

SURVIVORSHIP:

# LIFE WITH, THROUGH AND BEYOND HEAD AND NECK CANCER

Roundtable Discussion | 9 October 2018

For five years, The European Head and Neck Society (EHNS), along with the European Cancer Patient Coalition (ECPC), have led efforts in raising awareness on the needs of head and neck cancer patients through the very successful *Make Sense* campaign. As part of the 2018 *Make Sense* campaign, ECPC organised an event at the European Parliament under the theme **Survivorship: Life with, through and beyond head and neck cancer**. The aim is to promote better quality of life for cancer patients and survivors, as well as awareness of these cancers and call for prevention, earlier diagnosis and timely treatment.

## INTRODUCTION

Recent advancements in surgical procedures and the availability of innovative new treatments have changed the way that head and neck cancers are treated. These new treatment options impact survival outcomes for patients, allowing patients to live longer after treatment. However, as survival outcomes improve, more and more patients across Europe require appropriate support to overcome the physical and psychological challenges of treatment.

Head and neck cancer is a multifaceted disease. No two cases are exactly alike, but most patients will still experience invasive treatment and/or surgery affecting what they would describe as a 'normal' life. Therefore, it is essential that all patients across Europe are offered appropriate post-treatment support and guidance to overcome any physical and psychological challenges. The truth is that there are varying levels of care for head and neck cancer patients across Europe, and this needs to change.

To highlight the discrepancies across Europe, ECPC and the *Make Sense* campaign held a roundtable event at European Parliament to promote better quality of life for cancer patients and survivors, discuss the unmet needs and determine how patients can be better supported as they make the transition into survivorship.

# AGENDA

## Introductory Remarks:

- Lieve Wierinck, MEP, Alliance of Liberals and Democrats for Europe (ALDE), Belgium
- Ken Mastris, ECPC Board Member

## Presentations:

- Professor Lisa Licitra, Director of Medical Oncology Head and Neck Cancer Department at the Istituto Nazionale Tumori, University of Milan, Milan, Italy  
*A Physician's & European Perspective: ESMO Guidelines on Head and Neck Cancer*
- Alina Comanescu, Founder of Community Health Association  
*Best Practice and Examples of Collaborations From the Member States: Romania*
- Professor Françoise Meunier, Director of Special Projects at the European Organisation for Research and Treatment of Cancer (EORTC)  
*Introduction to Group Discussion*
- Magali Mertens, Travail et Cancer  
*The Message of Hope and Introduction to the Book, 'Je Rebondis Après Mon Cancer'*



## Introductory remarks

### **Lieve Wierinck**

MEP, Alliance of Liberals and Democrats for Europe (ALDE), Belgium

Ms Wierinck said that head and neck cancers are among the most common types of cancers in Europe with more than 150,000 new patients diagnosed every year. They are half as common as lung cancer but twice as common as cervical cancer. Although head and neck cancers are the seventh most common form of cancers worldwide, each individual tumour is classified as a rare cancer. Despite its severity and increasing prevalence in society, there is little awareness of head and neck cancer, and patient outcomes remain very poor for those diagnosed in the later stages. However, for patients diagnosed in the early stages there is an 80–90% survival rate. She stated that overcoming the physical and psychological consequences of the disease can be very challenging, and overcoming head and neck cancer is a unique experience; different for each person. However, the goal is the same for all patients: to regain the important aspects of their lives before cancer and find new pathways to a normal and fulfilling life.



Drawing on her own experience as a cancer survivor, Ms Wierinck said that former cancer patients are facing many issues in terms of follow-up care, the management of the delayed effects of treatment, and the improvement of quality of life in all aspects.

*“ Therefore, the encouragement and practical help of friends and family, support groups, healthcare professionals and policymakers in providing them with the right tools and ways to cope with the new reality is important. ”*

A strategic goal within the European Parliament MEPs Against Cancer Interest Group is to ensure a good quality of life for cancer patients and survivors.



## Introductory remarks and ECPC Involvement in Supporting Survivorship of Head and Neck Cancer Patients

### **Ken Mastris**

ECPC Board Member

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Mr Mastris said that ECPC now represents 400 organisations in 46 EU and non-EU countries. Its main mission is to empower European cancer patients, foster cooperation among cancer patient organisations, organise joint activities, fight against European disparities, and play an active role in shaping European and national healthcare policies. For several years, ECPC has partnered with the *Make Sense* campaign to help move the needle on head and neck cancer patient care, with the goal of improving outcomes for patients at every stage of their disease.

Mr Mastris said that the ECPC's working group on rare cancers (WGRC) counts on the expertise and collaboration of rare cancer patient organisations across Europe to continue to represent the rare cancer patient community. He believes that:

“ Although approximately 25% of deaths in Europe are caused by cancer, patients recovering from this disease are not given due attention. ”

The key to survivorship is for cancer survivors to regain as much as possible the most important aspects of their life, so they can lead a fulfilling life. The EU has recognised the need to invest resources in meeting cancer patient needs, partly due to the efforts of ECPC. Finally, he drew attention to the Patient Guide on Survivorship created by the European Society for Medical Oncology (ESMO) and ECPC in collaboration with the International Psycho-Oncology Society (IPOS).

