



# **MAKESENSECAMPAIGN**

## **Survivors' Stories**

# Introduction

Head and neck cancer is the 7th most common type of cancer in Europe, with more than 150,000 new patients diagnosed every year. Despite this, there is still limited awareness among the general public, with many cases diagnosed at late stage. In order to ensure the best outcomes for patients, investment into early diagnosis and timely treatment, as well as a multidisciplinary approach to care, is essential. Furthermore, ensuring appropriate support and guidance post-treatment is incredibly important for head and neck cancer survivors.

The *Make Sense* campaign, run by the European Head and Neck Society (EHNS), aims to raise awareness of head and neck cancer and ultimately improve outcomes for patients with the disease.

Head and neck cancer affects people in different ways; however, there are consistent experiences and challenges from diagnosis to treatment and beyond that remain a common theme for patients. *A Survivor's Story* tells the raw, real-life experience of six head and neck cancer survivors, who openly share the highs and lows they have faced, coupled with the varying levels of support they have received.

By understanding the journeys these patients have gone through, we can work to address the specific needs of head and neck cancer survivors, and develop unified guidelines for survivors and recommendations at a European level.

# Survivors' Stories

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\*Name has been changed for patient anonymity



# Magali, Belgium

My name is Magali, I am 36 and consider myself an idealistic dreamer, whose glass is always half full. I love to get lost in a good novel, meditating, swimming and running, all of which allow me to be truly mindful and in tune with myself. Long chats with my girlfriends over a good glass of wine and laughing with the ones I love, centres me.

## How did you feel when you were diagnosed with cancer?

I was diagnosed with Stage IV salivary gland cancer (with bone infiltration) when I was 30 and pregnant with my first child. I still cannot describe what it felt like when I was diagnosed; it was like a tsunami, devastating and impossible.

The delivery of my diagnosis was a trauma I had to work really hard to overcome, even after treatment. I had a poor prognosis, and the doctor spent just three minutes talking to me. I was standing there, pregnant, crying, still not really knowing if it was actually cancer or just a risk of cancer. I am now dedicated to educating young healthcare professionals on how to deliver news to patients at such a crucial and distressing time with empathy and patience.



**“The first time I saw my face in the mirror I almost fainted and couldn’t speak. The pain was unbearable.”**

## Since your treatment finished, what has been the biggest challenge you have had to overcome?

Simply put, relearning how to swallow, eat and speak. I didn’t have any teeth on my lower jaw for 2 years after my surgery, which, as a young woman is incredibly hard to deal with. I am still fighting against a Belgian insurance association for my dental prosthetics, because they are not reimbursed by social security, even after cancer. It is viewed as a question of aesthetics, instead of medical necessity, which is hard to swallow, literally. In comparison, breast cancer patients receive national funding for surgical reconstruction after treatment, which of course they should. In my view, all cancer patients should receive equal opportunities.

## How has your life changed?

Firstly, after my surgery, I constantly had to be careful with what I ate. I found that after reconstructive surgery, my mouth, and in many respects my confidence, never returned to how it was before.

The first time I saw my face in the mirror following surgery I almost fainted and couldn’t speak. The pain was unbearable. While things have improved since then, it has affected how I feel about my self-image. I no longer look or feel like I used to, and even though I have accepted how I look, it hits me hard when I come across an old picture of myself or see my reflection.

The biggest and most important adjustment I’ve made is to be ready and willing to live life to the fullest. I have learned that every moment is a gift, and today is the present.

## Do you think you have been offered adequate support since completing your treatment?

No. Not only do you fear for your life after being diagnosed, but returning to normality is equally challenging. Community services I took for granted before suddenly became unavailable or challenging after treatment, such as social security, employers, banking, and insurance. While I was encouraged to return to normal life, I was being treated like I had a death sentence. I had problems borrowing from banks as well as going back to work.

