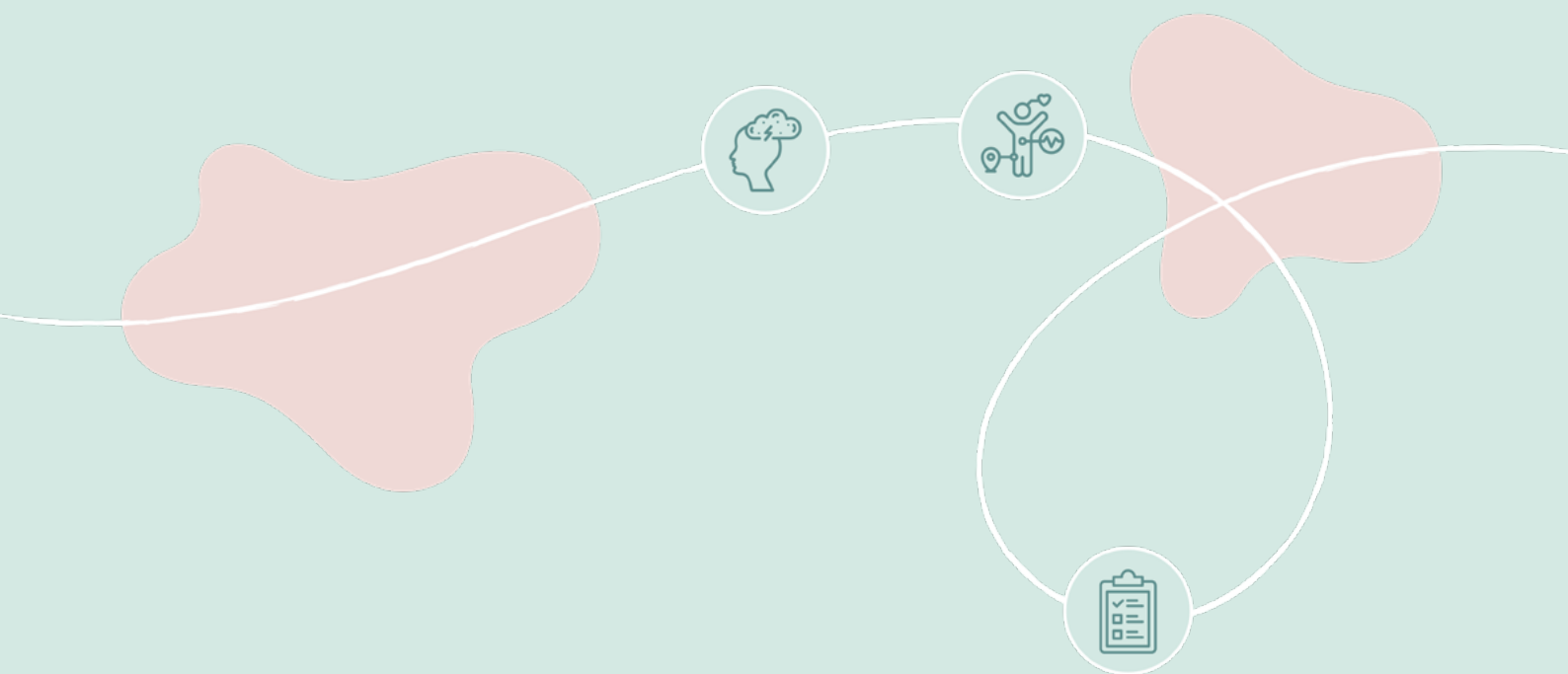




Invisible cancer carers: the hidden impact of caring responsibilities on your employees



Foreword

The incidence of cancer in the UK and its impact on the workplace is fairly well known. Every day around [1,000 people](#) are diagnosed with cancer, and while the incidence has been rising across all age groups, the number of people living with cancer who are of working age has [rocketed by 10%](#) in recent years. Consequently, close to half of all people living with cancer in the UK are of [working age](#). But what about those who are carers for people with cancer?

A cancer diagnosis is not only a major event for the person diagnosed, but also for their family – frequently the default caregivers. In fact, some studies report that the [impact on family](#) members can be even greater than that on patients. In the UK, a growing ageing population, longer survival rates, a move towards outpatient care, and with patients' wishes increasingly to be cared for at home, cancer care is now largely community-based. This has resulted in cancer becoming one of the most common health conditions in receipt of unpaid caregiving.

It will come as no surprise that in [more than 60%](#) of cases the burden of care when it comes to cancer falls on women – who are of working age. And, in general, more women from [ethnic minority](#) backgrounds have caring responsibilities than those from white backgrounds. The pressures on these individuals can be extreme, and not only on mental and physical health, but compounded by financial concerns. Let's not forget the devastating impact Covid-19 has had on cancer care within the NHS and charity-led support services, further increasing the strain on these carers.

