# How to manage cancer at work



A handbook for employers, HR professionals, managers, businesses & organisations



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#### Thank you

We would like to thank the ECL Patient Support Working Group (PSWG) for providing us with the original text of How to manage cancer at work.

#### About the ECL PATIENT SUPPORT WORKING GROUP

Since 2007, the *ECL Patient Support Working Group* (PSWG) connects cancer care experts who share knowledge and work together on developing best practice guides and informational materials to raise awareness and improve the quality of cancer care in Europe. The PSWG focuses on a wide range of cancer patient-related matters, including access to insurance and financial services, return to work, caregiver support, sexuality and relationships issues, cancer rehabilitation and palliative care. PSWG members strive to make the patient voice heard in national and European decision-making.

#### **Endorsements**

"In addition to the detrimental effects that being out of work has on an individual's well-being and finances, this situation has severe economic consequences for businesses and society as a whole. In fact, in 2009, working days lost as a result of cancer are estimated to have cost the European Union  $\in$  9.5 billion. Therefore, it is essential that companies implement effective strategies to help their employees get back to work following diagnosis of cancer."



Marine Cavet, Project Manager, Prevention and Research Unit, European Agency for Safety and Health at Work (EU-OSHA)

"With the current trend in Europe, it is increasingly likely that someone from your office will be diagnosed with cancer. It is beneficial for everyone concerned, even for the company, to support cancer patients, so they can work remotely during their treatment, they can return to work when they are ready and that they do not have to deal with stigma at work. Sadly, cancer often leads to discrimination in the workplace, it is time to adopt relevant guidelines to protect employees with a cancer diagnosis."



Jacqueline Daly, Board Member, European Cancer Patient Coalition (ECPC)

"EPF fully supports the ECL Patient Support Working Group's handbook How to manage cancer at work. A mindset change and cultural shift is needed to address the barriers that people with cancer face in the workplace to ensure wellbeing at work. If implemented well, this handbook has real potential to contribute to the creation of more supportive working environments, resulting in a hugely improved quality of life for cancer patients, that minimises the negative financial impact of chronic ill health, the risk of social exclusion and positively contributes to their mental health. With concerted action from a variety of stakeholders from different sectors, driven by political incentives at EU and national level, together we can contribute to help normalising the view that discrimination and exclusion in the labour market is not a patient's problem but a societal problem: with the right kind of support, we strongly believe that people with chronic conditions, who wish to continue working, can do so."



Katie Gallagher, Senior Policy Adviser, Forum européen des patients/European Patients' Forum (EPF)

"Working while caring for a person living with cancer isn't an easy task. Informal carers may feel as if they are juggling two jobs, but work can be important for their wellbeing, income and for maintaining social contacts. A key factor to combine work and care is the support received at work. The good news is that more and more employers are realising the benefits of developing care-friendly workplaces, likely to retain skilled, experienced and committed members of staff. This precious guide gives managers a set of practical tools to handle more easily these difficult situations."



Claire Champeix, Policy Officer, Eurocarers

### About this handbook

In many European countries, one in three people will be diagnosed with cancer by the age of 75¹. Therefore, as an employer, HR professional, manager or team leader, you are likely to face a situation when your employees or their loved ones are affected by cancer. This handbook (i) explains why it is necessary for employers and managers to adopt a comprehensive policy and set of procedures on managing cancer in the workplace and (ii) provides useful tips to help you navigate through cancer's challenges. In four chapters, the handbook aims to help you understand how to best support employees affected by cancer and provides practical advice to minimise the impact on your organisation and everyone involved. It highlights that colleagues and caregivers can also be affected by the situation and suggests ways to support them.

Quotes collected by national cancer societies as part of several surveys about cancer at the workplace have been added for authenticity.



"After the cancer & work workshop organised by the cancer league, I am aware of the importance of managing cancer at work and having an action protocol prepared before a case is diagnosed."

Manager at a small computer services company

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#### Introduction

In 2018, 4.2 million people in Europe were diagnosed with cancer and it is projected that this number will grow to 5.2 million by 2040<sup>2</sup>. In particular, around 1.6 million people of working age are diagnosed with cancer in Europe each year and cancer treatments are often accompanied by long periods of sickness absence<sup>3</sup>.

Thanks to advances in diagnosis, early detection and treatment, people are more likely to survive cancer and an increasing number of patients are able to return to work, or to (partly) continue to work during treatment.

However, returning to work is not always easy, as cancer survivors can experience physical and psycho-social problems, including social seclusion and discrimination. Some challenges might be less obvious, including cancer-related fatigue, cognitive impairments such as concentration issues (so called 'chemobrain') and feelings of distress, which are often reported by patients<sup>4</sup>.

Patients return to work for various reasons. These include (i) financial issues, (ii) the risk of poverty and social exclusion, (iii) work being part of people's identity, (iv) the need to feel part of a community and (v) to contribute to society in a meaningful way. It is important to highlight that, apart from the physical and mental effects of a cancer diagnosis, cancer can have a major financial impact, not only on the patients/employees, but also on their families. Being on sick leave often means dependency on benefits provided by employers, insurers and the government.

The duration of absence from work differs greatly among cancer patients, depending on their diagnosis<sup>5</sup>. In addition, each person reacts differently to the disease and deals with the situation in a very personal way. In general, people are often absent from work for quite some time, resulting in serious financial setbacks, especially when seen in combination with the rise in medical expenses.

Another reason for people to return to work after cancer is to re-establish their identity and former structure of everyday life. Work also contributes to social relations with others, can help to give meaning to life and positively affect people's quality of life, self-confidence and social status<sup>6</sup>.

Side-effects of cancer and its treatment often mean that an immediate full-time return to work is not possible. Therefore, having the opportunity to gradually return to work by starting part-time can make a very big difference. It allows patients to get re-accustomed with their working life. Other, sometimes temporary, adjustments can also help, such as flexible and reduced working hours, a change of role/position, being able to work from home, etc<sup>7</sup>.



Why is it important to address cancer in the workplace?

This chapter explains the extent of the problem and provides quantitative and qualitative incentives for employers to adopt a comprehensive cancer policy aimed at supporting employees affected by cancer.

