping and other domestic chores, it could be more about being a son, going through old photographs together, going out for meals and trips into Derbyshire, and reading poems and prayers.

My work on *Take Care* had a three-month hiatus when mum went in to a final, precipitate decline. I had always dreaded that I might be abroad for work and unable to get back in time. As it was, I realised mum was deteriorating, returned to Sheffield and then abandoned my return to London for meetings. It was good that I did. I was up all night with mum. The next morning, her long-standing GP who had only visited the day before, came back again and after examining mum, broke the news that she thought mum was dying. We both knew mum's wishes were to die at home. With the help of Ann, Jim and Pauline and wonderful district nurses, we were able to fulfil mum's wishes. My bedside vigil lasted

11 days and nights. Work colleagues were understanding and covered for me. It never occurred to me that my employer would be unsympathetic; but nor was I aware of formal policies for such circumstances. I simply intuited from my inchoate sense of the university culture. In truth, wild horses would not have dragged me away from mum, but it was still reassuring to feel the empathy and understanding of colleagues and employer. Once I did return to work some weeks after mum's death, I started to think not just about resuming work on *Take Care*, but also about how the university might turn informal custom and practice into a more structured Carers' Policy. My subsequent work on this book has, therefore, gone in parallel with some 'gentle nudging' (I am from Yorkshire remember!) of the University, as I will explain later on.

Looking after my mum in her later years, ensuring she could stay happily and safely in her own home and always have things to look forward to is the most important thing I have done in life and I imagine will remain so. I suspect a bereavement counsellor might consider, in some small way, *Take Care*, as my personal equivalent of 'H is for Hawk' — the acclaimed memoir of Helen Macdonald — a grief-stricken daughter who became obsessed with training a goshawk following her father's death, which won the Costa book of the year in 2015.

## ABOUT TAKE CARE

The book is written to be read straight through. However, for the time-pressed readers, there is an

overview at the start of each section, and key take-aways at the end of each section. There are profiles of nearly 50 different employers and how they help working carers, spread through the text (see the box below).

3M	Multinational conglomerate	US	123
AbbVie	Pharmaceuticals	Israel	72
Accenture	Consulting	UK	140
Ajinomoto Group	Food	Japan	111
Associe International Inc		UK	161
Astellas	Pharmaceuticals	Japan	125
Australian Bureau of Statistics	Government	Australia	140
Aviva Life	Insurance	UK	87
Be Inspired Films	Film-making	UK	159
BT	Telecommunications	UK/ international	118
Camstone	Consultancy	UK	157
CBI Health Group	Health & care	Canada	33
Centrica	Energy	UK/North America	173
Cranfield University	Higher education	UK	236
Credit Suisse	Financial services	UK/ international	143
Deloitte, accountancy & consultancy		Ireland	125
Emory University	Higher education	USA	125
Fannie Mae	Financial services	USA	126
FTI Consulting	Corporate communications	UK	99
Grosser Cleaning	Domestic services	Germany	160
GSK	Pharmaceuticals	international	112
Happy Consulting	Workplace well-being	UK	160

Harvard University	Higher education	USA	124
Hyde Housing	Social housing	UK	112
IBM	Multinational technology and consulting		39
J&J	Pharmaceuticals	USA/ international	88
Johns Hopkins University	Higher education	USA	83
Listawood	Manufacturing	UK	157
Lloyds Banking Group	Financial services	UK	133
London Fire Brigade	Public sector	UK	135
Metropolitan Police	Public sector	UK	82
Ministry of Justice	Public sector	UK	109
Mitsubishi		Japan	111
Network Rail	Transport infrastructure	UK	75
NHS Education Scotland			80
Otsuka	Pharmaceuticals	Japan	115
PWC	Accountancy & consulting	Australia/ international	93
Pukka Herbs	Food	UK	159
Sainsbury's	Retailing	UK	116
Scottish Courts & tribunal Service	Public sector	UK	136
Standard Life	Insurance	UK	147
Taisei	Construction	Japan	125
Thyssen Krupp	Engineering/manufacturing	Germany/ international	112
Unforgettable	Care	UK	161
Unilever	FMCG	UK/ international	125

Unipart	Logistics, supply chain, manufacturing and consultancy	UK/ international	128
Westpac	Financial services	Australia/ international	113
West Dunbartonshire Council	Public sector	UK	110
Wheatley Group	Social housing, community regeneration & care	Scotland	134

## WHO SHOULD READ THIS BOOK?

Ambitiously, I have a number of target audiences for this book: employers, consultants, carer organisations around the world, Workplace Specialists in Business Representative Organisations, Business Development Organisations, Corporate Responsibility Coalitions and Work-Related Think-Tanks around the world, HR academics and professional associations and Governments. This is a diverse group but what they have in common is that they, like me, care about caring. And each organisation can take specific actions to improve its quality.

