



**CAMPAIGN:  
INTERNATIONAL WORKERS' DAY 2024**

**1 MAY 2024**

## **ABOUT THE ECL PATIENT SUPPORT WORKING GROUP**

Since 2002 the ECL Patient Support Working Group (PSWG) connects cancer care experts who work together on topics such as access to insurance and financial services, return to work, caregiver support, cancer rehabilitation and palliative care. PSWG members share best practices, develop guidelines and other information sources to raise awareness and improve quality of care, and seek to empower the patient voice in national and European policy-making.

## **ECL CANCER AND WORK CAMPAIGN**

A cancer diagnosis can have drastic effects on an individual's career, as well as taking a physical and mental toll on the patient and their loved ones. In Europe, around 1.6 million people of working age are diagnosed with cancer every year. Treatment for these cases are often accompanied by long period of sickness, and the resulting absence from work. Cancer survivors have a 1.4 times higher risk of unemployment compared to their healthy peers.

By interviewing cancer patients and experts in the field of returning to work, ECL's Patient Support Working Group aims to raise awareness about the effects of cancer on patients in the workforce, and how employers can support employees diagnosed with cancer.

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## **INTERVIEW: SABINE SCHREIBER – CANCER EXPERT, GERMANY**

*Interview conducted by **Sabine Schreiber**, Co-Founder and Deputy Executive Officer of *Leben nach Krebs!*, Germany*

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### **How does a cancer diagnosis affect patients' work and career, in both the short and long term?**

A cancer diagnosis can affect a patient's work and career in many ways. During treatment, the patient may be unable to work for months or even years, depending on the diagnosis and course of treatment.

In the short term, a cancer survivor's career is often put on hold, as they need to take time for recovery and rehabilitation. In the long term, many cancer survivors go through a period of reorientation—for example, finding a new employer, reducing their working hours, retraining, or moving to self-employment.

A cancer diagnosis can also mark the end of a patient's career—for example, due to fatigue after cancer. In Germany, one third of cancer survivors do not find their way back to work. Although Germany has a well-established welfare system, many young cancer survivors who depend on state benefits live under the poverty line.

### **What can employers do to practically and emotionally support their employee(s) diagnosed with cancer?**

Employers should be aware of their duty of care for their employees and try to anticipate the challenges ahead. They need to be aware of the short- and long-term effects of cancer—which admittedly is no easy task since medical research still lacks focus on long-term side effects.

It goes without saying that employers should be careful not to put any pressure on their employees during their medical treatment and reintegration. It's a good idea to keep in (written) contact with employees on a monthly or quarterly basis without expecting any feedback on medical outcomes or prospects.

Employers should make sure they are up to date on their legal obligations—for example, offering a phased return to the workplace (see question 3). A mutual agreement between employer and employee on the conditions of the phased return that reflects the employee’s changed and evolving work ability and capacity is highly recommended. This agreement should be regularly evaluated and adapted as required. The employee’s job description may also need to be adjusted to the new situation—for example, reducing the number of business trips. A tandem partner and/or a designated contact person as well as a communication strategy is also desirable (see questions 4 and 6).

Some employers are able to fill the financial gap between sick pay and the regular salary for a certain period of time. This financial support prevents cancer patients with low salaries slipping into the poverty trap.

### **What are the legal protections put in place in your country/region to support cancer patients and survivors in the workplace?**

In Germany, there are legal obligations on the reintegration of employees after a period of absence owing to illness of longer than six weeks. The employer is obliged to inform the employee about the option of return-to-work management (“Betriebliches Eingliederungsmanagement” / BEM; §167 Neuntes Sozialgesetzbuch). The goal of this process is to identify and mutually agree on supportive measures to restore the employee’s ability to work, at least to a certain degree. This process is voluntary for the employee and requires their consent. The employee can involve someone they trust in the process.

