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Institute for Employment Studies

Cancer & Employment Survey

Summary of Key Findings

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In partnership with WORKING WITH CANCER

Institute for Employment Studies

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Contents

Executive Summary

Despite an encouraging increase in survival from cancer in recent years the proportion of people living with cancer who return successfully to work remains disappointingly low. In this survey of over 1,200 people living with cancer, we explore the factors which make a successful, sustainable and fulfilling return to work more likely, and explore the barriers which remain for those returning to work during or after treatment.

Among our findings are the following key points:

- The proportion of cancer patients working full time at the point they receive a diagnosis falls significantly once they have finished their treatment. However, the proportion who are the main income earners in their household remains very high suggesting that most want to continue to work and, for some, the financial pressure to remain at work can be significant.
- Among those who have returned to work, knowledge of the 2010 Equality Act and its provisions was low at 57 per cent. It is clear that HR and occupational health professionals are not doing enough to raise awareness of the obligation to offer reasonable adjustments and a phased return to work and wider employment rights.
- One-third of respondents did not phase their return to work and one-quarter had to take leave during their treatment.
- Those with advanced or metastatic cancer reported lower levels of support for their return to work. Those with breast cancer reported more support than people with other cancers.
- The frequency with which healthcare professionals discussed return to work is low. It is especially disappointing that GPs, occupational health professionals and clinical nurse specialists appear not to be prioritising return to work advice.
- Among those who have not yet completed their treatment, more than four in five plan to go back to the same job but almost three-quarters of the remainder planned to switch employers.
- Awareness of the Equality Act is higher in this group (ie those still in treatment) at 70 per cent and most are aware of their entitlement to a phased return to work.
- Nine in ten of our respondents reported positive experiences of support from their employer and from colleagues with many having access to time off for medical appointments and flexible working, although once more those with primary cancer and breast cancer reported better experience of this support.

- Among all respondents, where they had already returned to work or were planning to do so, there was strong demand for return-to-work coaching, flexible working including working from home, and reduced duties especially during a phased return.
- The majority of our respondents told us that the mental health consequences of a cancer diagnosis and subsequent treatment are considerably worse than the physical effects. This can lead to the psychological and mental health consequences of cancer being understated or even ignored by those with most influence over the work outcomes of many cancer patients.

The survey results suggest that many of those with advanced or metastatic cancer – and some with a terminal diagnosis – are struggling to get return-to-work support which meets their needs.

The experience of a cancer diagnosis and treatment frequently has a profound effect on working age people, often in ways not commonly appreciated by employers, co-workers and even some healthcare professionals. Employers cannot rely solely on the individual compassion and empathy of their managers and employees to improve the experiences of colleagues who are navigating their way through cancer treatment and recovery. They must embed solid principles of job redesign (in which work tasks are re-ordered to reduce workloads or work intensity), a phased return to work and vocational rehabilitation in their policies and practices to ensure that all employees with a cancer diagnosis (and other chronic conditions) have the best chance of thriving at work once they return.

Among healthcare professionals there needs to be a realisation that, for many cancer patients of working age, the risk of losing their connections with work, or having their employment status or incomes eroded by cancer treatment and its consequences can be very significant. For these professionals, more systematic consideration needs to be given to the possibility that a successful return to work may have therapeutic benefits for many patients and should be regarded as a high priority clinical outcome of cancer care.

The Institute for Employment Studies (IES) and Working With Cancer team are conducting follow-up interviews with some of our survey respondents and will be conducting more detailed survey analysis in the coming months to examine the experiences and preferences of specific groups of people living with cancer.

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1. Why is Work Important to Cancer Patients?

Even before the Covid-19 pandemic, there was a consensus that cancer represents one of the UK's most urgent public health challenges. Now, with concerning reductions in self-referral and delays in accessing both diagnoses and treatment, it will be some time before the true impact of the pandemic on cancer cases and survival is known. In the meantime, the incidence of cancer continues to rise, with half of those born after 1960 likely to receive a diagnosis at some stage.