I was fortunate to have a wonderful psychologist at the hospital, who never let me down and is always there when I need her. I am one of the lucky ones to have such support, enabling me to find ways to improve my quality of life. Coaching was a real lifeline for me, and empowered me to the point I became a life coach myself in order to help other patients. As I say, “when the tumour goes, there are a number of questions that remain unanswered”.

## What advice would you give a recent head and neck cancer patient?

It is normal to feel devastated, it is normal to cry and feel that the situation is unfair, but don’t hold a grudge – keep going and find out how truly strong you are. As impossible as it may seem at the time, transform this terrible experience to make it a springboard and live your life to its full potential! You are stronger than before, because you know yourself better!

# Umberto, Italy

My name is Umberto. I'm 73 years old and from Milan, Italy. My two favourite hobbies are reading and travelling. This love of travel led me to the UK, where I spent an extended period of time in London trying to improve my English.

## How did you feel when you were diagnosed with cancer?

In September 2003, I woke up with a hoarse throat, thinking it was nothing more than a cough. However, it persisted for a couple of weeks, so I went to see a specialist, where I was diagnosed with Stage III SCCHN cancer of the voice box (larynx).

Initially, I was very shocked, and concerned about how this would affect my life moving forward. It was suggested the recommended treatment would be surgery, potentially followed by chemotherapy and radiotherapy.

## During your treatment, what was the biggest challenge you had to overcome?

Thankfully, neither chemotherapy or radiotherapy was needed; however, the surgery itself involved having a laryngectomy, so my first concern was how I would cope with the physical and psychological changes following surgery. The laryngectomy involved making a stoma, a hole made in my neck, to help with my breathing following the surgery.



**“By far, the biggest challenge was losing my ability to speak after surgery. It was incredibly frustrating...”**

Learning to manage the stoma was the first in a long list of challenges I faced after surgery.

The biggest psychological challenge was not knowing the extent of how my life would change following my treatment. Nobody told me the quality of life I should expect after I was discharged, which added to my anxiety.

## Since your treatment finished, what has been the biggest challenge you have had to overcome?

By far, the biggest challenge was losing my ability to speak after surgery. It was incredibly frustrating trying to speak and be understood when people rarely had the patience to listen. Cancer completely changed my life and I had to deal with a number of issues on a day-to-day basis. These included struggling to build relationships and people not fully understanding my condition. I also battled with depression for a period of time after my diagnosis.

I was forced to search for alternative ways of communicating to help overcome the self-alienation and consequent depression I was struggling with. My research identified a rehabilitation centre, managed by the Italian Laryngectomies Patients Advocacy Organisation, which changed my life in so many ways.

The centre taught me a technique to produce an alternative voice that allowed me to communicate again. I was also introduced to a number of fellow head and neck cancer survivors, who taught me to view my situation as a new beginning. Following the rehabilitation programme, I was able

to rebuild some of my relationships and improve my overall quality of life.

## Do you think you have been offered adequate support since completing your treatment?

The laryngectomy caused speech difficulties and challenges with breathing; in fact, any physical activity would quickly cause me to experience a suffocating sensation.

I would like to have been given more information throughout my treatment, explaining how my life was going to change and what support was available to help cope with those changes. It would have been useful to have someone to speak to about my concerns at this time as I felt very alone.

## What advice would you give a recent head and neck cancer patient?

I would say be confident that you can overcome the disease, and that you will be able to resume a good quality of life. I found that speaking with other patients who received laryngectomies – and had regained their ability to speak – greatly helped me overcome my psychological issues. Therefore, I would recommend speaking to other patients to get their advice.

After my cancer experience, I underwent Laryngeal Speech Instructor Training, to enable me to help other head and neck cancer patients and their family members with psychological support and information about the challenges they face. I hope this support has a positive impact for them, as it does for me.