It is important to note that currently there is a lack of quality data assessing the impact of cancer on patients, employers and the economy as a whole. More up to date national studies and cross-national European comparisons should be conducted in order to fully understand the financial burden of cancer as well as the benefits of employee support throughout the cancer pathway.

#### 1.1 How big is the problem?

According to EU-OSHA, out of the 3.2 million cancer patients diagnosed each year in Europe, close to half are of working age<sup>8</sup>. Most patients are highly motivated to stay at or return to work. Studies show that 62% of patients of working age return to work within 12 months, while after 24 months this amounts to 89% of patients<sup>9</sup>.

Of all chronic conditions, cancer has the highest prevalence of work loss. Research shows that the risk of losing a person's job increases 1.4 times after a cancer diagnosis $^{10}$ .

This job loss is not always the (former) patients' decision. Cancer patients and survivors can be subject to workplace discrimination. This is the case when they are dismissed because of their cancer-related absenteeism

or when they do not receive the necessary 'reasonable accommodations' upon their return to work. Examples of such accommodations are (i) being able to gradually return to work by starting part-time, (ii) working from home, (iii) having shorter or flexible working hours, (iv) being allowed time for medical appointments, etc. Cancer is seen as a disability when the consequences of the disease and/or its treatment result in long-term physical, mental, intellectual or sensory impairment of employees which, combined with other barriers, may hinder their full and effective participation in society on an equal basis with others. In this case, employers are obliged to make reasonable accommodations for cancer survivors<sup>11</sup>.

#### 1.2 How much money does it cost?

The total economic loss to the EU due to lost work days as a result of cancer was estimated at  $\leq$ 9.5 billion in 2009<sup>12</sup>.

A study conducted in France estimated that the cost of sick leave linked to cancer cost employers €500 million in 2007<sup>13</sup>.

Cancer treatments also pose an increasingly high financial burden on patients and their families. A study conducted in 2018 in Spain found that (i) family income decreases by at least 25% when one of its members is

diagnosed with cancer and (ii) average monthly cancer-related expenses ranged between €150 and €300<sup>14</sup>. A similar study carried out in Ireland in 2019 found that, on average, a cancer diagnosis meant an extra €756 a month in expenses, and a drop in monthly income of €1,527<sup>15</sup>. 75% of respondents of a survey conducted in 2019 in Finland also highlighted a decrease in house-hold income due to cancer<sup>16</sup>.

#### 1.3 How much does it cost to the employer?

#### The cost of absence (absenteeism)

For an employer, costs related to staff sick leave could be divided into direct costs (continued payment of wages) and *indirect costs*, such as loss of production, loss of productivity, cost of sick leave, overtime paid to other employees and other administrative costs.

In 2009, the estimated average direct cost of absence per British employee was £595 ( $\sim$  €660), whilst the indirect costs per employee totaled £465 ( $\sim$  €516). In total, employee absence cost the UK economy £16.8bn ( $\sim$  €18.7bn) in 2009<sup>17</sup>.

#### The impact of employees' turnover

Although it is difficult to predict the actual cost of employees' turnover, due to factors including the impact of the legislative framework and socio-economic situation of each country, there are some major costs which would inevitably emerge<sup>18</sup>. These include:

- The cost of hiring a new employee which encompasses the placement's advertising, preparation of and time dedicated to interviews, screening of candidates and administration related to hiring a new employee;
- The cost of training a new employee, including the necessary time spent by their managers and colleagues;
- Loss of productivity. Depending on the role and the specific situation, it might take a new employee up to two years to reach full productivity;
- Customer service delays and errors, as new employees might take longer to solve issues and/or may be less adept at solving problems;
- Disengagement and potential loss of productivity of other employees who witness high turnover and question the reasons for a colleague's resignation.

# Patient productivity loss while at the workplace (presenteeism)

Employers and managers always try to control or avoid employees' absence, however, controlling absences is not always the perfect solution. Even if employees are physically present, it does not necessarily mean that they will be productive, especially while suffering from the impact of cancer and related treatment. It is important to note that cancer-related late effects may occur years after the diagnosis.

The overall cost of presenteeism in terms of loss of productivity to the Australian economy in 2009/10 was estimated at \$34.1 ( $\sim \le 20.8$ ) billion (nearly four times the cost of absenteeism). It was further estimated that in 2050, the total cost of presenteeism will rise to \$35.8 ( $\sim \le 21.8$ ) billion with a decrease in GDP of 2.8% <sup>19</sup>.

Therefore, in order to mitigate the negative impact of presenteeism, it is necessary to take the new physical and mental status of employees into consideration, rather than their capabilities prior to the illness.

#### The cost of reputation

A study conducted in the United States in 2019 has shown that the benefits employers receive from making their workplace 'patient friendly' far outweigh the associated costs. Employers reported that providing accommodations, such as (i) re-training valuable employees, (ii) focusing on improving productivity and boosting morale, (iii) reducing workers' compensation and training costs, and (iv) improving the company's diversity bring overall benefits to the workplace. 58% of the employers who participated in this survey reported that the accommodations needed by their employees cost absolutely nothing (\$0), while the average one-time expenditure for accommodations was only \$500 ( $\sim \$440$ )<sup>20</sup>.

#### 1.4 What are the benefits of supporting employees with cancer to stay at work?

As shown above, you can expect various costs related to the potential loss of an employee due to their cancer diagnosis. However, there is a way to minimise these costs by adopting a 'patient-friendly' cancer in the workplace policy. Additionally, such policy can also serve as a guidance for handling all long-term and chronic illnesses.

Allowing for some flexibility, introducing measures to address the new situation, and responding adequately to your employees' needs throughout the patient pathway, will bring the following benefits:

- Retaining the patient/employee's valuable skills, knowledge and experience while ensuring business continuity;
- Saving valuable resources (financial and staff time) that would go into replacing and training a new employee;

- Creating an inclusive work environment and a positive image for your company/organisation, which might contribute to attract talented workers;
- Fostering a greater sense of loyalty among affected employees and colleagues;
- Receiving more support from and boosting morale of other colleagues.
- Fulfilling your country's anti-discrimination law and other legal obligations to provide accommodations allowing employees with a disability continuous participation at work<sup>21</sup>.