Globally the annual incidence of cancer is in excess of 14 million (Ferlay et al, 2015) and this number is forecast to increase to about 25 million (Bray et al, 2015) new diagnoses a year by 2025. Because of changes to retirement ages around half of those diagnosed with cancer are of working age (Ferlay et al, 2018). This, together with improved survival rates, means that employees who want or need to continue working after a diagnosis will be more common in workplaces of the future. Yet the data tells us that achieving and sustaining successful return to work is much harder than it ought to be (Amir et al, 2018; Petersen et al, 2019; Tamminga et al, 2010). Sadly, fewer than two-thirds of employees with cancer have returned to work or are still working a year after getting a diagnosis (Mehnert et al, 2013). Recent research has estimated that job loss is experienced by up to 53 per cent of people living with cancer and unemployment can be 1.4 times more likely in people living with cancer than among people without cancer (Stapelfeldt et al, 2021).

Some of the barriers patients face are clinical. Profound fatigue, lack of stamina, the side effects of chemotherapy or radiotherapy treatment, frequent follow-up appointments and the need to avoid infection, for example, can interrupt regular attendance at work and make sudden and unpredictable absences from work common (Duijts et al, 2014; Dorland et al, 2018). Some barriers are psychological (Fong et al, 2018; Van Muijen et al, 2013). During and long after treatment, a lack of confidence – even among high performers – or low self-esteem are common, as is a fear of what the next scan might reveal and a worry that colleagues see you as a burden or 'flaky' and unreliable. Anxiety about being shunned at work, about your job or career prospects being permanently damaged, or colleagues not knowing how to talk to you are other common experiences (Stergiou-Kita et al, 2016; Duijts et al, 2017; Bevan, 2020).

As we have learned during the pandemic, work satisfies many more needs for individuals than just being a source of income. It is a way of remaining connected with others, is a source of identity, meaning and purpose, and connects people to their community and society as a whole. It is also a way of feeling that an individual can make a contribution and make a difference to others (Bevan, 2018, Armaou et al, 2018, Greidanus et al, 2018). Work can even have therapeutic benefits for those living with chronic or fluctuating health conditions and those who are experiencing anxiety or depression. With survival rates for people living with cancer on the rise, it remains a concern that so many working age patients find it so hard to remain in or return to work. To investigate why this might be and what might be done to help IES and Working With Cancer have collaborated on a new survey of people living with cancer. This document provides an overview of our survey findings so far and includes some anonymous ‘free text’ quotations from our respondents to provide some real-world examples of their experiences.

2. About the Survey & Our Respondents

The survey was conducted in the last quarter of 2021 and a total of 1,241 people completed all or some of the questionnaire, depending on which questions were relevant to their circumstances. Key characteristics of the respondents include the following:

- Over 90 per cent are female and 75 per cent were white (UK heritage).
- Almost 70 per cent are educated to degree-level or above.
- Almost 60 per cent work in professional roles and a further 19 per cent are in managerial/ technical roles.
- Just over 40 per cent of respondents received their diagnosis between the ages of 40–49 and 33 per cent between the ages of 50–59. Those with a diagnosis of breast cancer were, on average, in the younger age groups.
- Before their cancer diagnosis, 73 per cent were working full time, but this figure fell to 46 per cent post-treatment.
- Before their cancer diagnosis almost 58 per cent were the main ‘breadwinner’ in their household and, post-treatment, this proportion fell only slightly to 51 per cent.
- A total of 72 per cent of our respondents had returned to work after treatment and a further 28 per cent were still having treatment.
- When diagnosed with cancer almost 81 per cent had primary cancer and 17 per cent had advanced or metastatic cancer. At the time of our survey, 64 per cent were in remission, 18 per cent were having treatment for primary cancer and 15 per cent were having treatment for advanced or metastatic cancer.
- Over 80 per cent of respondents had received surgical treatment for their cancer, 70 per cent had received chemotherapy and 66 per cent radiotherapy. Over 97 per cent reported side effects from cancer treatment with fatigue (93%) brain fog (68%), pain (54%), anxiety (60%), loss of confidence (55%) and peripheral neuropathy (43%) the most commonly reported.