### 1. Employers

- HR directors
- Finance Directors/Chief Finance Officers – this is a bottom-line issue
- heads of Diversity & Inclusion / team members
- Corporate Responsibility / Sustainability directors

*Desired action:* Establish a carer policy if you don't yet have one; or review and improve if your organisation already provides some support for carers. Become part of a campaign to engage more employers.

## 2. Consultants in

- Talent management and Human Resources
- Diversity & Inclusion (D&I)
- Corporate Responsibility and Sustainability
- Work-life balance/Great Place to Work
- EAP (Employee Assistance Programme) specialist providers

*Desired action:* Add carer issues to your agenda with clients if caring for carers is not already included; or review and improve if you already have some support for carers in your agenda/offering to clients

## 3. Carer Advocacy and Support Organisations around the World

*Desired action:* Consider adding working and caring to your activities e.g. creating an Employer for Carers type initiative

## 4. Workplace Specialists inside Business Representative Organisations, Business Development Organisations, Corporate Responsibility Coalitions and Work-Related Think-Tanks around the World

*Desired action:* Add work and caring to your activities e.g. create an Employer for Carers type initiative in collaboration with your local carers organisations

5. Academics Specialising in Caring, Business School International Human Resource Management Faculty and HR Professional Associations (EG CIPD, SHRM)

*Desired action:* Develop the case for why employers should care for their employee carers, research emergent employer practice, and add supporting work and caring to your professional guidance and International Human Resource Management (IHRM) courses.

6. Governments and would-be Governments

*Desired action:* Politicians responsible for finance, work and pensions, social affairs and health and government ministries covering these topics. Besides an important role as employers of many working carers, a range of government policies and initiatives can support employers to care for working carers — or conversely make employer efforts less impactful.

## UNDERSTANDING SUPPORT FOR WORKING CARERS AS A CORPORATE RESPONSIBILITY ISSUE

My friends and colleagues say I am an inveterate networker and connector (some of them say any encounter with me usually leads to some commitment on their part to do something/meet someone etc!). It is certainly true that I have been a campaigner since before my childhood illness. I do like to spot and make connections for positive impact. In this case, there is a very obvious connection between my day job: as professor of Corporate

Responsibility at Cranfield University School of Management and my volunteering with Carers UK.

Corporate Responsibility is the responsibility which an organisation has for its Social, Environmental & Economic (SEE) impacts. A key part of corporate responsibility is the impact in the workplace: being a responsible employer — and ideally being a great employer.

Caring for working carers is like the missing jigsaw piece for several critical organisational strategies (Diagram 1). These include:

- creating a diverse and inclusive workplace
- talent attraction, retention and optimisation, especially in the context of an ageing workforce
- being a responsible employer

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**Diagram 1: Caring For Carers: The Missing Jigsaw Piece.**



- boosting health and well-being in the workplace and especially, helping to tackle the taboo and stigma of mental ill-health
- being a great place to work
- building employee engagement and advocacy
- sustainably improving profitability through reducing costs and raising productivity
- building organisational resilience and future-proofing.

In a previous role as the first chairman of the UK's National Disability Council (NDC) from 1995 to 2000 (appointed by Parliament to work to end discrimination against disabled Britons), I saw at first-hand how organisations could adapt and develop to become responsible employers of those of us with a disability.

Coming in to Carers UK, it felt like employers of carers were where employers of disabled people had been twenty years ago, in terms of being integrated within mainstream workplace responsible business policies and practices. Back in 1996 when I started as the first chairman of the NDC, I persuaded KPMG to do some pro-bono work looking at the major Corporate Responsibility coalitions internationally. KPMG found that these coalitions were largely silent then on disability issues. A quick trawl of the websites of the major coalitions in 2016 showed them largely silent about employment and caring. Yet as societies age around the world, and as public expenditures come under increasing pressure, how employers can enable their employees to stay in work and simultaneously be effective carers is becoming a global issue. Since I started work on

*Take Care*, I have learnt of interest in Australia, Canada, Israel, New Zealand and Sweden to help employers be better at supporting their employee care-givers. My goal is that this book will inspire and help business organisations, Corporate Responsibility coalitions, carer associations, individual employers and social entrepreneurs, to champion caring for carers — and also provide practical guidance to individual employers around the world.