In addition, European member states' governments often provide employers with incentives to keep people with chronic and long-term illnesses or disabilities, including cancer, employed. Ensure to check your national legislation to make the most out of your cancer policy development<sup>22</sup>.



# How to manage cancer in the workplace?

It is important to stress that the most successful accommodation programmes are multidisciplinary, i.e., include both psycho-social and physical accommodations for patients<sup>23</sup>. This chapter will elaborate on what to do when your employees get diagnosed with cancer and provide tips on how to best support them throughout the patient pathway. It will also address support for caregivers and how to manage the situation with the patient/employee's colleagues.

Depending on the size of your organisation, services to manage cancer in the workplace can be provided in-house or via a national/regional cancer society, patient organisation or other entity. Cooperation and good communication between different stakeholders, including occupational physicians and HR professionals, help the return to work process to be successful <sup>24</sup>.

#### Each case is unique

There are many types of cancers and each person reacts differently to the disease and the work situation. Cancer patients are generally highly motivated to return to work and the majority is able to work again after treatment<sup>25</sup>. Whether this reintegration is successful or not depends on both the physical and mental scars cancer leaves behind, as well as which measures were taken by the employer to support the patient/employee.

#### Managers have a key role to play

As a manager, supervisor or HR professional, you face a balancing act between responsibility and compassion. Honest information about your company's support limits and options creates the clarity necessary for dealing with the challenging situation. By maintaining careful, close and appropriate contact with your employees, you can have a decisive influence on the working environment and their reintegration process.

#### Where to start?

Before putting any specific policies in place, you should go through the checklist on the next page to ensure you have considered all the aspects mentioned. The tasks on the next page should be completed both when those affected are unable to work for a long period of time, as well as when employees can stay at work during their treatment.

#### Manager's checklist:

Task	Status	Staff responsible
I have checked the existing legislation in relation to employee protection in my country. I am aware of the benefits provided by the government to companies with employees with chronic diseases and disabilities (including cancer).		
I have informed the relevant authorities about my employees' absence.		
I have assessed the amount of cancer cases we have had at our company/organisation in the past years.		
I have decided who will oversee the development and implementation of the cancer in the workplace policy.		
I have reached out to expert/specialised organisations available in my country who can help me navigate through this situation (including national cancer societies, occupational therapists, insurance etc.)		
I have written down the short-, medium- and long term impact the potential absence of affected employees could have on the functioning of my company/organisation.		
I have written down which measures have been taken in the past, when we dealt with employees affected by cancer and assessed how flexible we can be when the situation occurs in the future.		
I have ensured the employees affected will be treated in an empathetic manner by all managers and colleagues and that communication will be clear and transparent at all stages.		

#### 2.1 When my employees get diagnosed with cancer

When your employees tell you that they were diagnosed with cancer, some questions present themselves immediately:

- will my employees be absent, and if so, for how long?
- who will take over the affected employees' tasks?
- will I have to find replacements?
- how do I best support my employees?
- who should I inform and liaise with regarding the issue?

Bear in mind, you are not alone in this situation. After checking with the affected employees and understanding their privacy needs, be sure to coordinate the response to the situation with the employees themselves, their teams, doctors, insurance, other management and the HR department<sup>26</sup>.

#### How should I respond to this situation?

## a. Showing your understanding and keeping in touch

At this stage, you should show your employees you understand their mental, physical and financial situation. It is possible the affected employees will not want to share details about their disease, as they might be scared of losing their job. Start by:

- asking what they would need from you and discussing how you would want to keep in touch. Employees are often very fond of their privacy during this period. You should find out what their wishes are and when/if you can call or visit them;
- clearly communicating their options, including that they can return to work after their treatment and discussing whether they wish to continue to work whilst receiving treatment. If you keep in touch regularly since the beginning, it will be easier to talk about return to work at a later stage;
- carefully checking whether your employees already know something about the length of their absence, however, at this early stage, it is often not possible to clearly know this. Do bear in mind that in some countries medical certificates are issued for a short period of time and the absence can be further extended. Depending on the type and stage of cancer, absence and complications differ greatly. Half a year absence is common, not an exception;
- asking what can be already communicated to their colleagues and deciding who should share the news at work.



"We try not to complicate the situation around his absence too much. We are solving it step by step. Nevertheless, in some way, I still ponder: what if it goes wrong? What if his illness has so many consequences that he would not be able to return?"»

Business owner real estate



"When I was on sick leave, no one from the company ever met me to ask about my state of health; they never called me nor discussed issues related to returning to work, at any point during the sick leave. The return to work was very hard and disappointing."

Administrative assistant in a multinational company, diagnosed with B-cell lymphoma

#### b. Showing your support

You can support your employees in different ways, including:

#### **Emotional support**

- Show empathy and understanding;
- Listen actively and reassure them regarding work security;
- Have a gift delivered;
- Understand and recognise their needs;
- Be tolerant of uncertainty and show discretion.

#### Practical support

- Give your employees time for additional medical appointments;
- Provide your employees with a support network, including expert counselling (e.g., provided by an occupational therapist, or cancer society);
- If your employees wish and feel fit enough, give them the option to complete the project/s they were working on;
- Help them with paperwork and filling in the necessary forms:
- Inform your employees about their rights and obligations in the event of their absence.

#### c. Covering the sick employees' tasks

If someone is ill, a replacement might not be immediately available, particularly in smaller organisations. If possible, and the affected employees want to, discuss with them and their colleagues who and how to cover their tasks in their absence.

Discuss your wishes and options with your employees. Is it possible to keep them at work? Do they want to stay in work? Will the work/projects run smoothly and be kept on track? Can other colleagues help with the patients/employees' workload? Do you need to hire temporary replacements?

Let's look at some options:

#### Can the affected employees still work?

- Some employees want and can stay in work (at certain times during their treatment);
- Check the requirements and obligations under your country's disability legislation, as contracts may need to be suspended in the event of disability.