The main focus of the survey was to find out more about the support which working age cancer patients receive both during and after treatment, the barriers they face to returning to work and the measures which employers and healthcare professionals are taking to make a successful and fulfilling return to work possible for a higher proportion of people living with cancer. Let’s look first at the experiences of those who have completed their treatment.

3. Returning to Work after Cancer Treatment

Almost three-quarters of our respondents had returned to work after completing their treatment – meaning that 25 per cent did not. Up to 40 per cent told us that they had worked during their treatment, although this was less common among those under 60 and those in manual or unskilled jobs. Almost 85 per cent returned to work with the same employer and, of the 15 per cent who returned to a different job, over half (56%) had changed employer. Although 98 per cent of these respondents told their employers about their diagnosis, those in non-standard work (eg temporary or agency work) were much less likely to disclose this to their employer or to colleagues.

I was lucky enough to be well enough to work during treatment, which had great psychological benefits, as work is a big part of my identity. I was motivated to find a new role following how my line manager had treated me, during treatment, but due to my physical appearance (no hair), my confidence was affected, and it took me a year to find an alternative role.

Overall, only 57 per cent of respondents who had returned to work were aware of the provisions of the 2010 Equality Act requiring employers to make ‘reasonable adjustments’ to support return to work. Of those who did know about this legislation, only 22 per cent had found this out from their HR or occupational health advisors

I was promised a phased return but when I came back to work this was ignored. I had to take annual leave for medical appointments. There was an expectation that as I looked normal I was fine. I would have liked some support including help with my workload.

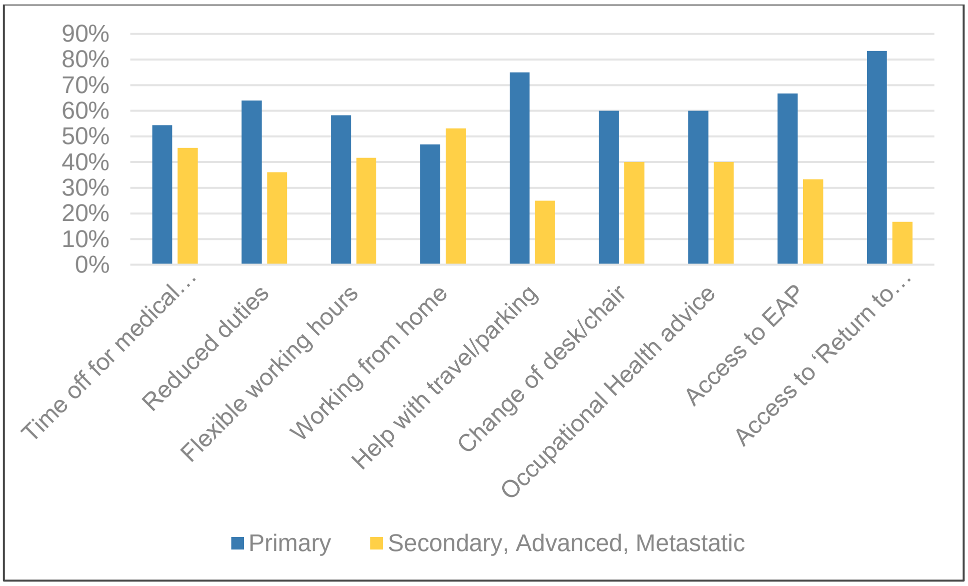
Only two-thirds of respondents told us they had a phased return to work, and almost a quarter had to take annual leave during their treatment. Almost 80 per cent reported that their employer had supported them ‘very well’ or ‘quite well’ as they returned to work and almost 90 per cent reported good support from colleagues.

I had very good support from my employer during treatment. I am hugely appreciative of all the support I had at the time of diagnosis and primary treatment (and since) from a number of people including medical professionals and people at work (whether line managers or HR contacts). I feel lucky to be where I am today 4 years on and want to be able to continue to work and be independent.