The result of such a BEM process varies depending on the circumstances. Often, participants agree on a time schedule for the employee’s phased return within what’s known as the “Hamburg Model”. For example, a returnee may start working 2 or 3 hours per day and gradually increase their working hours until they are back to their full capacity after 6 to 8 weeks (in most cases) or up to a maximum of 6 months. Other measures include adjustments to the returnee’s working conditions (e.g., more opportunity to work from home and to take breaks) and moving to other tasks or roles within the company.

However, experience has shown that many employers fail to offer their employees this structured BEM process as they are not aware of their legal obligations.

Cancer patients and survivors can also apply for disability status. This status affords some additional rights with respect to the design and organisation of the workplace, as well as five additional holiday days, tax relief, and stricter protection against dismissal.

### **What workplace policy changes can be made to support cancer patients and survivors in the workplace?**

Work arrangements like working from home and flexible working hours help cancer survivors to accommodate medical appointments and to manage fatigue and other side-effects of treatment. Reasonable accommodations such as relaxation rooms for breaks and a calm working environment can help cancer survivors get back to work.

Creating an open and safe environment for communication is essential. Asking for help should be a sign of strength, not weakness. An ongoing exchange of information on how the cancer survivor and their colleagues are coping makes it possible to readjust the workload and expectations as necessary, and strengthens team spirit and motivation.

Offering colleagues the opportunity to ask questions about the illness, therapy, and new challenges might ease the atmosphere.

Large companies could facilitate support groups, enabling cancer survivors to connect with others who have gone through a similar experience and to share advice, coping strategies, and encouragement.

### **What are the national/European policy changes that can be implemented to support employers who want to improve the position of cancer patients/survivors at the workplace?**

Re-skilling and up-skilling programmes funded by the European Social Fund Plus could help employees re-join the workplace.

National legislation should prohibit dismissals or redundancies during therapy and after one year end of therapy.

Employers should be given information on late and long-term effects of treatment, psychological distress, and the benefits of both counselling and exchange with other cancer survivors in the workplace.

Part-time sick leave as practised in Switzerland would take into account that many of those on full-time sick leave in fact work several hours a day/week, leading to more security and regulation.

A special European prize could be awarded to employers who protect and promote the rights of employees with disabilities and take measures to improve their security and well-being at work.

### **What kind of support do cancer patients/survivors need at their workplace?**

We believe there are several ways to support cancer patients and survivors at the workplace. For example, returnees could be allocated a tandem partner—a colleague who explains new rules and developments, can help manage tasks, and step in when the returnee feels overwhelmed or needs a break.

A good communication strategy (disclosure decisions) is also essential: It is important to define who tells what to whom (so that the returnee does not feel exposed or overwhelmed by their illness), and to offer the possibility for the returnee to give a talk about their personal experience, with room for questions. In order to create an atmosphere of trust and belonging, it is important not to shame and blame, but to be mindful and collaborative, helping the person to feel reintegrated after a diagnosis or treatment.

Some more practical implementations such as space for recreation/rest/breaks and flexible working hours should also be considered.

### **What kind of resources are available to cancer patients/survivors to support them with the return to work?**

A rehabilitation course lasting 3 to 4 weeks is usually financed by the health or pension insurance, in some cases a second rehab stay is also possible. A phased return to work within the “Hamburg Model” (see question 3) is usually financed by the health insurance company. As a result of the mandatory reintegration process (“Betriebliches Eingliederungsmanagement” / BEM; see question 3) the employer may agree to finance special equipment to adapt the workplace to the needs of the employee.

It is only in the last decade that training programmes, events, and counselling for cancer survivors returning to the workplace have been established. In Berlin, the initiative Leben nach Krebs! e.V. (Life Beyond Cancer!) pioneered workshops on legal, mental, and social aspects in cooperation with the consultancy KOBRA. A few years later, the Deutsche Krebsgesellschaft followed suit with similar events. However, these kinds of services are still the exception in Germany.

### **What further resources should be made available for other groups?**

Unemployed and self-employed cancer survivors face particular challenges. There is no one-stop shop in Germany offering information on legal rights and whom to contact. It takes a great deal of time and energy to access the necessary information. Many self-employed cancer survivors face financial significant insecurities.