#### How do I deal with the extra workload?

Below, we provide some short-term solutions that can help you while finding a sustainable solution to the new situation

- Communicate to your colleagues why certain measures are needed, so that they understand the reasoning behind the change;
- Allow colleagues to take on more tasks if they wish to, without over-burdening them and, if possible, offer paid over-time;
- Have regular meetings with colleagues to redistribute the essential workload. You can also rotate tasks among them;
- Postpone non-essential tasks, but be careful not to pile things up for when the affected employees come back;
- Depending on the size of your company/organisation's business, you may need to cover some essential tasks yourself.



"The company does not stop when someone is sick at home."

Business owner hairdresser's



"My colleagues covered me and redistributed my work while I was on sick leave. No replacement was needed. I had constant contact throughout the treatment with the team."

Technical engineer in an agrifood industry diagnosed with breast cancer

#### Short-term replacement

As you cannot predict how long the affected employees will be absent for, hiring help on an 'interim' basis or an intern/student can be a good solution. Replacing ill employees costs money and can be an additional source

of anxiety for the affected people. Whether or not you hire a replacement depends on:

- the tasks (e.g., are the tasks linked to confidential information?);
- your financial situation (can you afford extra help?);

- the resilience of the affected employees' colleagues (can they cover the tasks or is an extra pair of hands needed?);
- the length of absence of the affected employees.

Affected employees should have the peace of mind to know that their tasks are being covered and completed during their absence. You, as an employer, might have to make some difficult choices when your employee returns. Depending on national legislation, you might be obliged to offer employees the same position they had before getting ill or, if that is not physically possible, to adapt the tasks/positions to their new health condition.



"An employee suffering from cancer was always missing at work. These absences had to be compensated for by other employees, and this led to uncertainties within the workforce. Precisely because cancer in the workplace is an issue that firstly affects a lot of people, and secondly it is difficult for many to speak about, it makes sense to involve an external person."

HR of a medium-sized company after a workshop with Cancer & Work specialists

#### d. Informing colleagues about the cancer diagnosis

To respect your employees' privacy and comply with legislation, you need your employees' consent to share medical information and details about their cancer diagnosis with staff and co-workers. It is possible that affected employees prefer to inform their colleagues themselves.

Ask your employees explicitly what you can share with your staff. Colleagues may know each other well and might be naturally involved in each other's lives. Nevertheless, it is necessary to discuss this in advance with the sick employees. If your employees do not want to share information regarding their medical condition, you should decide together what you are going to tell other staff about their absence to prevent possible gossip.

#### Manager's checklist:

Task	Status
I understand my company /organisation's legal obligations when it comes to sick leave and labour protection of an employee with a disability or chronic disease (including cancer).	
I have informed the relevant authorities about my employees' absence.	
I have shown empathy, interest, concern and understanding after I have received the news about my employees' illness.	
I have kept in touch regularly (via the sick employees' preferred communication channel) to stay up to date with the situation and possible return to work.	
I have demonstrated practical and emotional support to the employees in this situation.	
I have made the necessary arrangements to temporarily cover the employees' tasks in their absence.	
I have informed all colleagues about the situation, based on the employees' wishes.	
I have redistributed the essential workload among other employees and looked into a more sustainable solution.	



"Open communication was very important to me. And it was nice to see that I was supported by my colleagues. I received calls and invitations to go for a walk together and even the school president said: 'You just work as much as you can.' This support and compassion were very good for me. I got additional help from the local cancer league. Together we drew up a plan for how I could return to school. The goal was for me to gradually increase my workload from February to summer, in order to return to my original percentage of jobs. At the same time, I also had to learn to regroup my strength properly. I had the clear instruction not to take on any additional work. I only completed my agreed workload. In this way, I was able to protect myself from being overloaded again. Today I am back at work. I could only do that thanks to the professional support of the cancer league and the support of my employer and colleagues."

Special educational needs (SEN) teacher, diagnosed with breast cancer

#### 2.2 Managing employees' absence during treatment

When your employees are absent, there are a lot of concerns you might have about the affected employees and your business, as well as things you can do to navigate through the situation while communicating with your sick employees.

#### Showing your continuous support

#### a. Emotional support

- Keep in touch with your sick employees in a way that was previously agreed by both parties;
- Show interest and concern for the affected employees, their families and work issues;
- Be aware that employees deal with the situation differently while some perceive it as a disruption in life or a very difficult period, others may think it brought life greater meaning. Be sure to adapt your communication accordingly. If you know this and recognise the differences, you will be able to better understand and support your sick employees. Those experiencing their

illness as "disruptive" may need additional emotional support; whereas those experiencing their illness as a difficult but temporary 'episode' may benefit from an approach focused on practical support. The latter category may want to share or talk more about their situation.

- Listen to what your employees want to share and acknowledge their needs;
- Have a card and/or a gift delivered (e.g., after the employee is discharged from the hospital);
- Invite your employees to events, such as coffee breaks with the team. Leave it up to your employees to decide whether they can make it or prefer not to come;
- Consider visiting sick employees at home (check if this
  is ok with them, what time is convenient, who from the
  team will be visiting them and whether they wish to
  discuss work-related issues).

#### b. Practical support

- Ask if there is anything you can do for your sick employees;
- Offer them the option to use company equipment (e.g., car or laptop) throughout their sick leave;
- Ask the employees if they want to be kept up to date with what is happening in the company/organisation;
- Bring up questions related to the length of their absence during one of your phone calls or visits.
   Explain why it is important for you to know how long they will be absent for, but do not insist (bear in mind the employees' right to privacy and that some people might not want to share medical information with you);
- If employees ask, present them with their return to work options.



"We experienced that period with him. Regular texts or phone calls, discussing what the progress was like or what the side effects of the treatment were."

Owner printing office



"We discussed with him, 'What should we do? How do you think the situation is evolving? Should we hire someone to take over your work, or what do you think?"

Wholesaler



"What employees appreciate is staying in contact, asking about how they're doing, talking about something else than cancer, and having a sense of belonging to the work community during their sick leave."

Employer



"During my sick leave, my colleagues set up a WhatsApp group entitled OneForAll and AllForOne."

Cancer patient

Sample questions to ask your sick employees:

- How are you feeling?
- When will you hear more from your physician?
- Would you like to be informed about what is going on at work?