## HOW THIS BOOK IS ORGANISED

In Part 1, I argue that looking after a loved one is part of what it is to be human: caring is deeply ingrained in faith and philosophical traditions; and that caring will affect most of us at different points in our lives. I look at the Caring Journey and explain why employers and society needs to support better those who are working carers.

Synthesising my knowledge and experience of both corporate responsibility and caring, in Part 2, I set out a Seven Step framework — drawn from my book co-authored with Adrian Hodges, *Corporate Social Opportunity* — which responsible employers can follow to improve their support for working carers for the benefit of their businesses, as well as the carers they employ. I also show that even small employers can care for their carers.

In Part 3 Chapter 1, I describe how organisations can develop their operational practices even further, reaching the highest stages of corporate responsibility “maturity”

to become “Champion” employers in their support for carers. In Part 3 Chapter 2, I consider how to support carers who are working as freelancers. In Part 3 Chapter 3, I suggest how governments and a range of other organisations and networks can build an enabling environment for more employers to take care of their working carers.

#### A THEORY OF CHANGE TO BUILD A SOCIETY THAT RESPECTS, VALUES AND SUPPORTS CARERS

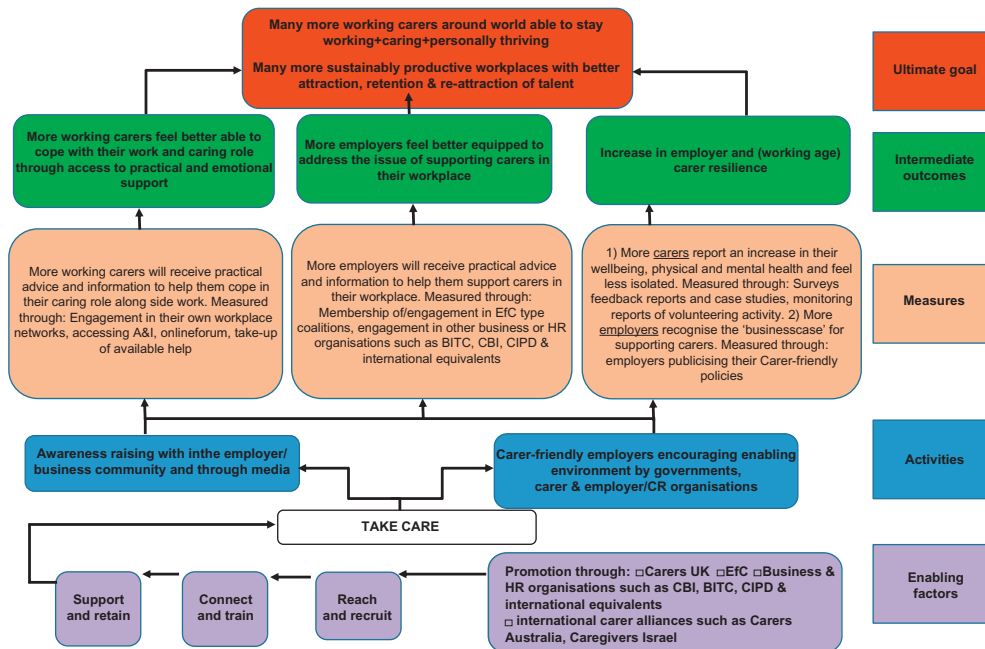
Carers UK has benefitted greatly from a collaboration with NESTA, the independent innovation foundation. NESTA puts a strong emphasis on supporting its partners to articulate a Theory of Change, that they are going to put into practice. A Theory of Change:

*explains how a programme has an impact on its beneficiaries. It outlines all the things that a programme does for of its beneficiaries, the ultimate impact that it aims to have on them, and all the separate outcomes that lead or contribute to that impact.*

This has inspired me to consider my Theory of Change for *Take Care* and the international movement I hope we can unleash. The model is adapted and internationalised from the emerging *Theory of Change of Employers for Carers* (see [Diagram 2](#)).

I discuss how we can collaborate to implement the Theory of Change in my conclusion.

Diagram 2: Theory of Change.



## WANTED: COMMITTED CITIZENS TO CHANGE THE WORLD

One thing that has powerfully resonated with me as I have researched and written *Take Care*, is the role of individual champions at all levels of organisations. Their stories are interspersed throughout the text. If ever I needed reminding of the famous observation of the late Margaret Mead: ‘Never doubt that a small group of thoughtful, committed, citizens can change the world. Indeed, it is the only thing that ever has’, my experience of the men and women I have interviewed and whose stories are told in the following pages, has done so. We need more of these ‘committed citizens’ — champions of carers in the workplace — to ‘come out’, tell their own stories and promote better help for working carers in individual workplaces and in wider society.