Parents of young children also face specific challenges. Seeing a parent suffer or being separated from them during cancer treatment, surgery, rehabilitation can be traumatic for children. Luckily, some institutions in Germany offer valuable counselling for parents with cancer and their children (e.g., Berliner Krebsgesellschaft).

### **How can mental health cancer experts/mental health professionals support cancer patients and survivors in the workplace?**

Many survivors need time for reorientation and a boost in self-confidence and self-efficacy after completing treatment. Some may need to adjust their expectations of their own productivity to a new (lower) level. The waiting times for psycho-oncological counselling should be reasonably short. Exchange with other cancer survivors is crucial for helping survivors to accept the new situation and learn to cope with it.

**How can family members/caretakers of cancer patients be supported in the workplace?**

Who takes care of those who take care of us? This is a question that often goes unasked, especially in the workplace. Family members and caregivers of cancer patients should be given the opportunity to reduce their working hours and be given more time to complete their tasks. Employees should take into account that caregivers may need to be absent more often due to doctor's appointments or caregiving responsibilities at home, which they should be able to do without feeling shame or pressure at work.



## **INTERVIEW: ESZTER SOLYOM FEKETE, CANCER SURVIVOR, HUNGARY**

*Interview conducted by **Eszter Solyom Fekete**, volunteer for the Hungarian Hospice Foundation, Entrepreneur, Assistant, Hungary*

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### **How has the cancer diagnosis affected your ability to work?**

**Employee (Assistant):** As I work from home, it did not impact my ability to work. However being able to show up on the doctor appointments, I needed huge flexibility from my employer.

**Hospice Volunteer:** As soon as the diagnosis was set, I could not continue my volunteering at the Hospice foundation as being a volunteer while affected by cancer is incompatible.

**Entrepreneur:** As I mainly function in supporting roles (coach, end-of-life dola, pelvic floor trainer) I had to make a decision to turn my attention fully for myself and for the healing, so I was temporarily out of business. As a pelvic floor trainer I also had to make this decision as I was physically disabled after surgery. But I could return after 3 months.

### **How has cancer affected your career in the long term?**

**Employee (Assistant):** I am really lucky, as my employer is very supportive, and also my work conditions are great (part time, working from home), so it does not affect this area. I am also planning to keep working here on long term.

**Hospice Volunteer:** I still couldn't return after almost a year. But I hope that I will be able to continue. I believe that this experience will have added value on my volunteering. So far I haven't thought about all the journey of a hospice patient but mainly the "before cancer" life and the current (no active medical care, only palliative care) state. But there is a huge road in between, which I did not consider before.

**Entrepreneur:** So far there is no change, only that the end-of-life doula services I am still postponing to restart. However as i started to focus on myself and tried different therapies and self-development programs, I met new methods which I am considering becoming an instructor/therapist in a 5 -year plan.

### **How important was it for you to go back to work?**

**Employee (Assistant):** I could return 1 week after surgery. And I am pretty sure that helped me to keep sane. It helped me to keep my self-esteem and the sense that I am needed, I can add value and not become desperate or feeling really down. Later she was the one who suggested an onco-psychologist for me when I needed one.

### **Were you comfortable with sharing your cancer diagnoses with your employer?**

**Employee (Assistant):** First I did not want to share the information, but as I got an emergency appointment at a doctor and I had to miss a regular call, I shared that it will be a doctor's appointment. And my employer replied that she hoped it was nothing serious. She is really caring, so I shared it with her right after this question.

**Hospice Volunteer:** it was really difficult. As I have been a volunteer for 9 years, going there weekly, it was part of my life. So it was really difficult sharing it with them, as it was another loss in my life I had to face besides my diagnosis. My heart was broken that I had to call off my duties.