# Anke, Germany

My name is Anke, and I am a 52-year-old full-time working mother of two teenage boys, living in Munich. Our family spends a great deal of free time outdoors enjoying activities such as running, hiking, mountain biking, camping, canoeing and skiing; I also enjoy yoga. One of my favourite things is Oktoberfest, and we are lucky to live just 200 metres from where it is held each year.

## How did you feel when you were diagnosed with cancer?

When I was diagnosed with human papilloma virus-related tonsil cancer I could not believe it. I heard the words and a part of me knew it was true; however, the other part of me thought this must be a mistake.

I've always led a healthy lifestyle, eating healthy, organic food, almost no sugar, no meat, lots of vegetables, limited dairy and almost no alcohol. I used to smoke, but only a few cigarettes here and there.

After diagnosis, I really struggled to understand how I could get cancer; it felt impossible. The only thing I could think of was how unfair it was. I went through the typical Kübler-Ross model, which is more commonly known as the five stages of grief. First I experienced shock, followed by anger, and then at my lowest point, depression.



**“I really struggled to understand how I could get cancer; it felt impossible.”**

From there my emotions rose again as I began to search for alternative treatment options. The turning point was discovering I was eligible for an alternative type of surgery which led to me finally accepting my diagnosis.

Sharing my fears and innermost feelings with my closest friends and family, made a huge difference to accepting what lay ahead, having their support helped me gradually come to terms with my diagnosis.

## During your treatment, what was the biggest challenge you had to overcome?

My biggest challenge was being faced with surgery. Initially my doctor recommended a surgery that involved making a large incision up both sides of my neck and splitting the lip and jawbone to remove the tumour at the back of my throat. This would result in irreversible facial disfigurement. After expressing concern about the approach, I was told that if I were to wear a shawl, or other form of cover-up, nobody would notice. I was horrified at his glib response.

I was desperate for a less invasive treatment and, whether it was just good luck or karma, I found an alternative option after conducting my own research. The new suggestion was to operate through my mouth without splitting the lip or the jawbone. It was a considerably less invasive option that, thankfully, was a complete success and the tumour was completely removed.

Today my quality of life is the same as before my diagnosis and I don't have to wear a shawl or cover-up. I feel lucky, and am very thankful that the team did such a brilliant job.

## If you were to speak to a head and neck cancer patient just completing their treatment, what advice would you give about the journey ahead of them?

My advice would be to stay confident and be patient: your condition will improve. Start moving and doing things that you like as soon as you can. Even if everything you do is at a slower pace, it will help you to get back to a normal routine. The healing has to start with your mind, and the body will follow. I would suggest starting physiotherapy and speech therapy as soon as you are able to.

Importantly, I would also recommend trying your best to celebrate life. Visit a city you have not seen before, and see friends you may have lost contact with. I've had so many unexpected, uplifting, heartwarming and surprising moments with people, which has helped me a great deal.

# Mariana, Portugal

I am 39 years old and I enjoy gardening and listening to good music. I also love to cook and eat, although, being thin all of my life, you wouldn't know by looking at me!

## How did you feel when you were diagnosed with cancer?

I felt lost, helpless, and deeply sad. I already have juvenile rheumatoid arthritis, so, surgeries, injections, pain and physical limitations are nothing new for me. I was always mindful of how my condition could progress in the future, but when the doctor gave me a diagnosis of cancer, I was speechless and unprepared, and I just wanted to get out and see my loved ones.

## During your treatment, what was the biggest challenge you had to overcome?

Surgery and treatment to the tongue imposes many difficulties, namely the limitations of socialisation; I had to use a pen and paper to communicate.

The consequences of surgery and treatment are long, painful and difficult. I had sores, swollen gums, vomiting, dizziness, toothaches, and excess and lack of saliva. This all affects eating, which is ironic given good nutrition is essential to the whole recovery process.

## Since your treatment finished, what has been the biggest challenge you have had to overcome?

The biggest challenge is undoubtedly the dietary restrictions, as spicy or acidic flavours and dry or textured foods can lead to a greater sensitivity of the tongue, manifested by burning.