My hope is that, working in collaboration with responsible businesses and other partners, we can make support for working carers ‘business as usual’. Many employers are already responding to the expectations and needs of more diverse, multi-generational workforces, with more customised work options. These can be easily stretched and adapted to meet the needs of working carers.

And yes, mum was pretty chuffed that she inspired this book!

## DISCLAIMER

I am chairman of Carers UK. All royalties from *Take Care* will go directly to Carers UK. I am deeply indebted to various colleagues in Carers UK for their help and advice as I researched and wrote *Take Care* – see acknowledgements. I very much hope that I have done justice to the experience and insights of Carers UK and our supporters; and also those of colleagues in a number of carer organisations around the world. Nevertheless, the views expressed in *Take Care* are my own and should not be assumed necessarily to represent the views of Carers UK.

# PART 1



## WHY CARE FOR CARERS?

# CHAPTER 1

## CARING AND CARERS

### INTRODUCTION

*Taking care of a loved one is part of the rhythm of life. The largest number of carers are those caring for a parent or other elderly relative, those looking after a partner with a long-term medical condition, and those caring for disabled sons, daughters or siblings. Ageing populations, advances in medical technology and pressures on state welfare budgets, all mean that in most parts of the world, the numbers of carers is increasing. This includes the numbers of those juggling work and caring. Work can be both a financial necessity and a respite for many carers. It can though also become part of a 'caring vicious circle'.*

Johnnie Walker — the veteran BBC radio disc jockey — and his wife Tiggy were on their honeymoon when Johnnie fell ill. He was diagnosed with a rare and very serious form of cancer. Overnight, Tiggy's own career as a successful producer of TV commercials had to be put on hold as she became Johnnie's carer, chauffeur, cook, contact with the outside world. Happily, Johnnie recovered. 12 years later, the roles were reversed when Tiggy

developed breast cancer and Johnnie became Tiggy's carer. For some, like Johnnie and Tiggy, becoming a carer can happen in a flash — like a bolt of lightning in a clear blue sky.<sup>1</sup> Sometimes by contrast, you slowly, barely perceptibly at first, start helping a loved one with chores and daily routines, until you turn round one day and realise you have become a carer — even if you don't use that word.

Richard is an expat — a Briton living and working in Paris at the headquarters of a major French Pharmaceutical Company. His parents who live in the South-West of England are starting to become frailer and whilst they remain fiercely independent, Richard is noticing that on each visit he makes home, they need a bit more support. He is starting to consider what changes in how he does his job might be needed in the future to care for his parents as a 'distance carer'.

### WHO IS A 'CARER'?

The Guardian and Observer Newspapers' Style Guide defines a carer as:

*An unpaid family member, partner or friend who helps a disabled or frail person with the activities of daily living; not someone who works in a caring job or profession. The term is important because carers are entitled to a range of benefits and services that depend on them recognising themselves as carers.*<sup>2</sup>

At Carers UK we say: ‘A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help due to illness, disability, mental ill-health or a substance misuse problem’.

The umbrella organisation Euro-carers defines a carer as a person who provides unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework. In some parts of the world, the more common term in use is ‘caregiver’.

Employers for Carers offers a working definition of Working carers as:

*Employees with significant caring responsibilities that have a substantial impact on their working lives. These employees are responsible for the care and support of disabled, elderly or sick partners, relatives or friends who are unable to care for themselves.<sup>3</sup>*

## WHY SHOULD WE CARE ABOUT CARING?

### Caring is Becoming a Universal Human Experience

As the Rosalynn Carter quotation at the beginning of Take Care makes clear: Most of us will be involved in caring: as a giver, receiver or probably both at different stages of our lives. At different stages of my own life, I have already been all of those. I had to rely on my parents and other family members when I had a life-threatening bone disease and was immobilised in plaster of Paris for

the best of a year. I saw my parents care for their parents; and I in turn cared for mine.

For many of us, this will include looking after someone else during our working lives. Caring is part of the human condition: It is part of what makes us human. It is integral to loving others and can bring great joy and emotional rewards. As one carer called Donna tweeted to me: ‘Caring: the most isolating, emotionally + mentally draining, worry-filled, financially breaking but best job ever!’