**Entrepreneur:** as a pelvic floor trainer I am in a license agreement with the owner of the method. I had to share it with her, as I was asking for an exemption and an act of kindness from her regarding my financial possibilities. I was thinking a lot about it, but decided that I will give it a try. I did not share the details, I only provided information that I was diagnosed with a malicious tumour, but no further details. But she was really nice, and wished me all the best.

### **Did you feel supported in your workplace by your employer and by your colleagues?**

**Employee (Assistant):** Absolutely! More than I could imagine. I feel really lucky that when this happened I was already working for her, as she supported me not only by providing flexible working hours, but also mentally. She was always checking on how I was, and also ensured that whenever I need a break, she is okay with it. However I did not tell it to my colleagues. As we work remotely, we don't have such a close relationship, but I might share it with some of them.

In the meantime I must admit that I did not feel comfortable sharing my diagnosis with people. Even in my family. Not because I was ashamed of it, but as I was not sure how I could handle the different reactions. My mental state was not stable, one day I was crying, the next day (or within an hour) I was all positive. I knew that my diagnosis wasn't the worst of all cancers, but I wanted to have the right to feel bad, sad, desperate when it was true, and okay when it was true. I did not know how I could handle reactions if one would be derogatory about my situation, or one would start talking about how others were through this easily, or their own "survival" story etc. I just wanted to allow myself to really be in what I felt, and not reacting to others or suppress my feelings.

**Entrepreneur:** The method owner was nice as I detailed in point 4. I did not share it with the other trainers, only with one of them, but only recently. We do not have such a close relationship.

### **What accommodations helped you to deal with your diagnoses in the workplace?**

**Employee (Assistant):** besides home-work I got flexible working hours, or rescheduling meetings when I had to be at a doctor's appointment.

### **What kind of workplace policies or accommodations would you like to have had?**

**Employee (Assistant):** as it is a small company, there is no need for policies, as the owner can make her decisions regarding the individual needs.

### **What kind of support in dealing with cancer diagnoses and work did you have outside your workplace?**

**General:** There are limited possibilities. And even you can hardly know the existing possibilities. For example I learnt that I can ask for travel expense reimbursement from a Facebook group. No doctor, no assistant informed me about that. But even this reimbursement is a bit difficult - you have to indicate it while on the appointment, and after that filling an e-form for this. But sometimes I as a patient was not aware of the code of the health care facility or unit, so it was declined. Also the amount is not even close to what my travel expenses were.

Also I found out (also from social media), that due to my cancer diagnosis, I can apply for disability pension support, which I did and received. But if I knew it before, if any of the health care workers (GP, oncologist, doctors, assistants) mentioned, I could have done that 3 months before, so I would not miss 3 month income.

I also asked for an onco-psychologist, which again was my own initiative, as none of my doctors mentioned or recommended it to me. I just felt that I need some kind of mental support, and as I mentioned above, my employer was so kind and referred one to me.

How did the return to work look for you? How has your employer supported you in this process?

**Employee (Assistant):** as I already mentioned, I could return one week after my surgery, but emphasising her openness to my absence and flexible time gave me a huge feel of safety.

**Entrepreneur:** there was nothing. As a coach we just restarted our sessions. As a pelvic floor trainer I informed the method owner, paid what I had to, and I just continued.

**What do you think are some important changes in both policies at the workplace and national policies/laws that would help cancer patients and survivors in their workplace?**

**General:** Even though my current situation is a bit unique, as I worked for big companies before as an HR I can see that being on sick-leave is usually a financial deficit for a cancer patient. The sick-leave allowance is much lower than the salary, and extra expenses arise. As I mentioned above, travel expenses, especially that many times the patients have to travel from far for the treatments, and only part of that is reimbursed. If there would be a chance for “paid-as-worked” - example even if one is on a 40 hrs/week contract, but only able to work for 20 hrs/week due to appointments or physical ability due to treatments, it would be great if that would work automatically, and would not need to go on sick-leave.