Here is how you can deal with the different mental states patients might experience throughout their cancer journey:

Despair				
Feelings employees experience	<ul> <li>See no future and experience loss of hope.</li> <li>Feel completely overwhelmed by everything that is being experienced.</li> <li>Feel like they are standing on the sidelines.</li> <li>Experience and show intense emotions.</li> <li>Feel hampered by loss of experiences: loss of work, loss of identity.</li> </ul>			
How should employers respond?	If you recognise any of the above in your employees, you should focus on providing them with emotional support - showing understanding and giving them attention. Check whether they are receiving sufficient support from their health professionals or patients organisations.  If your employees experience such despair, it is possible they will not be able to return to work either due to the severity of the illness or the lack of emotional support they receive.			
Temporary uncomfortable period, but life goes on				
Feelings employees experience	<ul> <li>Focus primarily on the healing process and do what needs to be done.</li> <li>Expect life to be the same as before the diagnosis as soon as possible.</li> <li>Are fully aware of the difficult period that they are going through.</li> <li>Feel strong and present themselves as decisive.</li> <li>Try to stay positive.</li> </ul>			
How should employers respond?	If this is the case, your employees might mainly need practical help with their return to work (e.g., less working hours or different types of tasks).  When sick employees experience cancer as an 'episode', this might mean that they quickly get better and are able to resume working without any problems.  You can ask them how they are doing, but keep conversations tactful and more businesslike. Do not ask them about their feelings and emotions. If possible, make plans for reasonable adjustments in advance.			
Meaningful period				
Feelings employees experience	<ul> <li>Think and reflect a lot.</li> <li>Look for the reason for their illness: 'Why did this happen to me?'</li> <li>Will live more consciously and accept what happened.</li> <li>Look for the positive sides of it - it is a chance to see what is really important in life and start doing things differently.</li> <li>Try to put the difficult period into perspective, sets new priorities and breaks old habits.</li> <li>Feel more mature: 'I have learned a lot from it.'</li> </ul>			
How should employers respond?	Provide them with an opportunity to talk about their illness and different options for returning to work. Show understanding for the possibility that your employees might want to organise their future differently. Suggest keeping each other informed regularly.  It is possible employees will decide they are not capable/do not want to work anymore, and you need to respect their decision.			



"Give me a week of my life before the diagnosis, another week of work, again the woman I was. Now I am deprived of everything, everything is taken away. Your work is gone, your colleagues are gone, your contacts are gone, your appearance is gone. You don't know what kind of impact that has."

Woman with breast cancer



"From one moment to the next everything was different. I was only able to hand over the most important dossiers to my deputy, then I underwent surgery and was absent for a long time. In retrospect, I would do a lot differently. It was not a good thing that I could not personally inform my employees about my illness. They were shocked and unsettled because they didn't know how things would go at work. External help (e.g., from a specialised organisation) can work miracles ... You don't feel left alone as a manager with such a difficult subject."

CEO of a small company diagnosed with breast cancer

#### Keeping business going

- Redistribute the tasks of the absent employees internally;
- Postpone or shift work, tasks or priorities;
- Hire interim staff or students to help with some tasks;
- To help you with business planning, but only with patients' permission, you can discuss what you know with an occupational physician. This healthcare professional might be able to tell you more about the expected chance of the affected employees being cured and/or able to return to work. If you are not in touch with a physician, you can learn more by getting in touch with national/regional cancer leagues or patient organisations or other organisations, but make sure your sources are legitimate.
- Bear in mind that general predictions about prognosis are difficult to make, and every situation is different.
   The chances of getting cured depend on many factors, such as the type and stage of the diagnosis, the age and health history of the ill person, whether there are metastases or not and the type and effects of treatment.

#### Starting negotiating employees' return

Most patients wish to go back to work, as it is a distraction from their illness, which usually provides them with energy and can also be part of their recovery. However, employees may have concerns about possible side effects or a relapse.

Employers usually do not feel called upon to discuss the return to work process. If your sick employees are only absent for a short period of time or have just undergone the first treatments, is not appropriate to discuss the matter just yet.

As often happens, you should wait until the affected employees start talking about it. But, for your and your employees' peace of mind, you can certainly mention their return to work during a visit or a phone call.

Depending on the specific situation, after some time, check whether the affected employees are ready to return to work. Here are some tips on how to bring it up:

- Discuss both your and your employees' wishes and possible options;
- Encourage your employees to discuss their (partial) return with the doctor in charge (occupational therapist, GP, etc.). If your employees agree, it could be helpful if they allow you to join their conversations with their physicians. Depending on your employees' preference, this can be done directly with the physician (in oral or written form). This should be preferably done with the affected employees present, so that they do not feel things are being decided behind their backs.



"She says: 'I don't know if I will be able to handle it.' And then we advised her: 'go and see if you can possibly start again gradually.' She didn't know about that possibility at first."

Employment agency manager



"She asked the question: 'and how do you see my return?' Since we did not have an immediate answer, we asked instead: 'what do you think would be the best way for you to return?'"

Owner consultancy company



"During the joint meeting with the occupational healthcare professional and my employer, I felt I had to act healthier than what I actually was. I felt that a return with a 100 % capacity was the only option. The employer hadn't considered alternative options for a return to work plan. I also felt the preparations as burdensome."

Cancer patient

# How should I organise my employees' return to work?

It is not easy to resume working full-time after cancer. Starting part-time with a progressive structure is often the best option, as the affected employees may still suffer from side effects or still recovering.

In case of partial or gradual return to work, it might be possible to combine sickness benefits with work wages.

If you need more guidance about how to best organise your employees' return, consult your HR department or seek more information from external experts, such as cancer societies and social workers, who are best placed to advise you on the best way to approach the patients/employees whilst respecting your country's legislation.

#### 2.3 Employees' return to work after treatment

While most employees would want to come back to work, it remains a challenge to properly plan their return and you might need support from a specialised organisation or consultancy. Bear in mind that cancer and/or its treatments can have long-term impacts on your employees. Hence, it is important to re-evaluate

the situation regularly, even if everything seems to have gone back to normal. It is also crucial to assess one's work ability in relation to their individual work tasks. It is better to pay attention to your employees' work ability rather than to potential disabilities.