The sheer scale and scope of caring, as well as the growth in carer numbers, illustrates how widespread and diverse the caring experience is becoming in our society. In the United Kingdom, for example, there are 6.5 million carers (58% women, 42% men). The majority are caring for parents, are aged 45–64 years, are juggling work and care, and are more likely to be women in this age group (one in four compared with one in six men). Men are more likely to be caring for partners, women more likely to care for parents and children. 1.4 million are caring over 50 hours/week, 4 million provide 1–19 hours care per week. Today’s 6.5 million carers are projected to grow to 9 million by 2037.<sup>4</sup>

It is estimated that 20 million people across the European Union provide over 20 hours weekly of unpaid informal care work.<sup>5</sup> In the Netherlands, for example, data suggests that in 2014 over 4 million people (33% of Dutch adults) had provided some form of informal care in the year preceding. Informal care is interpreted broadly here, and includes things such as providing emotional support or helping with transport 10% of informal carers provide help only with emotional support or companionship. Many people help long-term (>3 months) but not

intensively (maximum 8 hours/week). Roughly one in six informal Dutch carers provide help for more than 8 hours a week. Over 600,000 people provide help for more than 3 months and more than 8 hours/week. These figures exclude the ‘usual help’ which household members are expected to provide to each other.<sup>6</sup>

In the United States, there are an estimated 65 million caregivers. According to the US National Alliance for Caregiving (NAC), family caregivers provide an average of 20 hours of care per week, and for most, caregiving isn’t limited to a few months, or even a year — NAC’s research found that caregiving lasts an average of almost 5 years.<sup>7</sup> By 2020, one in six Americans will be over 65 years and more than one in three Americans will likely have eldercare responsibilities. In Australia, there are 2.6 million carers.<sup>8</sup>

According to Statistics Canada, in the 15 years from 1997, the number of Canadian caregivers increased by over 5 million, from 2.85 million in 1997<sup>9</sup> to over 8 million in 2012.<sup>10</sup> 8.1 million or 28% of Canadians were providing such care. Of this group, three-quarters (6.1 million) were in the workforce, representing 35% of employed Canadians. The number of Canadian seniors requiring care is projected to double between 2012 and 2031.<sup>11</sup>

Even in Scandinavia where there is a tradition of public social welfare provision, budget pressures are leading to increasing numbers of informal caregivers. As an important study from the influential Chartered Institute of Personnel and Development (CIPD) noted in 2016:

*The relatively good level of state provision in place for eldercare in Denmark means that the*

*families of older people typically do not have to arrange and manage care for them. Danish studies have shown that only a minority of elderly citizens who need care rely on personal help from their family members or other members of their social networks, because the state provision is comprehensive. However, some economists in Denmark note that, in the longer term, the Danish economy will also be under pressure because of the ageing of the Danish population and this trend will eventually bring pressure to bear on the system as it currently stands.<sup>12</sup>*

The study goes on to argue: ‘Providing help for older workers with care responsibilities should be a priority for employers’.

A survey conducted by the OECD in 2011, found that around one in 10 adults in OECD countries were involved in informal, typically unpaid family care.

Encouragement and support for voluntary caregivers is included within the new United Nations Sustainable Development Goals (SDG) adopted in September 2015. SDG 5.4 is to:

*Recognise and value unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate.<sup>13</sup>*

Chris Minett, Founder of Ageing Works (now part of Mercer), talks of the ‘seismic shift’ that will be needed by

individuals and by employers, as many more of us are called upon to care for parents and other elderly relatives.

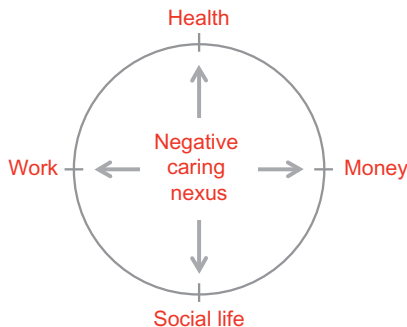
### The Challenges of Caring can Impact all Aspects of Life

Being a carer can be very rewarding, but caring can also have significant impacts on work, social and family life. Caring can also involve great sacrifice – and have physical, mental, social and financial costs. These costs can become negatively reinforcing: a kind of caring vicious circle. Reducing or giving up work generally means less money, which leads to a reduction in opportunities for a social life and increasing isolation, which in turn can impact negatively on physical and mental health (Diagram 1).

It is in the interests of carers themselves, those being cared for, employers and society at large, to tackle the caring vicious circle. No one group alone will be able to defeat the caring vicious circle. It will require

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**Diagram 1: Caring Vicious Circle Nexus Diagram.**



commitment and collaboration. Take Care emphasises the particular contributions that employers of all shapes and sizes can make.