If there would be a leaflet for the benefits, allowances, reimbursements, which can be required due to the diagnosis, it would be great. Currently many people miss these opportunities (disability pension and travel reimbursement), as when you get the diagnosis, this is not the first thing you are thinking about, but your journey for life and health. Or providing free public transport to the treatments. Or free parking at the facilities for cancer patients. I have to go back at least once a month, but sometimes 3-4 times per month to the hospital, and the parking is very expensive, there is no financial support for that.

It would also be great if there would be information books regarding the cancer we are in: what can you expect, what can you do to make it easier, better, what are the possible next steps. What can you do if you have another side effect, pain etc. Like I have joint pain since my surgery, but it is difficult to find my way and next steps: rheumatology? Orthopaedist? Corrective-gymnastic therapy? I know that each case is different, but if someone gets chemotherapy or radiotherapy, hormone therapy, there could be information about it. What are the most common side effects, and what can we do about it? So we don't need to look it up on the internet and get all the horror stories.

I know that in some facilities these exist, but it is not a national way and it varies by institution. Like in my case many people got corrective-gymnastic therapy already 1 day after the surgery. I was told not to do any, and when I informed my doctor that I have mobility difficulties, I was told to look for exercises on YouTube. Until today I could not get an admission for corrective-gymnastic therapy (9 months after surgery).

So probably there are lots of possibilities, but it is not ensured that a person with cancer gets to know the possibilities, or know what to expect, especially if someone is not using the internet or social media actively.

## **INTERVIEW: AECC – CANCER EXPERTS, SPAIN**

*Interview conducted by the Patient and User Services Area and the Political Advocacy and Institutional Relations Area of the Spanish Association Against Cancer:*

- **Begoña Castro Torrego** (*Trabajadora Social*)
- **Alejandra Agudo Gómez** (*Psicooncóloga*).
- **Ana Monroy González** (*Psicooncóloga*).
- **Carmen Yélamos** (*Responsable de Atención Psicológica*)
- **Sara Crespo Romero** (*Responsable de Atención Social*)
- **Nuria Masana** (*Directora de Gabinete y Relaciones Institucionales Gabinete Técnico del Consejo Nacional*)
- **Lucía Aboud** (*Responsable de Relaciones Institucionales e Incidencia Política*)

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### **How does a cancer diagnosis affect patients' work and careers in the short term? What are its effects in the long term?**

The diagnosis of cancer has a great physical, emotional and social impact on the person diagnosed. When they receive this news, their life is paralysed and they begin to experience changes in all spheres, including work. The impact of cancer in the workplace will depend on different factors such as the person's age, level of education, the type of diagnosis, the stage of the disease or even the type of job.

In the short term and even prior to diagnosis, the person's life and daily activities will be altered, including his or her work, which will begin to be affected by absences for medical visits and diagnostic tests, a situation that will be even more pronounced when the diagnosis is confirmed and treatments are started. These treatments will have a series of side effects that may have a psychological impact (fear, uncertainty, anxiety, depression, cognitive deterioration), physical (fatigue, tiredness, sequels) and/or social (economic impact, changes in family dynamics, limitation of autonomy) and may have repercussions on the capacity of the patient.

In Spain, the current Social Security legislation allows that, when a person is unable to maintain his/her work routine due to an illness, he/she can take a temporary interruption called medical



leave or temporary disability, this being the procedure that justifies to the company the absence of the worker due to a health reason and that allows the worker to access to an economic benefit to cover the loss of income during the time the leave lasts. As established in the regulations and depending on the situation of each person, this benefit for temporary disability can reduce income by up to 25%, generating a loss of income which, together with the increase in expenses derived from the illness, can generate a situation of economic vulnerability in the diagnosed person.

In the long term, the person may have temporary or permanent sequels and/or limitations that prevent or make it difficult to return to work, requiring the search for alternatives. In these cases, Spanish legislation provides for the adaptation of the workplace (Law 31/1995 on Occupational Risk Prevention) or the initiation of procedures for permanent disability (economic benefit provided for in the General Law on Social Security, Royal Legislative Decree 8/20215, of October 30, which seeks to cover the loss of income suffered by a worker when his or her working capacity is reduced or annulled due to illness). On many occasions, the person must consider new scenarios for continuing to develop his or her professional career (reinventing himself or herself or changing direction).