Equally challenging is the tiredness that I sometimes feel at the end of a day. It can also be an effort to speak, and that sometimes ends up affecting communication with others.

## How has your life changed?

My arm and neck movements were quite limited following surgery, but regular physical therapy and weekly acupuncture certainly helped.

**“I felt lost, helpless, and deeply sad.”**

Lastly, my eating habits have changed, which has been challenging given my love of food. I'm constantly on the hunt for healthy, tasty choices that don't aggravate my symptoms.

I have to be disciplined and listen to my body to help manage my fatigue and I need to rest more as per doctor's orders.

## Do you think you have been offered adequate support since completing your treatment?

Yes, I have been fortunate to be cared for by an experienced team of professionals. The majority of my care was provided by the National Health Service; however, I also obtained support from private clinicians when needed. I strongly believe that all patients who require oral rehabilitation should have full state reimbursement.

I think it is necessary to highlight factors that I believe can increase the risk of cancer and poorer outcomes for survivors. Along with alcohol, smoking and human papilloma virus, these include a stressful lifestyle and an inadequate diet. More awareness and education among the public is needed, as well as support for head and neck cancer survivors.

## If you were to speak to a head and neck cancer patient just completing their treatment, what advice would you give them about the journey ahead of them?

Don't be afraid to reach out to associations that can help: in Portugal there is ASADOCORAL. It's important to focus on a good diet, and to maintain a healthy lifestyle. It is also essential to preserve a stress-free living environment and peace of mind.

It is indeed possible to overcome the illness, but a good support network of family and friends who are able to help, understand, and support you throughout physical and psychological challenges is important. It is, however, also important that close family members and friends also receive support throughout the process.

Finally, have hope and courage; everyone has the capacity to adapt to a new reality however difficult it may be. It is in the difficulties and obstacles of life that we learn the best lessons.

# Tom, UK

My name is Tom; I am 30 years old and live with my wife in Suffolk, England. We have a red Labrador named Lola, whom we adore and I love everything related to sports, particularly skiing and shooting.

## How did you feel when you were diagnosed with cancer?

In May 2014, when I was 26, I found a lump on my tongue. Initially, I wasn't worried by it and waited to see if it would disappear on its own; I didn't even consider cancer. However, it didn't go away and so I visited my doctor who suggested I see a specialist to check it out. They arranged for a biopsy to be taken of the lump, which confirmed that it was mouth cancer. The diagnosis was a massive shock as the type of cancer I had is mainly found in elder people and is very strongly linked to heavy drinking and smoking, neither of which I did. In fact, I lived a very healthy lifestyle.

I was quickly referred to a Professor who specialises in head and neck cancer, who recommended surgery to have the cancer on my tongue removed; however, there were questions over whether it had spread to other parts of my body. The Professor suggested two options: have a sentinel lymph node biopsy to see if the cancer had spread or have an elective neck dissection to take away all the lymph nodes as a precautionary measure.



**“I worry about the cancer coming back and I suspect that worry will never really go away.”**

I chose to have a sentinel lymph node biopsy in an effort to ascertain whether it had spread whilst minimising invasive surgery and the added risks and side effects associated with it. Thankfully the cancer had not spread and they managed to remove the tumour on my tongue along with the sentinel lymph nodes from my neck in a single operation.

## Throughout your treatment journey, what was the biggest challenge you had to overcome?

Throughout my treatment I was determined that life, as I knew it, was to remain as normal as possible. I kept working and was reluctant to take any extra time off work as I preferred to keep busy. As soon as I was able, I filled my days with gym, sports and other activities, keeping some semblance of normality to my daily routine. I deliberately avoided reading about the type of cancer I had, as I didn't want to know the statistics or any more details than I needed to in order to beat this thing. I was hoping to defy the odds as I was still young and lived a healthy lifestyle.