We need to act now to minimise the effects of cancer on our workforce and give both those directly affected, and those caring for someone with cancer, the right support at the right time. To help you to do this, in this green paper we outline who the cancer carers in your workplace are likely to be, their responsibilities in providing care, and the impact caring for an individual with cancer can have on their health, while our toolkit outlines key factors to consider when building a policy framework.

With one in two of us likely to have cancer, almost all of us will undoubtedly be impacted in our lifetimes. It is not a matter of 'if' someone in your organisation gets cancer, but 'when.' **Providing effective, comprehensive cancer support must therefore become an essential part of any employer's inclusive wellbeing strategy, to improve outcomes for us all and to protect your most valuable asset – your people.**



Kelly McCabe
CEO and Co-founder, Perci Health

Defining cancer care and carers

Cancer care is defined as the care provided during and following primary cancer treatments such as surgery, chemotherapy and/or radiation therapy, or the longer term care of someone recovering from or living with cancer in the community – including end of life care. The responsibility for this type of care tends to fall on those closest to the individual with cancer. While the estimated number of cancer carers in the UK was thought to exceed [1.4 million in 2016](#), the true number is thought to be much higher as the caring status of many carers goes undocumented. In the workplace, employers have lacked accurate data on carers in their employment, in part because the majority of caregiving employees do not relate to the term carer, taking up to [two years on average](#) to recognise their role, or because of concerns employees have around the impact on their jobs of disclosing their caring status – all of which has made the challenge for employers in developing appropriate policies even greater.

According to the [UK Government](#), unpaid or ‘informal’ care is a private arrangement whereby someone cares for a family member, friend or neighbour who has a long-term physical or mental health condition or disability, or needs care due to old age, and couldn’t otherwise manage by themselves. [Macmillan Cancer Support](#), one of Britain’s largest cancer charities, defines a carer as someone who provides more than five hours of care per week to someone living with cancer, or provides one to four hours of care per week and says that this has a negative impact on their life.



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Defining cancer care and carers *(Continued)*

But why and how do people become unpaid carers? The majority of caregivers take on the role of caring because they feel a family responsibility to do so, and/or because there is little other choice and no one else to provide care to their loved ones. The support tasks involved in being a cancer carer will of course vary depending on the patient and type and stage of cancer. In general though, carers could be providing any or all of the following types of support:

- Providing or assisting with personal care including washing, dressing, bathing and toileting;
- Administering or monitoring the provision of medication (from providing simple pain relief to injections) and ensuring treatment continuity;
- Providing domestic care, including cooking, cleaning, shopping and collecting prescriptions;
- Organising or providing childcare;
- Facilitating access to or providing transportation to get to and from medical appointments;
- Providing emotional and social support; and
- Assisting with financial management tasks.



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The burden of care

Throughout the UK it is estimated that an additional [4.5 million people](#) instantly became carers in March 2020 as the pandemic hit. And many employers only became aware of the true burden of cancer on their workforce once Covid-19 restrictions came into effect, as employees with caring roles explained that their need to provide support for loved ones was impacting their capability to work. Even those who had previously had paid care in place were now left coping entirely, or almost entirely, alone in caring for family members with cancer.

Even before the pandemic, [more than two thirds](#) of UK cancer carers were women, with the majority aged 45–64 and therefore of working age. Women caring for those with cancer are also more likely to become ‘sandwich carers’ – those needing to care for young children as well as parents with cancer. Shockingly, the majority, [almost 90%](#), of sandwich carers are also juggling a job. In total, the average cancer carer spends over [10% or 17 hours](#) of each week looking after someone with cancer. Add children and a job on top of this and the idea of a work-life balance that the rest of us crave suddenly feels frivolous.

In general, women who are sandwich carers are likely to report that their caring responsibilities limit job opportunities and career progression substantially more compared to men in caregiving roles, according to a recent [UK survey](#). The same survey also revealed that more people from ethnic minority backgrounds have caring responsibilities than those from white backgrounds, with one in two ethnic minority carers saying that they had been unable to pursue certain jobs or promotions as a result. The argument for supporting gender and ethnic equality in the workplace becomes even clearer knowing this, and catering for cancer carers alongside those with cancer, should be part of any holistic wellbeing workplace strategy.

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Physical, mental and financial impacts

Unpaid carers are generally more likely to suffer from [poorer mental and physical health](#) compared to those without caring responsibilities – from lack of sleep and exhaustion, to depression and loneliness. In a [2013 State of Caring survey](#), 84% of all carers across the UK said that caring had had a negative impact on their health. In 2021, alarmingly [the same survey](#) revealed that 91% of carers felt their levels of stress and anxiety had increased, 77% reported worsened mental health, while 67% reported worsened physical health.