In short, this disease process has a direct short- and long-term impact on the person's professional career, which is affected by the stoppage that this situation entails, together with the consequences and sequels of the treatments received.

### **What can employers do to support their employee(s) diagnosed with cancer?**

Currently, in Spain there is no law or specific strategy at governmental level that regulates the actions of the company in the event of a diagnosis of cancer in any of its workers. From the Spanish Association Against Cancer we are working on the creation of an action protocol that determines the necessary measures and actions to be carried out, both at the level of awareness and intervention in a disease situation.

In this line, it is essential that the objective of the company is aimed at trying, as far as possible, that the person can continue working whenever he/she can and wants to do so. To this end, it is important for the company to encourage communication with the diagnosed person at all times, always showing accessibility, respect, trust and support for everything the person wants to communicate.

Another important aspect is the direct support provided by the company, which will always try to favour adaptation to the situation both during the treatment process and during reincorporation into the work environment with measures such as: flexible working hours, teleworking and adjustment of the position, among others.

Finally, it is essential that due to the impact that this disease has on the diagnosed person, the company can offer services that can facilitate the accompaniment of the affected person (specialised psychological care, social care, health care, legal and labour care) as well as the necessary means for the person to access these services if needed.

It should be borne in mind that there may also be workers in the company who are family members of cancer patients, so that they may also need a series of measures, especially in terms of flexibility and support resources.

The presence of the oncological disease in the work environment also has a direct impact on the person in charge and colleagues of the diagnosed person. Therefore, it is important to create spaces for awareness, communication and knowledge about the oncological disease that will allow them to accompany the affected person in the work environment in the best possible way.

### **What are the legal protections put in place in your country/region to support cancer patients and survivors in the workplace?**

In Spain, the General Social Security Law, Royal Legislative Decree 8/20215, of October 30, regulates two types of benefits when the worker is unable to work due to an illness, either temporarily or permanently:

- **Temporary disability:** or also called medical leave, is what justifies that the person cannot attend work due to a medical situation on a temporary basis. It provides a benefit to the worker.
- **Permanent disability:** there are several types of permanent disability, it is a benefit when the person cannot work in a more permanent or long term way, due to the sequels or limitations that make the development of the labour activity impossible.

In those cases where the person, due to his physical condition or illness, requires certain adaptations in his work place so that his work activity does not imply a risk, the option of adapting the work place can be assessed. In Spain this action is regulated by the Law on Occupational Risk Prevention, article 25, which states that the employer is obliged to adopt the necessary measures for the adaptation of the work place and the accessibility of the company..

### **What workplace policy changes can be made to support cancer patients and survivors in the workplace?**

It is necessary for labour policy to incorporate a plan and regulations that cover all the needs of a person with cancer in relation to his or her work activity. These measures should facilitate both the treatment process and the return to work.

It is necessary for this labour policy to be accompanied by other regulations that favour the care of the sick person. In Spain at present, due to the lack of resources and/or implementation of policies in the public health system, psychological care in cancer is not integrated into the portfolio of services and a large part of these services are provided by professionals specialised in oncology belonging to non-profit organisations, such as the Spanish Association Against Cancer.

With regard to public policy changes, there are three areas in which progress should be made: permits, training and economic support:

- I. Possibility of reducing the working day when the worker returns to work after a long period of sick leave due to serious illness, allowing a gradual return to work without

reducing his/her economic capacity, evaluating the possibility of supporting small and medium-sized companies, as well as the self-employed, to meet these objectives.

