

Living and working with cancer: A policy briefing for employers and people managers

April 2022

In April 2022, Business Disability Forum’s policy and research team provided written evidence to the UK’s Government’s Department for Health and Social Care (DHSC) on their proposals for what a cancer care strategy for the next ten years should look like. To help inform our response to this consultation, our research included having conversations with seven employees working in our member organisations who are living and working with cancer or who are close to someone living with cancer. Their views informed the policy recommendations we made to the Government.

Everyone we spoke to agreed that a kind and supportive response from managers and the wider organisation makes the whole experience of being diagnosed, treated and living with cancer “that little bit easier”. As a result of employees sharing their experience with us, we could identify some recommendations and tips for employers to consider ensuring they are providing a supportive experience for employees at work or when an employee is returning to work after or during a diagnosis of or treatment for cancer.

We have collected those recommendations and tips here. They cover language, the experience of treatment, workplace adjustments, occupational health, private health care and Group Income Protection, employee assistance services, and ensuring discussions about individuals’ careers are never ‘taken off the table’.

We would like to thank everyone who got in touch to share their very personal experiences of living with cancer, whether they live with cancer themselves or are close to someone who does.

Some terms explained

- **“People managers”**. In this context, “people managers” refers to anyone managing processes or teams that directly relate to supporting people living with cancer. Specifically, as a few examples, this includes human resources, project and people managers, line managers, inclusion teams, and disability support and workplace adjustments teams.
- **“People living with cancer”**. People we spoke to generally said their preferred phrase for their experience is “living with cancer” rather than “having cancer”. This is because

some people have received a “No Evidence of Disease” (NED) confirmation, but they were still living with the lasting impact and effects of cancer or treatment.

- **“People close to someone living with cancer”**. For those whose relationship with someone who has had cancer or is living with cancer may appear to others to be a ‘caring’ relationship (i.e., they ‘care for’ someone with cancer), the term “carer” did not come up in any of our discussions, whether the discussion was with a parent of someone who is living with cancer, or whether they are a partner of someone living with cancer. We are therefore using the phrase “close to someone living with cancer” during this project. This does not mean the term “carer” is ‘wrong’; it just was not used in the discussions we had with people.

A supportive manager

The experience provided by line managers is everything. Employees living with cancer generally say that their line manager defines their experience of working with cancer. If you, as a manager, feel you would not know how to respond to someone who tells you they have cancer, or you feel you would not know what support you could offer that is provided by your organisation, find out today; your HR, inclusion or workplace health team should be able to help. The chances are if you are not aware, other managers are probably not aware either, so it might be that the organisation would benefit from more communications to managers and employees about what support and help is available.

It is ok not to know the answer if you are asked a question, but it is good to find out and, at the very least, if asked, make sure you get back to the individual promptly.

Flexible processes for unpredictable experiences

Employees often recalled that their direct line managers were generally supportive, and the level of flexibility they had was the difference between them staying in and leaving work. There was a general feeling that HR and employee policy teams were more ‘rigid’ as they had “forms and processes to stick to” which required ‘definitive’ answers, such as return to work dates and end dates of treatment. However, such definitive answers are rarely known throughout someone’s ‘journey’ through cancer. In one employee’s words, “I wasn’t expecting to be as ill as I was on chemo”.

HR and employers have set, structured processes to manage workplace health situations and it is often desirable to have a “clean” ‘one stop’ list of what will happen when - i.e., when someone will be having treatment, how long the effects of treatment will last, and when that person will be back to work.

The experience of cancer is rarely like this. People with cancer and people close to them often have some definitive dates – the dates of when the next bout of treatment is scheduled for is one example – but it is unpredictable how the individual will respond to the treatment. Therefore, employees we spoke to could not say to their employer when they would be able to come back to work and to what extent (usual hours or reduced

hours and duties, for example). Employers should be sympathetic to this and keep in touch appropriately throughout an employee's diagnosis and treatment.

Employers should therefore make sure that training, briefings and information given to people managers as well as HR and EP teams is consistent. This helps ensure that a kind and compassionate response to employees needing time off, having treatment, working flexibly, or going to hospital appointments prompts a consistent response from the employer as an organisation, and is not reliant only on a 'pockets' of flexibility depending on who an individual employee's manager happens to be.

Know the right time to engage your occupational health team

When individuals do not know their prognosis or how they will respond to treatment, it is often because their oncology team does not yet know either. In such cases, occupational health advisers also cannot be expected to know. Depending on the type of arrangement you have with your occupational health provider, engaging them at this stage can be helpful if they provide general support throughout an employee's whole cancer 'journey'. This is more commonly available when OH advisers are available 'in house', and less available when OH services are paid for 'per referral' or when outsourced.

Managers therefore need to identify if they are referring employees to OH at the right time and stage in their diagnosis or treatment process for the type of OH service their organisation provides. Otherwise, you risk putting employees through 'another' additional process which could cause additional stress when they are already tired, uncomfortable or unwell, and have a lot to think about. In one employee's words:

"You go through the motion of occupational health because that's the policy, but it's not helpful [at this stage]".