Head and neck cancer not only alters the appearance and the personal functions of people with cancer, but also it forces patients to reconsider their outlook on life, their role within a family, their professional life and their future. Moreover, even for a survivor, the ongoing effects of the disease have overpowering psychological and physical consequences. In order to ensure the best outcomes for survivors, investments into early diagnosis and timely treatment are also essential. The perspective of an experienced physician was therefore considered of great importance to the ongoing debate.







## A Physician's & European Perspective: ESMO Guidelines on Head and Neck Cancer

### **Professor Lisa Licitra**

Director of Medical Oncology and Head and Neck Cancer Department at the Istituto Nazionale Tumori, University of Milan, Milan, Italy

Professor Licitra said that globally more than 600,000 people are diagnosed with head and neck cancers but there is still a low level of awareness of the disease. Unfortunately, when the disease is diagnosed at the late stages, only half of patients survive, hence it is extremely important to drive awareness and encourage early diagnosis. Thankfully, the chances of success are continually improving thanks to innovative treatment options, although she believes that more needs to be done to tackle the treatment as well as the patient's life after treatment. She outlined the challenges that survivors face, which include physical, psychological, aging, financial and work challenges.

Professor Licitra pointed out that multidisciplinary care is needed during the treatment phase and

“ she advocates for coordinated survivorship care, which should include speech therapists, psychologists, physiotherapists, social workers, nurses and other healthcare professionals. ”



She would also like to see patients empowered and sufficiently informed to be able to request the right and appropriate help in the right way at the right time. Quality of life is also crucial and patient-reported outcomes are key. It is also crucial to manage side effects during treatment, and tackle the survivor needs during follow-up.

In Professor Licitra's opinion, early diagnosis is vital in improving outcomes for head and neck cancer patients. This cancer is very difficult to prevent by altering social practices (e.g. by stopping smoking or drinking), but there is a big opportunity for early diagnosis, which is a key goal of the *Make Sense* campaign. In partnership with ECPC, ESMO developed a survivorship guide especially focusing on head and neck cancer, as well as a multi-language cancer guide for patients. ESMO also successfully worked on two types of multidisciplinary guidance involving three societies.

*What is decided on a European level is not always implemented the same in different member states. The following presentation looked at disparities between Western and Eastern Europe.*

## Best Practice and Examples of Collaborations From the Member States: Romania

### **Alina Comanescu**

Founder of Community Health Association

Ms Comanescu pointed out the serious disparities between Western and Eastern Europe when it comes to head and neck cancer care. Ms Comanescu stressed that these disparities will remain if the issues are not addressed. For example, in Eastern Europe there is a lack of multidisciplinary care, national cancer boards, access to treatments, vital therapy services, palliative care, psychological support, and effective preventive programmes.

On the other hand, online patient groups – in particular social media groups – are very active in Romania and are a good source of data. Another important resource is speaking with the physicians, to gain their perspectives. A needs evaluation survey was conducted in Romania to find out how patients can be supported, and the findings revealed that a patient's main focus is on improving their quality of life following treatment.





This was therefore the focus of the first patient survivor guide created by Ms Comanescu. Subsequently, a second patient survivorship guide has been developed that provides information and support on how to deal with surgical reconstruction methods, as well as the level of social support that is required for survivors to reintegrate into their normal social environment and return to work.



*As one of the objectives of this event is to raise awareness of the specific needs, issues, and challenges of head and neck cancer survivors, the following presentation focused on the challenges of the differing legal framework for cancer survivors across Europe.*

**Professor Françoise Meunier**  
Director of Special Projects at the European Organisation for Research and Treatment of Cancer (EORTC)

Professor Meunier said that there are different definitions of survivorship, but the way in which head and neck cancer survivors are treated is changing. She is particularly focused in the challenges facing a cancer patient after being given the all-clear, which is usually five years after the completion of their treatment. These patients face issues such as employment, access to financial services, insurance premiums, quality of life and fertility.

*“ There is a need for more research into the challenges that cancer survivors face adjusting to normal life after treatment, and the impact this has on their quality of life. ”*

Professor Meunier discussed how she has organised three cancer survivorship summits in Brussels, attended by up to 400 participants, to assess the needs of cancer survivors and in particular to discuss the legal framework. For example, she pointed out major inconsistencies exist across

Prof Françoise Meunier  
EORTC



Europe regarding access to financial services, and stated that, “In 2018 it is easier to cure cancer than to change banks and insurance.” However, France has implemented a legal requirement that ensures that ten years after treatment for cancer, the insurer may know that a person has had cancer but cannot reject their request for insurance, nor offer an increased premium. This law translates to English as ‘The Right to be Forgotten’, and France is the only country in Europe with such a law. Professor Meunier considers this an outstanding law, but does not understand why it cannot be implemented elsewhere in Europe. She would like to see the European legal framework for insurance access harmonised, and asked, “What are we waiting for to implement a successful model in Europe?”