2. Increase of the temporary disability benefit to 100% of the regulatory base to reduce the financial toxicity of people with temporary disability due to serious illness (to develop the list at a later date) and also in the case of self-employed workers.
3. Access to regulated paid leave to attend medical appointments and/or treatments for people with serious illnesses and their caregivers (modifications have already been made along these lines for family caregivers). Some modifications have already been introduced in the ETT for family caregivers.
4. Access to training to update knowledge after long-term sick leave, facilitating the worker's reincorporation and the adaptation of his/her functions. Possibility of incorporating an adaptation of occupational risk prevention.
5. Suspension of the payment of the self-employed contribution from the first month of the temporary disability, without impact on their contribution, when a sick leave due to serious illness is foreseen.
6. To offer help to self-employed workers who are affected by a serious illness and whose working and economic capacity is diminished, in order to be able to maintain their work activity by hiring workers at a reduced contribution rate.
7. Modify the current regulations so that in situations of unemployment, temporary incapacity due to serious illness does not consume the periods of contributory unemployment benefit, and also in the case of self-employed workers.

### **What are the national/European policy changes that can be implemented to support employers who want to improve the position of cancer patients/survivors at the workplace?**

(Mentioned in the previous answer).

Incentives for small and medium-sized companies, such as self-employed workers with dependent workers that make it possible to reduce working hours when returning to work for a person on long-term sick leave due to serious illness.

### **What kind of practical support, and what kind of emotional support do cancer patients/survivors need at their workplace?**

As for the practical support that the affected person will need, it will depend on the type of work, as well as the sequels or limitations that he/she has. In this sense, it is important to be able to facilitate as much as possible the reconciliation of work and the needs of the person with options such as: teleworking, reorganisation of the work schedule, facilitating the ability to attend medical appointments, reorganisation of work and tasks where the patient feels comfortable, etc. It is vital that the person has all the information regarding their rights and resources to which they have access, since having all this information puts them in a position of greater knowledge and security when making decisions.

In order to resolve these questions it is important to go to the Social Work Units located in the hospitals themselves, or to the social work professionals of organisations such as the

Spanish Association Against Cancer, where the necessary information is provided to the patient, accompanying them in their situation, as well as in the different social problems.

At an emotional level, fluid, open and frequent communication between the company and the affected person is essential during the whole process of the disease, fostering safe and trusting spaces. It is essential that communication is based on knowing the person's needs through active listening and empathy, respecting his or her decisions. The work environment must take into account that the person will go through periods of great uncertainty, suffering and emotional variability. It is also important for the company to be able to orient the diagnosed person to the existence of specialised resources that can accompany him or her in this process. In Spain, the Spanish Association Against Cancer provides a specialised psychological care service accessible to all those who may need it, both patients and their families.

The reincorporation to the work environment after the disease process is also a period in which the person will need practical and emotional support, since the person is not the same as before the diagnosis. The disease has generated a series of important changes, possible sequels and time away from the company, so it is essential that this reincorporation be gradual and adapted to the person's situation, especially bearing in mind the possible physical and psychological (emotional and cognitive) sequels.

Therefore, it is essential to provide spaces for respite and self-care, flexibility before medical check-up appointments and, of course, that all this continues to be closely accompanied by trusting and accessible communication between the worker and the company.

### **What kind of resources are available to cancer patients/survivors to support them with the return to work?**

Return to work can be a complex process for the affected person because there can be different scenarios. On the one hand, although the active treatment phase has ended, the person may not have recovered either physically or psychologically. In addition, there may be pressure due to the economic need to return to work, even though he or she is not yet ready to do so. On the other hand, it may be that the affected person's environment considers that he or she is not yet ready to resume daily life and return to his or her job. These scenarios hinder the process of reincorporation into the work environment.

Third sector organisations such as the Spanish Association Against Cancer offer diagnosed persons the following free services to attend to their needs and accompany them at this time:

- Individual and group psychological care to address the difficulties that the affected person is going through, working on the identification of current needs, the management of the impact of the disease at a psychological level, existing concerns about returning to work and to their daily activities, how to deal with communication with their colleagues and with their family and social environment, etc.
- Social care to guide and inform the patient on different social and labour issues, informing him/her about the different resources or rights, as well as making possible referrals to other internal or external resources. In the specific case of cancer survivors, information is provided regarding the end of temporary incapacity (medical leave), permanent incapacity

processes, or the need for job adaptation, etc., with the aim that the person can resume their activities and basic routines, adapted to their new needs.