Access to Workplace Adjustments

We asked respondents who had completed their treatment and returned to work which adjustments their employer had provided. The results appear below (Figure 1).

Figure 1 Workplace Adjustments Received – by Stage of Cancer Diagnosis



Source: IES/WWC Survey, 2022

The most common adjustments were 'time off for medical appointments', flexible working hours, working from home and reduced duties – although each of these was more common for those with a diagnosis of primary cancer than those with advanced/metastatic cancer. A higher proportion of those with a breast cancer diagnosis reported having access to these adjustments than those with other cancers.

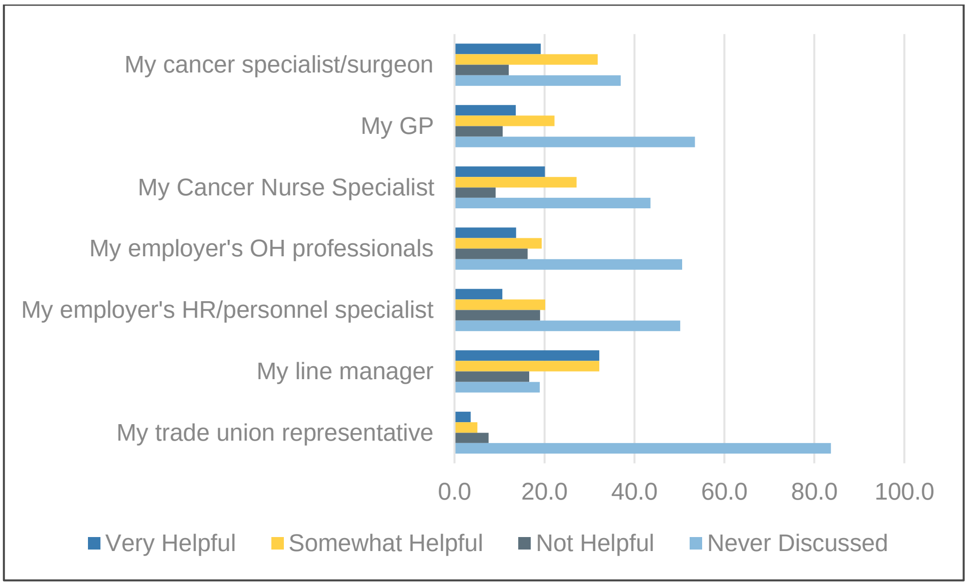
> *When I was on sick leave after surgery and whilst I was recovering - my colleagues kept in touch and could be kind. The difficulty really started at the point of my return - particularly from my manager. Despite my GP and consultant pressing for a phased return my work were totally unsupportive and denied this. I used my annual leave for medical appointments and my psychologist appointments arranged by the hospital. HR were not supportive even saying after my DIEP reconstruction 'well aren't you lucky having a boob job and tummy tuck'. No I was not lucky.*

When we asked respondents about the kinds of support they would have liked more access to, almost a third cited 'return to work coaching' and 1 in 5 mentioned both 'reduced duties' and 'EAP counselling'.

> *You go back to work after 18 months off and everything has changed including your body and its very hard to get back to normal. Physically I was and have never been the same person. Mentally it was extremely hard to get back to normal life.*

We also asked this group of respondents about the helpfulness of the advice they were given by various professionals when returning to work. The results are presented in Figure 2, below.

Figure 2 – Helpfulness of Return-to-Work Advice



Source: IES/WWC Survey, 2022

These results show that helpful conversations about a return to work (RTW) after cancer treatment are being held relatively infrequently by both healthcare professionals and HR/line managers. For example, more than 50 per cent of respondents had no RTW conversations with their GP (53%), with their employer's occupational health (OH) professional (51%) or with their HR professional (50%). Similarly, no such conversations were held with cancer nurse specialists in 44 per cent of cases.