## Since your treatment finished, what has been the biggest challenge you have had to overcome?

My recovery after the sentinel lymph node biopsy part of the operation was fairly straightforward. I have a relatively small incision on my neck which has healed really well. The recovery from having the tumour removed from my tongue was definitely more of a challenge. When I woke up from the

operation, I really struggled as my tongue had swollen and filled my mouth. Simple tasks like breathing, eating and speaking were suddenly a huge challenge. The most difficult part was not being able to speak immediately following the operation, which left me feeling very isolated. I hadn't expected that and it took quite a while before I sounded like myself again.

## How has your life changed?

I worry about the cancer coming back and I suspect that worry will never really go away. Your mouth is pretty active and there is always a lot going on. I never really paid attention to weird things here or there, little pains or lumps, whereas now I am a lot more conscious than what is probably normal. I have made a conscious effort not to let this experience drastically alter my life other than having gained a new, more rounded perspective on life and relationships.

## If you were to speak to a head and neck cancer patient just completing their treatment, what advice would you give them about the journey ahead?

You can't dwell on having been unlucky that you got cancer. Of course, take time to let it sink in but then, roll your sleeves up and focus on doing everything possible to get rid of it. During your treatment, try to keep your life and relationships in perspective and carry on as normally as possible.

## Ioanna, Greece

My name is Ioanna, and I am 59 years old. I enjoy the simple pleasures of swimming, the company of good friends, strolling in the countryside and collecting wild flowers and also love going to concerts. A funny story while receiving my chemotherapy treatment was that I had to collect my urine for a medical check-up that would take place the day after a concert with my favourite singer. Being a huge fan, I had to go, so I used a urine bag and carried it with me during the concert!

### **How did you feel when you were diagnosed with cancer?**

After being diagnosed with metastatic nasopharyngeal cancer, the name of which I could not even pronounce, my thoughts went straight to my three children. How would I take care of them while I was in treatment, and would I be able to see them grow up?

### **During your treatment, what was the biggest challenge you had to overcome?**

My biggest challenge was being able to raise my three children and fulfil the requirements of my job, where I had been taking on more and more responsibilities. I didn't ask for help, even when absolutely exhausted, which in hindsight didn't help my recovery.



**“Believe that the disease is something you can fight, despite the fear and dread the word cancer raises.”**

I now see life from a very different point of view; I am doing my best to leave my worries behind and focus on keeping a reserve of energy.

### **Since your treatment finished, what has been the biggest challenge you have had to overcome?**

When my treatments finally finished, I felt strong enough to speak openly about the disease, give details, and answer questions. This renewed strength bolstered my participation in advocacy group activities to help other people deal with this traumatic, life-changing condition.

### **How has your life changed?**

During the treatment, it was challenging for me to speak, so I was forced to communicate by jotting down short notes. This adjustment seemed easy in comparison with the ordeal of mealtimes; it was an ongoing challenge to eat, and as a result, I lost 17 pounds. On the plus side, it got my weight under control as extra weight had always been a concern. Losing my hair was a shock initially but again I rallied and looked for a solution by finding wigs, turbans and scarves.

### **Do you think you have been offered adequate support since completing your treatment?**

My husband, children, parents, relatives and friends were all by my side during my painful

experience with cancer. I want to thank them all and express my gratitude, because I am now able to feel that I had luck on my side. In the end I felt fortunate, because I wasn't alone; my loved ones helped share this heavy burden with me. I am also thankful to all the doctors and nurses who helped me win the fight against cancer.

### **If you were to speak to a head and neck cancer patient just completing their treatment, what advice would you give them about the journey ahead of them?**

Believe that the disease is something you can fight, despite the fear and dread the word cancer raises.

You have to be committed to your treatment, by going to the hospital, undergoing medical tests, and following the doctors' instructions.

The journey seems endless and tiring, but you should find strength to carry on living and reacting as if everything is normal and under control.