Specifically, when it comes to cancer caregivers, [a number of studies](#) have shown that women report higher perceived levels of negative experience in caregiving, such as lower mental health, lower physical health, poorer health-related quality of life, lower life satisfaction and decreased marital satisfaction when compared to men caring for cancer patients. Tiredness is unsurprisingly the [most common physical impact](#) on carers. And when caregivers experience poor health, this has shown to lead to [poorer care outcomes](#) and psychological distress for the people they care for – leading to a vicious cycle negatively impacting their ability to work.

Unpaid care provided by family and friends to cancer patients in the UK is estimated to be worth close to [£3 billion each year](#). Financial consequences to the individual carer can result from providing travel costs when taking a patient to and from hospital, providing private care, and when it comes to their employment, as a consequence of having to take time off work to provide care, as well as taking sickness leave where a carer's own health is being impacted.

Due to the pandemic, HR and wellbeing leaders are more acutely aware than ever before of the impact on employees of caring for those with chronic conditions such as cancer, while also juggling the demands of the workplace. How well the physical, psychological and social-wellbeing needs of cancer carers are met, can determine whether their transition back to work will be successful or not. Employers can take a number of steps to support carers as they return to the workplace – from providing access to support services by partnering with or signposting to expert providers of mental health care such as psychotherapists and psychologists, to speaking with employees to understand their needs to return to the workplace confidently from a physical perspective, and clarifying the rights of employees caring for loved ones with cancer – from flexible working options, sickness payments, to communicating extended absences.

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Helen Addis's Story

Helen Addis, founder of the C-List and popular instagram account @thetittygritty shares her experience of undergoing treatment for breast cancer whilst working in a senior role, and the impact this had on her family.

"Before I had my diagnosis, I was a Features Editor for the ITV Lorraine show. I have been there for 20 years now and have built incredible relationships with both my manager and team.

When I was told I had Grade 3 ductal invasive breast cancer which had spread to my lymph nodes, everything moved very quickly – from being told I would have a mastectomy in a week's time, followed by chemotherapy treatment the one after.

I'd told my boss before my diagnosis, "Boss, I'm going to be late tomorrow, I've had a biopsy done on a lump which I need to pick up the results for. So I'll be late in". I then didn't go back. My next phone conversation with her was me telling her I had breast cancer, which was just the strangest thing.

I was off work for about 18 months in total. I'm really aware that I was very lucky to work for a company which could afford to pay me my salary for six months and then move me on to statutory sick pay. It's such a different situation if you are self-employed, for example. Depending on your length of treatment, the longer that you're off, the more there are financial implications and pressures on your return. You've got to keep afloat financially, as well as stay alive.

I liken going back to work after cancer to returning after maternity leave: my life was very different after having children and my life is very different now after cancer. I have this extra element to me, that I'm not sure people will ever understand unless they've been through it too. When you've had a baby your priorities are your baby. My priority is very much my health now as well.

The work/life juggle is now work/life/health. I chose to go back part-time which has really helped me to carve myself a bit of balance. But that comes at a financial cost because I've had to take a pay-cut, which is frustrating because before cancer I was very career driven. The 'old Helen' would have been gunning for it all, but my goalposts have changed now and I try to go easy on myself.

Helen Addis's Story (Continued)

It wasn't just me that was impacted, but my family too. My husband had to work from home a lot more and take days off to accommodate my appointments. We found it incredibly tough to juggle childcare commitments. On the days my husband was in the office, I had to sort school runs. I also heavily relied on friends to help, but in the end we had to get a nanny, which was expensive for us as a family.

In hindsight, I now see the serious impact this has had on my husband and my children – they needed just as much emotional support and information as I did. I wished I had taken their mental health more seriously from the start. I tended to rose-tint everything to protect them. My children could've done with more support at school and my husband could've done with some advice too...just knowing what to expect etc."

Helen Addis has a community on Instagram under her handle @TheTittyGritty. She is also co-founder of The C-List which suggests skin and beauty products for people living with and beyond cancer, and a member of the Perci Health Client Board – a group living with and beyond cancer who guide our service development.

One of my biggest concerns when I first started going back to work was the constant questions from people that I hadn't seen for a long time. It was just really hard constantly retelling my story. So I spoke to my HR in the end and said, "Look, can we just somehow let everybody know what my deal is?". It was in no disrespect to any of my colleagues because they were just being nice, but by having HR speak to people about my situation it made things easier on me.

Helen Addis
Co-founder of C-List



Toolkit – building a cancer carer policy framework

Including support for cancer carers in employer wellbeing strategies could undoubtedly have multiple benefits for both employers and employees, from leading to better employee engagement and productivity, to resulting in fewer days lost due to workplace absence – all contributing to a positive result for employers and leading to happier and healthier employees.