- Legal Labor Attention, we deal with problems that involve a legal conflict in labour and Social Security matters, such as medical discharge claims, dismissals, drafting of claims, denial of rights, etc. In order to support, accompany and / or resolve procedures or claims that the patient needs in their work environment.
- Health Care: to address the physical aspects that impact on the daily life of people with cancer, with the availability of Physiotherapy, Nutrition, Speech Therapy, Physical Exercise and Health Guidance services. In each of them, the aim is to improve the quality of life by preventing, facing and reducing, as far as possible, the different sequelae of the disease or treatments suffered, as well as educating in the management of the problems that may arise during the course of the disease.

These services can be applied both in person and digitally. There is also an Infocáncer telephone helpline (900 100 036) and an online consulting service (<https://www.contraelcancer.es/es/te-ayudamos>), available 24 hours a day, through which people diagnosed with cancer and their families can contact the organisation with their needs and doubts and receive a response tailored to their needs, offering the appropriate resources and services according to their needs.

### **What is the role of cancer experts/mental health professionals in supporting cancer patients and survivors in the workplace?**

Currently, the Spanish National Health System does not include psychological care for cancer patients during the disease process. For this reason, people affected by cancer do not have professionals specialised in psycho-oncological care integrated in oncology and palliative care units. Mental health services in the hospital and primary care setting, currently overwhelmed in Spain due to the lack of resources, do not cover this type of need and are neither trained nor specialised in cancer. There are no psychological care departments in companies either, so it is a service that is difficult to access, and private care is the most commonly used route, either through NGOs or private consultations, which entails an additional cost to the disease process that not all family economies can afford.

In Spain, mental health professionals specialised in psycho-oncology will be the people in charge of being present throughout the oncologic process, accompanying the person diagnosed with the impact and emotional discomfort derived from the disease. The psychological intervention focuses on addressing the individualised needs of patients on an emotional level, the management of the changes brought about by the presence of cancer in their lives, learning assertive communication skills and strategies to share with their circle the needs they have, limits and information related to their disease situation. The impact of the after-effects of treatments such as hair loss, amputations, colostomies, lymphedemas, among others, is also addressed. This psychological care will also work on the impact and emotional discomfort that the relatives of these patients have, since it is a disease process that affects them directly.

The approach to the mental health of cancer patients and survivors is largely carried out by third sector entities such as the Spanish Association Against Cancer.



## **How can family members/caretakers of cancer patients be supported in the workplace?**

The oncological diagnosis also has a direct impact on the closest relatives of the sick person, which implies that they will have needs and difficulties associated with the disease process of their loved one. On an emotional level, they will experience emotions similar to those of the patient him/herself, such as fear, anger and sadness, among others. Worry and uncertainty will also be very present in them, which implies that at a cognitive level they will also be affected. Therefore, it is necessary for the company to understand that, although the family members are not experiencing the disease first hand, at a psychological level they have similar needs to the affected person and may need psychological care to deal with the emotional impact of the news and the disease process.

As for the needs with respect to the company, they are again very similar to those of the patients; communication between the worker and the company will be fundamental in order to have information available. To this end, it is important to generate this space of accessibility and trust, promoting it without fear of the possible consequences or other types of difficulties.

In relation to adaptations, they will also need to have some time flexibility to be able to be absent and accompany their family member to medical appointments and treatments. In Spain, there are occasional leaves of absence for surgery or hospital admissions, but these are not sufficient to provide the support needed by cancer patients, especially during active treatments and in advanced stages of the disease, when the need for accompaniment increases due to physical limitations and the emotional impact.

The National Health System does not provide the necessary support for psychological and social care for the families of cancer patients, so third sector organisations such as the Spanish Association Against Cancer once again cover these services, which are so necessary at this time.