# THE NEXT CHAPTER

**As the stories in *A Survivor's Story* show, head and neck cancer not only alters the appearance and the daily activities of people with head and neck cancer, but also forces patients to reconsider their outlook on life, their role within a family, their professional life and their future. Moreover, the ongoing effects of the disease may have overpowering psychological and physical consequences. Early diagnosis and timely treatment is essential to ensure the best outcomes for survivors.**

*A Survivor's Story* highlights some of the needs, issues and challenges that head and neck cancer survivors face once treatment is complete. A lot more could and should be done to ensure survivors are receiving support that effectively meets their needs. The *Make Sense* campaign will continue to support the interests of head and neck cancer survivors, by executing activities and creating resources, in direct collaboration with survivors, which meet the ongoing needs of patients and their families.



The Campaign will work with the European Cancer Patient Coalition (ECPC) and other campaign partners, to stress the importance of supporting head and neck cancer survivors at the European parliament and among other European stakeholders. A key element of these activities will include laying the groundwork for the development of unified guidelines and recommendations for survivors.

Head and neck cancer is a life-changing disease; raising awareness of the signs and symptoms and encouraging early diagnosis is central to the campaign's mission. Additionally, it is our responsibility to continually reinforce the importance of patients receiving appropriate support through every stage of the disease. Appropriate care and support can, in some cases, reduce the risk of recurrence, but also ensure patients have the highest quality of life possible.



# European Head and Neck Society

The European Head and Neck Society (EHNS), established in 2006, is a multidisciplinary body that brings medical experts together from across Europe from many disciplines, including head and neck cancer specialists, oral and plastic surgeons, radiation therapists, medical oncologists, imaging specialists, and pathologists. The society also brings together other stakeholders, including speech therapists, cancer nurses, psychologists, physiotherapists, dieticians, social workers, basic scientists, and patient organisations involved in any aspect of head and neck cancer.

The EHNS aims to promote the exchange of knowledge between head and neck cancer experts to promote the highest standards of research, education and training, disease prevention and patient care.

In order to drive awareness and understanding of head and neck cancer among the general public, patients, caregivers and healthcare professionals, the EHNS engages in a number of activities. This work began with a pan-European survey series called 'About Face', which revealed a concerning lack of

awareness about head and neck cancer across Europe and a need for further education. Head and neck cancer is the 7th most common type of cancer in Europe, with more than 150,000 new patients diagnosed every year. Many potential symptoms and known risk factors of head and neck cancer are not recognised by the majority of the general public, which could lead to delays in symptom recognition and diagnosis, and – as a result – poor prognosis. The survey also made it clear that more education and information is needed, not only for the public, but also for healthcare professionals, in order to ensure appropriate detection and management of the disease.

In response to the needs uncovered in the 'About Face' survey, the *Make Sense* campaign was created to help address some of these key challenges and needs. Through the *Make Sense* campaign, the EHNS aims to raise awareness of head and neck cancer symptoms and subsequently drive earlier presentation, diagnosis and referral, along with standardised care, improved quality of care and quality of life after diagnosis.

# Thank you

Thank you to the survivors who took part in the creation of this booklet by sharing their personal stories. Your insights into life with head and neck cancer and your experiences following treatment are crucial in supporting the need for ongoing support and understanding the challenges faced. This ultimately inspires us to work towards increased awareness and better outcomes for all head and neck cancer patients.

For more patient stories, please visit the *Make Sense* campaign website [www.makesensecampaign.eu/en/stories](http://www.makesensecampaign.eu/en/stories)

# Support the Campaign

If you are interested in finding out more or getting involved in the *Make Sense* campaign please contact the secretariat by emailing [secretariat@makesensecampaign.eu](mailto:secretariat@makesensecampaign.eu) or visit the *Make Sense* campaign website [www.makesensecampaign.eu](http://www.makesensecampaign.eu)

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European Support for the *Make Sense* campaign is provided by:

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