"Doctors must advise in order to protect the health of the patient. But the mental aspect is also very important. And if an employee gets more energy because he can come and work here for an hour every day, that must be encouraged."

Wholesaler

#### First, you need to answer the following questions:

- Which tasks can my employees do without problems?
- Which tasks are my employees not able to do yet?
- Which tasks are more tiring and which ones can energise my employees?
- What solutions and options can I consider/propose?
   What solutions and options do the occupational physician/physician in charge propose?
- Is partial/gradual return to work an option?
- What solutions and options do the affected employees propose?

# Second, think about the flexibilities you can offer to the employee:

- A different job role and/or tasks
- Guidance or training to learn new, different tasks
- Fewer tasks
- Flexible working hours (or different schedule e.g., no night shifts)

- Workplace accommodations including changes to the physical office environment (different chair, personal protective equipment, quiet workspace, reserved parking etc.)
- (Partial) work from home/telework

The necessary steps you should take to manage your employees' return smoothly are outlined below.

#### Inviting your employees for a conversation

You should indicate that you wish to prepare their return to work and discuss options together. Try to be flexible and open to negotiation when presenting your wishes and expectations, as it might be difficult to meet all of them. If you cannot find a suitable solution on your own, you should rely on the expert opinion of an occupational physician or a specialised organisation. After you have discussed how you both envision their return and what the physician/expert advised, compile a written report indicating what was discussed and agreed during the meeting.



"We are not going to suggest this is what we would like. We are really going to see what the employee says, together with the doctor."

Owner of Call Center

#### Striving for a win-win situation

If national legislation allows for such scenario, allow your employees to get back to work in a gradual way by starting out part-time, so that you can fully benefit from their skills and expertise while not over-burdening them with work.

To strike the perfect balance, try to have a clear view of the consequences of the different return to work options for your employees, for you and for your company and staff. It is helpful to do a SWOT analysis<sup>25</sup> and put everything together in a table (e.g., the possible employment options (full-time, part-time) on the vertical axis and the benefits and points of attention regarding finance, tasks and the impact on colleagues on a horizontal axis).

If your employees want to immediately return to full time employment and you have some doubts, do voice your concerns. Show that you understand their request but explain what your expectations are and indicate possible limits. If employees start part-time, they can often do so faster and then gradually take on more hours/shifts. Be sure to check what your responsibilities as an employer are under your national legislation. In Luxembourg, employers are obliged to offer part-time gradual return to work if the doctor or insurance recommends doing so.



"During the sick leave, I received very little attention from the company and contacts were very sparse. When I returned to work, I felt ignored and displaced. I was entrusted with the management of a new portfolio of clients with a much lower profile than I had managed before. This made me rethink my relationship with the workplace and I took the initiative to negotiate a retirement."

Commercial manager affected by cancer

#### Setting the terms of employment

#### a. Type of contract:

There are different types of employment contracts with different sets of rules, depending on:

- The status of your employee (temporary worker, employee);
- The type of contract (full-time, part-time);
- The duration of the employment contract (permanent, fixed-term).

Be sure you know your legal obligations under the labour legislation of your country and be mindful of the health condition of your employees.

Check if you are entitled for tax premiums from your government for employing a person with disability (incl. cancer). Be sure to also inform yourself about any potential financial support your employees could receive from the state.

#### b. Customisation of work:

Often, employees do not dare to ask for accommodations themselves. You should be the one asking your employees what kind of help they would need upon resuming their job (e.g., a separate room to work, no customer contacts), but also be clear about limits.

Be clear and go through all the return to work aspects (working hours, accommodations, etc.). Present your expectations and check how your employees feel about them and whether they understand your arguments. Agree on all the terms and conditions and prepare a written statement.



"He wanted to come back. Yes, the job was the same. With slightly less customer contact. So more at the office and less outside the office. He immediately said, 'Yeah, I can't sit in a meeting for 4 hours.' For us, this was a small adjustment to make."

Real estate business owner

#### Welcoming your employees back

Inform your staff about your sick employees' return and explain what agreements have been made. Do not forget to take into account the emotional impact their return might have on yourself and other employees. Discuss what support you expect from your staff and why.

Make sure your employees feel safe and at ease. Be supportive and do not respond too dramatically. Ensure the work environment has been prepared and tasks communicated appropriately. Do not assign unknown or new tasks to them, especially at the beginning. Write down together what has been agreed and set clear timelines, so that the matter is not forgotten in the rush of everyday life and work.

Be flexible and helpful. You can start by:

- Introducing your employees to their new colleagues (if any);
- Giving them the opportunity to rebuild relationships, knowledge and skills;
- Understanding the limitations of your employees;
- Providing a point of contact: a buddy/colleague who can be available for an informal chat;
- Asking how things are going every now and then (but not too often), as people affected by cancer may wish to be treated like everyone else.

#### Manager's checklist:

Task	Status
I have thought about solutions for my employees' gradual/flexible return to work tailored to their needs and wishes.	
I have had a constructive exchange about possible options and wishes with the affected employees.	
I have made mutually beneficial adjustments and customisations to their workload so that the employees can start working at their own pace while ensuring key tasks will be covered in due course.	
I have made the necessary and requested accommodations for the employees to come back to work smoothly (e.g., office space, material, parking spot etc.).	
I have kept an open line of communication with the affected employees and responded promptly to their needs (e.g., regular face to face meetings, phone calls).	
I have appreciated the work done and treated the employees with respect despite the difficulties they experience.	



"I had my first day at work today after my sick leave. I felt like a foal free in the pasture. My colleagues were already all fed up, and I was like, don't you guys understand how wonderful this is."

Cancer survivor

# Keep supporting your employees once they return

When your employees are back, make sure you provide them with emotional and practical support by:

- Not putting pressure on them or setting tight deadlines (e.g., do not call your employees on their off days);
- Giving moral support and recognising them for work well done;
- Allowing further flexibilities and accommodations, if necessary (including workload adjustments);

- Giving employees enough time to organise the work by themselves and setting your and their colleagues' expectations;
- Showing understanding for reduced productivity;
- Continue to praise your employees' qualities and respect the changes that might have occurred;
- Openly discussing physical and mental issues the employees may experience and find mutual solutions where the needs and wants of both parties are understood and can be met;
- Providing time off for medical follow-up appointments and treatment.