‘Caregiving is a nuanced issue; the intensive, short-term needs of caring for a terminally ill parent contrast greatly with the decades of on-going care required for a child with a disability. We need to recognise that different people need different accommodations in different situations,’ says Stephen Shea, Senior Partner of the Accountants and Consultants at EY (Ernst & Young Global Limited) in Toronto, who chaired a panel on caring and carers for the previous Canadian Government of Stephen Harper.

### Caring Takes its Toll on Carer Health and Well-being

Finding time for yourself is hard and it’s easy for your own health and well-being to become a low priority.

The most recent UK Census (2011) suggests that those providing over 50 hours of care per week are twice as likely to be in bad health compared with non-carers. The GP Patient Survey 2015 showed that whilst 51% of non-carers had a long-standing health condition, this rose to 63% of all carers and 70% of those caring for 50 hours or more. Carers’ own experiences suggest that long-term back problems and mobility problems are caused by long-term physical stress, moving and handling without the right equipment or training. Anxiety and depression rates are high, with Carers UK’s 2015 survey of carers

providing significant care — 77% recording anxiety and 83% recording depression since becoming a carer.<sup>14</sup> 71% of employee carers report loneliness and social isolation.

Carers UK work with carers for our *Alone and Caring Report* found:

- 8 in 10 (83%) carers have felt lonely or socially isolated as a result of their caring responsibilities.
- 57% of carers have lost touch with friends and family as a result of caring and half (49%) of carers say they have experienced difficulties in their relationship with their partner because of their caring role.
- 38% of carers in full-time employment have felt isolated from other people at work because of their caring responsibilities.
- Carers who have reached breaking point as a result of caring are twice as likely to say that they are socially isolated because they are unable to leave the house and are also more likely to have experienced depression as a result of caring.<sup>15</sup>

*Juggling caring and work responsibilities is becoming increasingly difficult for carers, employers...and economies.*

## WORKING CARERS

In Israel, it is estimated 1:4 employees are also caregivers. In Australia, it is estimated that 1:8 (12%) of the working populations are carers. 60% of the estimated 65 million US caregivers were employed at some point in the past


year while also caregiving. There are currently 6.1 million employed Canadians, or 35% of the workforce, providing care to a family member or friend. Most employed caregivers spend 9 hours or less per week caring, but many (24%) are spending up to 30 hours – and some even more. The recipients of care are primarily seniors, and most caregivers are 45 years and older, often talented and experienced employees possessing deep company or industry knowledge. These are key contributors to an organisation and to the Canadian economy broadly — people employers don't want to see exit the workforce.<sup>16</sup>

About 4.3 million out of 6.5 million carers of the United Kingdom are of working age – but only 3 million are in work. Men are more likely to be working full-time and caring for their partner. Women are more likely to be working part-time. In an average, UK workforce, 1:9 employees will also have caring responsibilities. An estimated 2.3 million people in the United Kingdom have given up work at some point to care and 3 million have cut working hours. Many of these employees – the 45–64 years old, often at the peak of their careers – are among organisations' most skilled people.

As the pension age increases, the likelihood of caring during working life, is increasing. Employers, through Carers UK forum and through others like CIPD, are reporting increasing numbers of employers seeing stress, ill-health and difficulty in juggling work and care amongst their employees and rate this as one of the fastest growing issues in their workforce. Despite the challenges of combining care with employment, 400,000 people are

doing a full working week alongside long hours of care (20 hours or more). As social welfare nets decline, it is likely that these numbers will become increasingly similar pro-rata in other countries (Diagram 2).

**Diagram 2: Caring and Working Across the European Union.**

 **Caring for elderly or disabled relatives among people in employment, EU28**

*(At least once a week, by age and gender, 2011/12)*


	Male		Female	
	Carer	Non-carer	Carer	Non-carer
18-24	11%	89%	10%	90%
25-34	7%	93%	10%	90%
35-49	12%	88%	18%	82%
50-64	18%	82%	22%	78%

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 **Providing care at least once or twice a week**

		Non-carer	Working carer	Other carer
Cluster 1:	Sweden, Denmark, Finland	89%	8%	3%
Cluster 2:	Austria, Belgium, Germany, Netherlands, France, Luxembourg	86%	9%	5%
Cluster 3:	United Kingdom, Ireland	82%	10%	8%
Cluster 4:	Italy, Greece, Portugal, Spain, Cyprus, Malta	86%	7%	7%
Cluster 5:	Poland, Hungary, Czech Republic, Slovakia, Croatia, Slovenia	83%	10%	7%
Cluster 6:	Latvia, Lithuania, Estonia	81%	11%	8%
Cluster 7:	Romania, Bulgaria	85%	8%	7%
EU28:		85%	9%	6%