Know what your Private Medical Insurance and Group Income Protection products offer

While OH has a vital role in workplace health, some employees spoke about other interventions that they felt they needed when learning to live with "treatment fatigue" or re-learning skills now that their body has different limitations and capabilities, particularly before considering a return to work again. Some could not return to the job they were doing, and others needed to work with rehabilitation services who could support them to build up stamina to do work each day and regain skills that were 'put in the background' during a lengthy phase of being off work. These services may help someone re-build confidence and stamina to independently carry out daily living skills (such as getting dressed or making something to eat) or help people re-learn skills that they would need before they come back to work, such as re-learning how to type on a computer keyboard or trying out assistive technologies that they may now need to use.

Example of the type of rehabilitation services that could help support people learn and regain such skills are vocational rehabilitation or occupational therapy. These would help prepare an individual with the confidence and mental and physical skills to be ready for a

comfortable and sustainable return to work. Unfortunately, though, they are currently rarely available from the NHS.

However, Private Medical Insurance (PMI) or Group Income Protection (GIP), typically provided by employers in the private sector, often do provide access to these helpful and important services when someone is re-learning skills to live and work again.

If you are not aware what your PMI or GIP products offer to which employees, it is worth finding out from your HR team today. Our research shows many managers are not aware of these important products that are provided by their own organisations, and many very useful interventions therefore go unused while still being paid for.

The most helpful workplace adjustments

Employees living and working with cancer agreed on the ‘top six adjustments’ that had helped them at some stage during their diagnosis, treatment, or when returning to work. They are:

- Being able to do more hours when they are well, and less hours when they are not as well.
- Working from home, particularly (but not exclusively) during treatment when immunity may be lower.
- Phasing a return to work gradually and with ‘trial’ phases that can be flexed and agreed when they know what works for them.
- Time off work for treatment and appointments, some of which are often in locations far away from home or work locations.
- Postponing annual leave to the following year to allow a break after treatment.
- Being flexible with and reasonably adjusting sick pay policies.

Being able to flex when hours are worked and allowing time off for appointments and treatment were the most popular types of adjustments among people close to someone living with cancer, too.

Adjustments are of course subject to what is ‘reasonable’ for the individual, the employer, and the job the employee does.

Social and diverse teams are supportive teams

Beyond the ‘adjustments’ managers provide to employees working with cancer, individuals said the general support from their colleagues was crucial. This was not necessarily ‘support’ in terms of talking about cancer all of the time or even at all; it was more about the ongoing daily social spaces of making time for one another to talk, to “back one another up” on general work issues, and to “talk and laugh” about the “normal every day” things. One person also commented on how being in a team where others also had a

long-term condition in itself made him feel valued and supported – again, even if those conditions were not spoken about all the time, or at all.

Private health care and Group Income Protection

Many employees working with cancer had used their private health care plan provided by their employer. However, some individuals said they have had to ask their employer if their policy can be changed because the policy did not cover what they needed for their cancer treatment.

We also heard that, depending on where the individual lives (and therefore which NHS trust they are 'being treated' under), if they use any of their private health insurance to access some of their cancer care, they cannot access any NHS support for their cancer care as well. Employers should be aware of this, because it means some employees have been left with bills of tens of thousands of pounds to pay for ongoing cancer medication, just because they used their employer-provided health care support. BDF is trying to change this but, in the meantime, employers should be aware of the impact this could have on employees.

In addition, it is common for some private health care policies to cover some treatments for a given period of time. As an example, this means if an employee uses their private health insurance policy to pay for treatment for four years and they need it for five, they could be left to find the money for the last year themselves unless the employer revises, edit, or flexes the policy.

Employees also said their employer's Group Income Protection was a "comfort" and using private health insurance meant they could "take back control" and get quick access to diagnosis and treatment instead of going through the NHS' unfortunately lengthy waiting periods for diagnosis, appointments, and ongoing support.

A career with cancer

Some people had lengthy periods of leave from work. This ranged from two months to two years. For someone else, they had taken ill-health retirement to 'recover' and was then ready to work again six years later.

People living and working with cancer may need breaks and to 'slow the pace' of work at some stages, but may be ready to further their career, retrain, or do a different role later, sometimes years later. In one employee's words:

"Then, I just wanted a steady career – a few years later, I was looking to develop again"

For others, things were different and 'finding the balance' between what they wanted to do and what they felt they could do was recognised by them:

"I want to do lots of things, but I also need to be realistic".

Therefore, employers need to ensure they do not make assumptions about someone's career or job ambitions in the short or the long term as these may change as their conditions or treatment changes. Even if someone has not expressed any interest in progressing or promotion (for example) for a few years, do not stop including them in conversations about their ambitions and what they want for their working lives.

Employers can remove some stress

Ultimately, when employees had employers who were kind and flexible, employees said work was one less thing they had to worry about when going through a diagnosis or treatment.

“Work were amazing. It makes going through treatment so much easier when you don't have that stress and worry of how your employer will respond”.

For further information

If you have any questions, please contact Business Disability Forum's policy and research team at policy@businessdisabilityforum.org.uk