"When someone comes back, it is important to take their needs and limitations into account. Someone who is absent for a year, you cannot expect that they immediately are the same as before. And as an employer, you also have a social function in matters like these."

Catering industry business owner



"And then after a while, in consultation with her, we said, 'You can't do that, because that's too stressful for you.' Not in a patronizing way, but more out of concern for her well-being."

Owner Employment Agency

#### What are the common issues sick employees experience after treatment?

Memory issues, concentration problems, depression and anxiety, problems with physical strength, sensitivity to noise, slower thinking, fatigue, loss of productivity, etc.

# Agreeing on mutually acceptable solutions to the new situation

Concentration problems and other side effects of cancer and its treatment can take a long time to fade, but they are not necessarily permanent. Ask yourself the following questions:

- Can my employees' qualities and expertise compensate for their limitations upon returning to work?
- Can I postpone/extend deadlines?
- Should the affected employees be able to do everything they used to do upon their return?

Try to explore different options or make new agreements about hours, days, tasks and other accommodations. Sometimes, employees need more rest. You can suggest them to take longer lunch breaks or extra rest breaks or days off.

#### Is return to work not possible at all?

If your employees are no longer able to perform their jobs and tasks due to medical reasons, they can be declared permanently unfit for work, possibly resulting in the termination of their employment contracts.

#### 2.4 When returning to work is not possible

# When your employees go on sick leave again

This may be due to a relapse or strong physical and emotional side effects of the disease and its treatment. Stay in contact, be empathetic and show your support for your employees so they do not feel pushed away.

You may be confronted with a situation in which your employees might be seriously ill, and recovery is uncertain. To respond to such situation, make sure to:

- Express your interest and concern, show empathy and understanding for your employees' needs;
- Listen carefully and give enough room to your employees to open up and talk about it;
- Do not say that everything will be alright;
- Make sure you send a gift (e.g., card, flowers) and call regularly;
- If the employees want, visit them;
- Take the time to inform your staff about their colleagues' situation.



"Before, I made one or two communications to the team itself, to the direct colleagues. In the sense of 'look, if you want to send her another message, you have to do it this week'. And then I said: 'If you want to talk to someone about it: the door is open. Come and talk."

Wholesaler

You may prefer not to think about it, but you should be prepared to deal with the death of your employees. Mourning largely exceeds the private sphere. You should inform your staff, get in contact with your employees' family and start making the necessary arrangements at work.

#### a. Informing colleagues

The death of a colleague has a major impact on your company/organisation. As an employer, you should be well prepared to handle such an eventuality. It is important to give yourself and your staff the time and opportunity to grieve, talk about the situation and process it. Your staff can also help you with some tasks, such as writing an obituary/'in memoriam' article for your company's newsletter. You should also think about notifying external contacts your employees regularly worked with and providing information to your staff about how to get external help to cope with the situation.

#### b. Contacting the family

Depending on the cultural customs in your country, you may consider:

- Expressing condolences and asking if everything is all right;
- Asking the family how you can be of help and discuss their wishes regarding the funeral (e.g., should someone from the company attend, should you say a few words at the ceremony?);
- Sending a card and flowers on behalf of the company/ organisation;
- Arranging a meeting with the family to discuss outstanding issues and next steps (e.g., financial affairs, handover of personal items).

#### c. Making necessary arrangements at work

Consult with your HR department and staff about temporary and long-term solutions linked to the replacement of the deceased colleague.

# When it is the employees' decision not to return

In some cases, employees choose not to return to work for various reasons, including not being physically fit enough, seeking a career change after their disease, or focusing on other activities after the illness. Make sure you give your employees enough time to realise whether this is the right decision for them and respect their wishes.

Support your employees in taking such decision by:

- Encouraging them to seek counsel before leaving the job, and taking some time to evaluate their decision;
- Offering alternatives that will allow them to postpone
  their final decision about returning to work until they
  have completely healed. These alternatives could
  include offering vacation time in advance, time off
  with the possibility of returning or a temporary unpaid
  leave;
- Being understanding and coming up with alternatives that can motivate your sick employees to continue to work, so they do not feel pushed away. On the other hand, do not make them feel bad if they really wish to terminate their contract and respect their decision.

# When it is the company's decision to end the collaboration

Sometimes, particularly if you are the owner of a microbusiness, cancer and its effects might make it impossible for you to await the return of your sick employees or keep them on a part-time/flexible basis.

Make sure your sick employees understand your decision and show your continuous support by thinking about how you can help them finding a new job, such as contacting other companies, giving them a recommendation letter, providing training resources, or contacting organisations that support workers with chronic conditions and disabilities.

If you and your employees disagree on whether the contract should be terminated, contact a social worker or an independent expert (e.g., union representative) who can help mediate this situation. Try finding a solution that is acceptable for both parties.

It is crucial to communicate this decision sensibly to your staff. Bear in mind that the way you manage an employee's farewell affects your reputation and that of your company/organisation internally and externally in the long term.



"When I came back to work after my treatments, the circumstances in the company had changed quite a bit. Generational change was taking place and the one who had always been my boss was retiring. On the other hand, the financial situation of the company was difficult. The company fired me, but they gave me a portion of my client portfolio with the intention of helping me to drive my own project."

Commercial Manager in a small real estate company affected by cancer

#### Manager's checklist:

Task	Status
I have discussed with my sick employees why returning to work is not an option for me, for them, or for both.	
I have communicated the new situation to the team and close colleagues of the affected employees.	
I have contacted their families and offered my support (if appropriate).	
I have dealt with all administrative and financial aspects of the contract termination.	
I have made all the arrangements necessary to temporarily cover my employees' workload and hiring new employees.	



What to do when you are employing a caregiver?

Many Europeans provide ongoing care for loved ones with chronic health conditions (including cancer). Caregiving takes a major toll on employees' work. Thus, supporting caregivers in the workplace is crucial. This chapter will provide you with useful tips on what to do if you are employing a caregiver<sup>26</sup> who, on the top of their day job, needs to care for a close person who is affected by cancer.