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**Caring several times a week  
or more often**

		Non-carer	Working carer	Other carer
Cluster 1:	Sweden, Denmark, Finland	95%	3%	2%
Cluster 2:	Austria, Belgium, Germany, Netherlands, France, Luxembourg	92%	5%	3%
Cluster 3:	United Kingdom, Ireland	89%	5%	6%
Cluster 4:	Italy, Greece, Portugal, Spain, Cyprus, Malta	89%	5%	6%
Cluster 5:	Poland, Hungary, Czech Republic, Slovakia, Croatia, Slovenia	88%	7%	5%
Cluster 6:	Latvia, Lithuania, Estonia	85%	9%	6%
Cluster 7:	Romania, Bulgaria	89%	5%	6%
EU28:		90%	5%	5%

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## CARING, REDUCING OR GIVING UP WORK AND IMPACT ON FAMILY FINANCES

Giving up work partially or altogether, will have both immediate and long-term negative impacts on the carer's finances: an immediate drop in income and frequently also eating into savings; but also the carer's eventual pension pot will be much smaller.

Having to juggle work with caring duties can lead to significantly lower earnings, as people reduce their working hours, pass up promotion and overtime or even quit. This also has a knock-on effect on the carer's pension funds. According to 2016 research by Age UK and Carers UK, pension savings of those receiving Carer's Allowance are 90% smaller than the average. Many feel forced to give up their own paid work, finding the juggling too

much to bear on top of the strain of looking after someone they love.

Age UK and Carers UK concluded: ‘But when they do stop working the financial loss they incur is huge and often has consequences for the rest of their lives. It is morally wrong that people who do the right thing by becoming a carer should so seriously undermine their own financial security as a result’.

An additional £5.3 billion would flow back into the economy if carers could stay in the workplace until normal retirement age.

From the employer’s perspective, many of the people giving up work to care, will be in the 45–64 age range — which in many organisations equates to the peak years of experience and productivity.

According to the AARP (formerly the American Association of Retired Persons) Public Policy Institute, quoted in *Juggling Life, Work and Caregiving*, American working caregivers often have to alter their working situation, to the detriment of long-term career advancement and financial security:

*‘68% of caregivers have had to make work accommodations, such as taking time off, coming in late, leaving early, refusing a promotion, reducing working hours, changing jobs or quitting. Low-income employees, minorities and women are most likely to make work accommodations to care for older relatives. Cutting back on hours or quitting can hurt earnings as well as health insurance, social security benefits and contributions to retirement plans.*

*19% of retirees stopped working earlier than planned because of caregiving, with significant loss of income: Female caregivers aged 50+ who stop working to care for a parent lose an average of \$324,044 in wages and benefits over the course of their lives: Male caregivers aged 50+ lose an average of \$283,716.*

*Caregivers who work are more likely than their non-caregiving colleagues to have health challenges and report fair or poor health in general.<sup>17</sup>*

A 2016 survey amongst over 3,600 employees at eight Israeli employers conducted by Caregivers Israel found that:

*85% of respondents said their work schedule was disrupted by caring*

*81% reported absences from work due to their caring responsibilities*

*19% had thought about changing their job*

*and 13% had declined a promotion because of juggling job and caring.<sup>18</sup>*

## TRIGGERS TO GIVING UP WORK

Carers New Zealand says there are a number of triggers that may see employees who have caring responsibilities consider leaving. These include:

*An increase in their level of caring*

*An increase in their workload*

*A change in working hours, shift patterns or rosters*

*The start of caring responsibilities, which can be a stressful time for families*

*A sudden health trauma or accident in the family, or a distressing diagnosis*

*Lack of support or understanding from managers or colleagues*

*Inability to work flexibly*

*Struggling to find (and afford) reliable relief care during work hours.*

*In most cases, therefore, making it easier to carry on working – even if it is part-time – will be in everyone’s interest.<sup>19</sup>*

## CARING IS INVALUABLE BUT ECONOMICALLY UNDERVALUED

A 2009 study estimated the imputed economic cost to replace family caregivers in Canada with paid workforce (at current market rates and usual employee benefits) totalled \$25 billion.<sup>20</sup> This equates to 14% of the total healthcare expenditures in Canada.<sup>21</sup>

According to [Family Caregiver Alliance](#),<sup>22</sup> there are approximately 65 million family caregivers in the United States providing care for parents, relatives, spouses and children. The [Valuing the Invaluable: 2015 Update](#)<sup>23</sup> reports the estimated economic value of their unpaid

contributions was approximately *\$470 billion in 2013*, up from an estimated *\$450 billion in 2009*.<sup>24</sup> That is more than twice what is spent nationwide on nursing homes and paid home-care combined.