> *I think health professionals themselves continue to learn about the emotional and physical effects post cancer, and my experience is that their knowledge and understanding of post cancer effects on emotional and physical health varies widely.*

By contrast, cancer specialists and surgeons held such conversations in 63% of cases and line managers in 68 per cent of cases. Only a minority of respondents worked in unionised environments, which accounts for the low incidence of RTW discussions reported. Where RTW conversations were held, those with cancer specialists/ surgeons, cancer nurse specialists and line managers were felt to be the most helpful. A clear message here is that the return-to-work advice which is given by cancer nurse specialists is widely regarded as helpful, but that only a minority are providing it routinely to their working age patients. This appears to be an area where clear improvements can be made.

> *My manager made it clear she did not want me back, she suspected that I would be unreliable. She undermined my confidence to the extent that I was a nervous wreck. She kept saying 'so*

many things had changed', but refused to tell me what, even shouting at me that she wasn't my Mother, I would have to find out myself. She kept saying she thought I wasn't safe & I was 'woolly headed' & acting like I didn't really want to be there. She accused me of not being proactive. My union said they could approach her on my behalf, but it would be like 'putting a stick in a hornet's nest'. I eventually resigned'

I recognize that I am very fortunate in my employer. This makes me reluctant to change jobs, which will probably affect my career progression. Also, I have turned down progression opportunities in favour of remaining in a job I know whilst waiting for cancer related surgery that was cancelled during the pandemic second peak.

Although the majority of our respondents who had completed their treatment reported examples of being supported in their efforts to return to work, a quarter did not return to work at all. In addition, the proportion working full-time fell from 73 per cent before treatment to 46 per cent after treatment. In addition, while 58 per cent were the primary income-earners in their household before treatment, even after treatment over half (51%) remained the main breadwinner. This suggests that, while working part time can help the process of adjusting to work again, the financial pressure to return can also be significant.

In the next section, we look at the experiences of cancer patients who are planning to return to work but who have not completed their treatment.

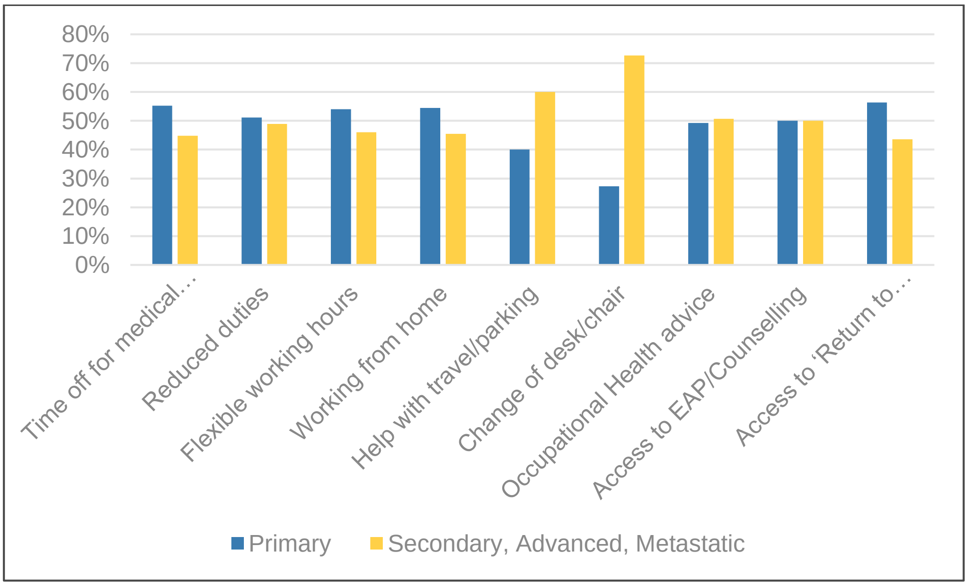
4. Planning a Return to Work

We were also interested in the return to work plans being made by survey respondents who had not yet completed their treatment. In this group, 86 per cent plan to return the same job, although among the 14 per cent planning to RTW in a different job, 72 per cent plan to change employer. The majority had told their employer (98%) and colleagues (92%) about their cancer. Over 70 per cent were aware of the provisions of the 2010 Equality Act, although the main source of this information was social media rather than their employer. Over 80 per cent reported that they were aware of their entitlement to a phased RTW.