# Knowing the legislation that protects informal caregivers

Each country's legislative framework provides different protection for informal carers. Make sure you know how much time off in terms of paid leave are your employees entitled to take to tend to their loved one with cancer.

The EU Work-Life Balance Directive, which entered into force on 1 August 2019, introduced carers' leave for workers providing personal care or support to a relative or person living in the same household. Working caregivers are entitled to 5 days of leave per year. The Directive also extended the existing right to request flexible working arrangements (reduced working hours, flexible working hours and flexibility in place of work) to caregivers<sup>27</sup>.

In some countries, carers and their organisations are very active and willing to engage with enterprises to help them develop a caregiver-friendly workplace, where people having to juggle work and care responsibilities are supported rather than discriminated against. Some local authorities play a key role in this respect. You might, for instance, get inspiration from the *Employers for Carers* initiative in the UK<sup>28</sup> et Carer Positive Employer in Scotland<sup>29</sup>.

#### Showing support to the caregiver

It is important that HR staff and team managers are made aware of the challenges linked to cancer caring and of the possible support options. Support can be shown, for example, by:

 Showing empathy and understanding, particularly in regards to caregivers' emotional well-being;

- Making yourself or an HR colleague a key contact point available to listen to the caregivers' problems;
- Respecting caregivers' privacy (also whilst communicating with other staff and their colleagues);
- Keeping an open dialogue with caregivers to understand how their loved one's disease might affect their work;
- Monitoring the situation carefully and evaluating whether they can handle all their tasks or if a change to the workload is needed;
- Offering caregivers more flexibility in terms of time off even on short notice (e.g., to attend medical appointments with their loved ones, flexible working hours, possibility to work from home, possibility to work parttime, etc.);
- Organising regular meetings with caregivers to make mutually acceptable arrangements related to their tasks and roles;
- Assuring caregivers about the security of their jobs even though their workload might be reduced;
- Providing caregivers with a support network, including the option to get counselling or utilise external support, such as psycho-social services provided by a national cancer society or a patient organisation;
- Providing caregivers with support services' contacts that might help them deal with the situation (e.g., social services, patients organisations);
- If possible, providing financial compensation when caregivers have to reduce their working hours or take unpaid time off.



"When my seriously ill mother was also diagnosed with breast cancer, I was in shock. For the first few days, I went to work like a robot, didn't say anything to anyone and tried to persevere somehow. Then I took heart and spoke to my boss. Her understanding and sympathy have given me the floor. We were then able to talk about very practical things and she helped me with the information in the team."

Caregiver

# Organising workload in a sustainable manner

Caregivers might need to change their working hours and significantly reduce the workload while taking care of a family member with cancer. You might need to redistribute some of their tasks among other colleagues or hire temporary help.

Make sure you offer enough flexibility and achieve the right balance between helping your employees navigate through the difficult situation while, at the same time, ensuring all professional goals are met.

Be mindful that the disease and its consequences can impact on caregivers for a long time. As long-term solutions might need to be put in place, it is important to keep an open line of communication with both your employees and your HR department.



"My wife has incurable cancer and will not live long. Now I have to take care of her, our children and everything organisational. I can still reduce my overtime and take a vacation. However, as a team leader, I am very challenged at work and have to make sure that my work is somehow done. What happens when I run out of time? And when and how can I relax myself?"

Caregiver



"When my wife was receiving treatment, I was allowed to accompany her to the doctor and hospital appointments. I didn't have to recover those working hours."

Caregiver

#### **Terminology**

Absenteeism = a recurring pattern of absence from work, e.g., taking regular sick-leaves, coming late to work

**Cancer league** = a non-profit organisation addressing all aspects of cancer control, including awareness raising about cancer risk factors and prevention, cancer diagnosis, funding cancer research, advocating for access to cancer treatments, developing services for cancer patients and survivors etc.

Cancer patient = a person who is undergoing cancer treatment or a person diagnosed with cancer

Cancer survivor = a person who has undergone treatment and is cancer-free or lives with cancer

**Caregiver/Carer** = a person who provides (un)paid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework

**Cognitive impairment** = when a person has trouble remembering, learning new things, concentrating, or making everyday life decisions

**Complete remission** = when tests, physical exams and scans show that all clinical signs of cancer are gone. Patients are generally perceived as cured if they are over 5 years cancer-free

Direct costs to employer = payment of employees' wages

**Discrimination** = when one person is treated less favourably than another is, has been, or would be treated in a comparable situation, based on a particular characteristic they hold or when an apparently neutral provision, criterion, or practice would put one person at a particular disadvantage compared with other people

**GP** = a general practitioner, a primary healthcare professional, or a community doctor

HR = human resources, those responsible for hiring and managing staff in organisations

**Indirect costs to employer** = loss of production, overtime of other employees, loss of productivity, etc.

**Occupational therapist** = a healthcare professional who utilises evidence-based practice, research, scientific evidence, and a holistic perspective to promote independence, meaningful occupations, and patients' functional ability to fulfil their daily routines and roles

**Patient organisation** = a non-profit organisation connecting patients and/or carers, representing and amplifying their voices in health decision-making

**Presenteeism** = the practice of going to work despite illness, anxiety, or other physical or mental health issues, often resulting in productivity loss and exhaustion

**Reasonable accommodations** = are defined by EU law (Directive 2000/78/EC) as "appropriate measures to be taken by the employer, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer".

**Social worker** = helps individuals and families adjust to changes and challenges in their lives, such as illness or unemployment, helps them navigate through governmental benefits and refers them to community services

Stigma = when certain differences (or imagined differences) are labelled or pointed out and given negative associations

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# **Notes**

# The Fondation Cancer, for you, with you, thanks to you.

Founded in 1994 in Luxembourg, the Fondation Cancer has worked tirelessly for 25 years in the fight against cancer. In addition to providing information on prevention, screening and living with cancer, one of its missions is to help patients and their families. Financing cancer research projects is the third aspect of the Fondation Cancer's mission, which organises the major solidarity event *Relay for Life* every year. All these missions are made possible thanks to the generosity of our donors.

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