In developing a wellbeing policy framework for cancer carers, employers should consider incorporating the following factors:

Set a clear, inclusive definition of the term ‘cancer care’

- The majority of caregiving employees do not identify as carers. Providing a clear definition can help employers to both identify the number of individuals impacted in the workplace, and to direct those impacted to appropriate resources early on.
- Creating inclusive communication around the definition of a cancer carer will support employees in disclosing their caring status without fear of consequences to their employment status, and assist managers in recognising the importance of caregiving.
- As a guide, the charity [Macmillan Cancer Support](#) defines a cancer carer as someone who provides more than five hours of care per week to someone living with cancer, or provides one to four hours of care per week and says that this has a negative impact on their life. This definition can be included within your organisation’s cancer policy, and communicated to all line managers.

Understand the baseline level of support you provide to cancer carers, and consider how this can be enhanced

- The mental and physical impacts of caring are common among cancer carers. Consider taking an active, innovative role in providing access for employees with cancer caregiving responsibilities to experts such as psychotherapists and psychologists.
- Cancer carers will have hundreds of questions relating to their loved ones condition, care pathway and eligibility for support. Providing access to trained professionals, such as cancer nurses, to answer these questions can save them hours of time and worry spent looking for answers online.
- The financial consequences of caring can be substantial. Pointing caregiving employees to external resources, such as grants, benefits and allowances for carers available through the NHS and charities can help to ease the burden.
- Empower cancer caregivers by making access to resources easily available and discrete for those not wishing to disclose their carer status, for example through digital tools.

Toolkit - building a cancer carer policy framework *(Continued)*

Provide flexible working arrangements

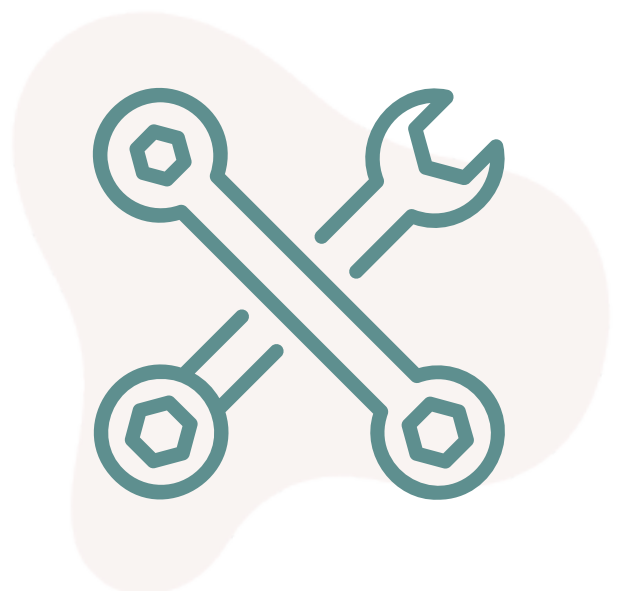
- Demands on cancer carers will vary depending on the type and stage of cancer. Providing flexible working arrangements, for example, where the employee can work from home or during alternative hours, will support a carer in remaining productive and in employment while acting as a caregiver.
- Consider including a number of paid days in addition to existing annual leave to allow cancer caregivers to attend medical appointments etc., and also to help avoid stressful conversations with managers around the need to take time off work.
- It is not unusual for a cancer carer's own health to be negatively impacted as a consequence of their caring responsibilities. Accommodate the need for paid sick leave.

Create a manager training programme

- Understanding the daily demands on cancer carers, and the demographics of employees most likely to be impacted by caring responsibilities (largely women and those from ethnic minority backgrounds) can help managers to be sensitive and respectful. Being aware of their company's carer resources can help managers to feel more confident in supporting employees in a caregiving role.



Dr. Sheela Sharma
CFO & COO, Perci Health



About Perci Health

Perci Health is a workplace cancer support platform. Our personalised one-to-one appointments with qualified healthcare professionals provide your employees with a safe space to ask anything about the effects of cancer.



Inclusive support for every employee

Designed to help your employees during the most complex and challenging times of their lives, whether personally affected by cancer or supporting a loved one with cancer.



The right care at the right time

Virtual access to a multitude of cancer experts - including specialist cancer nurses, psychologists, dietitians, physiotherapists, sexual therapists, hypnotherapists and many more - wherever your employees are based and whenever they need them.



Individually tailored, bespoke plans

We combine technology with human touch points providing holistic, hands-on support for every employee's physical and mental wellbeing.



Positive results for you and your team

Empower employees to define their own goals and make positive, measurable improvements to their lives. Enable leaders to understand and proactively manage the true impact of cancer in the workplace with aggregated and anonymised data.

percihealth.com/employers

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