Over 90 per cent of respondents told us that their employer was treating them 'very well' or 'quite well' while they were receiving cancer treatment – those with breast cancer reported significantly better support from their employers than those with other cancers. Similarly, 94 per cent of respondents told us that their colleagues were being 'very' or 'quite' supportive. However, these positive experiences with colleagues were reported less frequently by those with advanced/ metastatic cancer than those with primary cancer.

We asked respondents still receiving treatment about the kinds of support they had from their employers, 93 per cent said that they had been given time off to attend medical appointments, 78 per cent reported having access to flexible working arrangements and 70 per cent said they were able to work from home. Figure 3, below, shows how access to these arrangements varies between those with primary and advanced/metastatic cancer.

Figure 3 Workplace Adjustments Received – by Stage of Cancer Diagnosis



Source: IES/WWC Survey, 2022

Overall, those with primary cancer reported having better access to most types of support than those with advanced/ metastatic cancer. Once again, those with breast cancer reported having better access to support than those with other types of cancer.

> *I don't feel like my brain has ever recovered from chemo and this has had a massive impact on my work, I constantly worry I'm going to make mistakes or forget things. I have a really poor concentration span & dreadful memory.*

When asked about the additional support they felt they would need to support their return to work in the future, 52 per cent mentioned 'time off for medical appointments', 49 per cent 'flexible working', 41 per cent 'reduced duties', 32 per cent 'RTW coaching' and 31 per cent 'working from home'.

> *I am amazed at how supportive my employer is - they are going above and beyond, and it does not feel like the norm. This is not my first diagnosis or treatment, and I know going back is going to be really hard. I want to be doing some training during chemo, but so far haven't been feeling well enough. Learning to start almost from scratch next year will be almost as tough as the treatments, I think.*

It seems that the impulse to return to work after cancer treatment is strong in this group of respondents. This, in part, is because work is a powerful source of social connection and provides many with an animating purpose and a return to 'normality' after the often difficult experience of cancer treatment. A return to work can represent a very significant psychological and financial 'milestone' on the pathway to recovery which some healthcare professionals and employers may not fully appreciate.