An August 2015 study by the consulting firm Deloitte calculated that the replacement cost of informal caring in Australia would be Australian \$60 billion p.a. or 3.8% of Australian gross domestic product (GDP vs. Aus \$40.8 billion in 2010).<sup>25</sup> Carers New Zealand estimate that the benefits to the New Zealand economy from unpaid care work probably accounts for around 5% of GDP, or NZ \$10.8 billion a year.<sup>26</sup>

The economic value of the contribution made by carers in the United Kingdom is now £132 billion/year, almost double its value in 2001 (£68 billion).<sup>27</sup> £132 billion is close to the total annual cost of health spending in the United Kingdom, which was £134.1 billion<sup>28</sup> in the year 2014–2015. It is more than the market value of HSBC Holdings or Visa PLC.<sup>29</sup>

The 2015 UK figure is 7% higher than the figure for 2011. This is mostly because carers are providing more hours of care (82%), and partly due to the increased hourly cost of paid home-care (18%). The figures mean that, in 2015, the value of the contribution made by the UK's carers saves the public purse enormous sums every week, day and hour of the year:

- £2.5 billion/week
- £362 million/day
- £15.1 million/hour.<sup>30</sup>

## WHO CARES? CARER ARCHETYPES

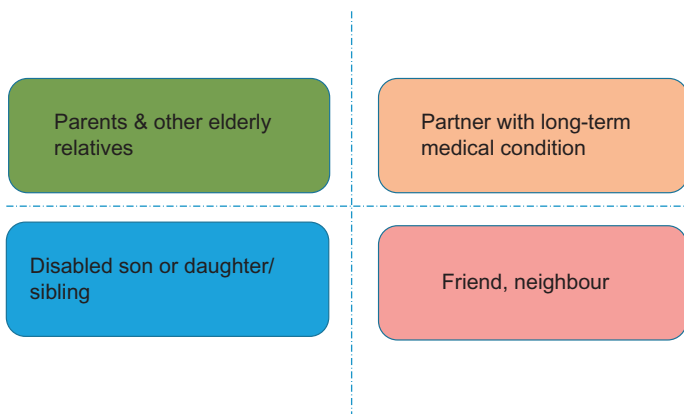
By far the largest group of carers are those caring for an elderly parent or other elderly relative. As populations age across the world, this will become even more pronounced with a growing number of ‘young old’ caring for the ‘old old’. Often, an ‘old-old’ husband and wife will be caring for each other. Over 80s carers are a fast-growing component of carers in a number of countries. My Mum was principal carer for my Dad up to his death aged 86 years. Mum was then 88 years. One reason why populations are growing is because more of us are living longer, thanks to advances in medical technology.

Similarly, more people with severe disabilities are surviving and becoming adults. Significant numbers of carers are looking after a disabled son or daughter. Siblings may suddenly face a double-whammy — needing to start looking after their elderly parents, and also their disabled brother or sister who previously their parents had been caring for, but are no longer able to do so. ‘What if I can no longer care for the person I love?’ asked Bruce Bonyhady, then Chairman of the Australian National Disability Insurance Agency.<sup>31</sup> This will become an increasingly common fear.

A third significant group of carers are those caring for their spouse/partner. This may be for short, intensive bursts as in the case of Johnnie and Tiggy Walker quoted above, or it may involve looking after the partner for several decades if it is a long-term medical condition.

There is also a smaller, fourth quadrant of people caring for friends and neighbours although typically they will be caring less intensively, less intimately than the first

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**Diagram 3: Carer Segment.**

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three quadrants; and children/young people caring for a parent or another, older relative (see [Diagram 3](#)).

Carers may also be defined by the long-term medical condition of the person they are caring for such as carers of people living with dementia or with mental illness, or with an addiction. Another carer segmentation is by communities of identity of the carers themselves such as BME (Black and Minority Ethnic) carers or LGBT (lesbian, gay, bisexual or trans) carers.

#### TAKE-AWAY

Most of us will look after a loved during our lives. Many of us will do so several times. Caring can be one of the most rewarding things we ever do; but it can also have physical, mental, social and financial costs. Early self-identification as a carer and timely access to relevant information and support, can make caring much easier and more rewarding.