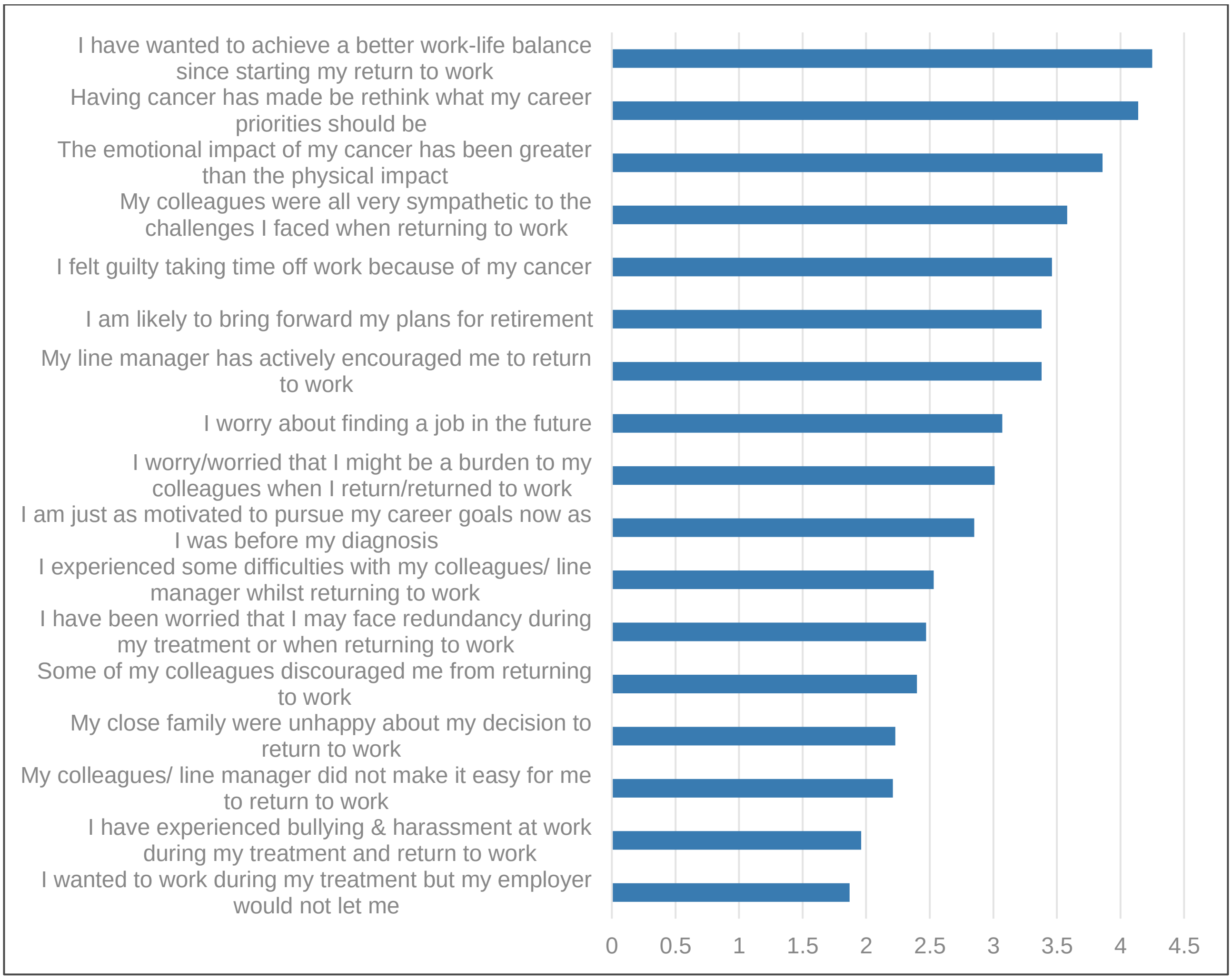
Our survey data suggests that, for many people contemplating a return to work, their concerns focus on both the practical barriers they have to overcome and the psychological adjustments they will need to make. The data shows that many were confident that some logistical help with time off for medical appointments and access to flexible working arrangements would be provided by their employer. However, for many, there was also a desire for ongoing support through coaching or counselling to help them to sustain a psychologically healthy and successful return to work.

We also asked our respondents a number of questions to explore the concerns they had about returning to work, and these are summarised in the next section.

5. Impact of Cancer on Working Life

We asked all of our respondents to indicate whether they agreed or disagreed with a number of statements about the impact of their cancer and cancer treatment on a number of aspects of their working lives. The results are summarised in Figure 4, below, with higher scores equating to high levels of agreement with each statement.

Figure 4 Impact of Cancer Treatment on Working Life *(high score=agreement)*



Source: IES/WWC Survey, 2022

The statements attracting strongest agreement indicate that:

- work-life balance is a big priority for most;
- many have started to reassess their career priorities because of cancer;

- most feel that the emotional impact of cancer treatment exceeds the physical impact;
- colleagues have been very supportive; but
- many have felt guilty about taking time off work because of their cancer.

I am lucky that I can afford to work part time which is great for me My work has been unfailingly supportive - my manager and work colleagues. I do feel guilty that I'm not pulling my weight as I'm not doing face to face work which means my colleagues do this in my place. This is made worse by the fact that I am feeling physically well just now.

There were some differences in the ways different groups responded to these questions, most notably:

- Younger respondents (34–44 years) were more likely than older respondents (55–64 years) to say they remained motivated to pursue their career goals. As might be expected, older respondents were more likely to indicate that they were likely to bring forward their plans for retirement.
- Those with breast cancer were more likely than respondents with other cancers to say that the emotional impact of treatment was greater than the physical impact.
- Fear of redundancy was higher among respondents working full-time.
- Older respondents were more likely to agree that they had experienced bullying and harassment at work during their treatment than younger respondents. Younger respondents told us that they felt guilty about taking time off when having treatment.
- Respondents with breast cancer were more likely to express concern that they might be a burden to their colleagues when returning to work.
- The majority of our respondents told us that the mental health consequences of a cancer diagnosis and subsequent treatment are considerably worse than the physical effects. This can lead to the psychological and mental health consequences of cancer being understated or even ignored by those with most influence over the work outcomes of many cancer patients.

Our data on the concerns of our respondents shows clearly that the experience of a cancer diagnosis and treatment frequently has a profound effect on working age people, often in ways not commonly appreciated by employers, co-workers and even some healthcare professionals. Employers cannot rely solely on the individual compassion and empathy of their managers and employees to improve the experiences of colleagues who are navigating their way through cancer treatment and recovery.

I feel my biggest barrier to doing more work now (and maybe in future) is that with lower life expectancy I feel more duty to prioritise time and energy for my young kids who are probably going to have to live without a mum for much of their childhood. I have no desire to work less or

> *change my ambitions but i know having everything is not possible. Can this be part of the debate?*

6. Conclusions

For many cancer patients there is no doubt that navigating a return to work after cancer treatment is becoming easier than even a decade ago. Sadly, there are still too few who can be sure of the kind of support offered by the best employers and our survey has highlighted some of the areas that still need to change.

Employers must embed solid principles of job redesign, phased return to work and vocational rehabilitation in their policies and practices to ensure that all employees with a cancer diagnosis (and other chronic conditions) have the best chance of thriving at work once they return (Islam et al, 2014; de Boer et al, 2015; Brusletto et al, 2018; Lamore et al, 2019). This requires planning, preparation, capability-building, education and awareness-raising among managers and a strong voice for cancer patients themselves. The ideas of self-management and co-production are key here – the person who is in the best place to judge what will facilitate a successful return to work is most often the employee him or herself (Stergiou-Kita et al, 2014; Sesto et al, 2011). As we have seen, however, they can often be anxious about asking too much of their employer, their boss and their colleagues. Innovative approaches to peer support and coaching interventions which support both employees and managers can help make a sensitive topic less difficult to discuss (Tavaarwerk et al, 2016; Nitecki et al, 2022).

Among healthcare professionals there needs to be a realisation that, for many cancer patients of working age, the risk of losing their connections with work, or having their employment status or incomes eroded by cancer treatment and its consequences can be very significant. For these professionals, more systematic consideration needs to be given to the possibility that a successful return to work may have therapeutic benefits for many patients and should be regarded as a high priority clinical outcome of cancer care (Yagil et al, 2018).

More specifically we would like to see changes in the ways that both healthcare professionals and employers manage return to work for people living with cancer:

- There should be improved training on having return to work conversations for cancer nurse specialists, GPs and occupational health professionals – with a specific recognition of the mental health challenges faced by many patients.
- Oncology medics and cancer nurse specialists should introduce integrated care & work protocols for working age cancer patients both before and after their treatment ends.
- Employers should update their return to work policies to recognise the provisions of the Equality Act as it relates to people living with cancer.

- Employers should offer 1:1 coaching on effective, flexible and compassionate return to work pathways for both cancer patients and line managers.
- Employers should support & fund ‘buddy networks’ of employees who have had experience of cancer to help provide peer support and guidance for colleagues and their managers.

Almost everyone has a cancer story, and many people have a profound fear that they or a close family member may receive a diagnosis one day (almost 50%, sadly, will). Despite some incredible improvements in cancer treatment and care, this fear and stigma can still condition our response to cancer among colleagues. On top of this, ‘self-stigma’ can prevent some working age patients from benefiting from the therapeutic nature of a (good) job they enjoy and where they feel appreciated, useful and supported. Although the results of this survey show that many people living with cancer have positive experiences when they decide to return to work, for too many there are still preventable barriers which make the physical and psychological challenges of cancer treatment which they are trying to overcome much more difficult than they need to be. This need not be the case and our profound hope is that, with better awareness among healthcare professionals and employers, the route to a full and fulfilling working life should be open to all those cancer patients who want it.

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