## GROUP DISCUSSION

*After the formal presentations, the debate was opened up to delegates. The discussion was lively and inspiring, with many thoughtful and relevant interventions from participants at the event.*



### Bulgaria

A patient group representative expressed that the main problem in Bulgaria is that physicians do not have good practices when it comes to diagnosis and treatment. There are inconsistencies in the treatment available, with many physicians directing patients to care facilities in other countries. In turn, this means that care becomes expensive and unaffordable; therefore, it is considered impractical. In order to help give physicians the education and experience they need, it was recommended that a forum to support best practices would be useful. The suggestion was validated by an individual from Romania.

### Belgium

Magali Mertens from Travail et Cancer shared her belief that patients need guidance and support to navigate issues that affect them in returning to 'normal' life, including returning to work and receiving appropriate insurance coverage. In Magali's case, she was in need of dental/facial prosthesis; however, this was considered 'purely aesthetic', when in fact it was essential to her feeling 'normal' again. She was able to navigate the system herself, but realised that there were probably many people who did not have that expertise or access to that type of expertise.

## Norway

Representatives from the Norwegian patient group, Munn- og halskreftforeningen, reiterated that a head and neck cancer diagnosis is challenging both physically and psychologically. In an attempt to help current patients, the group are committed to visiting people who have recently been diagnosed. They have found that this peer system helps new patients by giving them a chance to ask all the questions they have and may not feel comfortable asking their physician or nurse. Finally, working closely with the dental profession is critically important to early identification and diagnosis. The group concluded that:

“The pathway for patients in Norway from diagnosis to treatment is very well defined, but the support stops once you have completed your treatment, and this should be addressed.”





## OPEN DISCUSSION

Head and neck cancer is generally a disease of the elderly, not the young, and these patients also face age-related issues, which add to the impact of cancer treatments. Therefore, people at risk of head and neck cancer need to be encouraged to go to their doctors if they notice one of a number of symptoms that last for three weeks or more.

Professor Licitra said that:

*“Early diagnosis is key to prevent head and neck cancer, and early diagnosis should be a particular focus in countries where treatment resources are lower, as the cost of early diagnosis is lower than treatment.”*

Ms Wierinck confirmed she is fully behind ‘the right to be forgotten’ law that Professor Meunier is advocating and believes that something should be implemented so the law is enforced across more European countries. She believes that there is a need to share best practices among head and neck cancer physicians, and suggested that an exchange programme such as Erasmus could be used for doctors to work six months in another country and learn best practices, which could then be implemented in their own country. Professor Licitra suggested that the power and influence that Europe has over Member States should not be underestimated.

Finally, a delegate from the European Pharmaceutical Students’ Association (EPSA) added that pharmacists also need to be educated on the importance of early diagnosis of head and neck cancer patients, as pharmacists are often the first people approached by a patient.



The Message of Hope and Introduction to the Book, 'Je Rebondis Après Mon Cancer'

## **Magali Mertens**

Travail et Cancer

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Ms Mertens shared her own story, highlighting the challenges she faced as a cancer patient and survivor that led to her starting Travail et Cancer (Work and Cancer). She stressed the importance of communication with employees, and to use their challenging experiences as a springboard into a new life, rather than a hurdle that is insurmountable. The book focuses on how a cancer survivor can make new objectives and identify the resources needed in order to write a new chapter in their life.

## CLOSING REMARKS

Ms Wierinck thanked everyone for their participation, and was glad to see many aspects being openly discussed. She said that follow-up care and survivorship care are key areas where there are unmet needs for head and neck cancer patients and policymakers need to address these issues as a whole rather than as individual components. She will share the outcomes of this meeting with the European Parliament MEPs Against Cancer interest group.



“*Follow-up care and survivorship care are key areas where there are unmet needs for head and neck cancer patients and policymakers need to address these issues as a whole rather than as individual components.*”

## CONCLUSION

In conclusion, this roundtable discussion highlighted that there is a disparity in the care of head and neck cancer patients in Europe. Early diagnosis remains vital in reducing the impact of the disease, especially in countries in Eastern Europe that have fewer resources. Head and neck cancer patient representatives from Belgium, Norway, Romania and Bulgaria all shared their experiences, which highlighted that there are a number of significant unmet needs that must be addressed to ensure head and neck cancer survivors are receiving appropriate support post-treatment. There was agreement among the group that more support is required when it comes to survivorship care in head and neck cancer and patients/survivors should be at the centre of everything when it comes to post-treatment care.



## NEXT STEPS

There is the potential to create a working group that includes head and neck cancer specialists, patients and professional organisations to review existing survivorship guidelines, with the aim of adapting and updating the existing guidelines to meet the needs of head and neck cancer survivors. By building on existing guidelines and using the experience of the working group to identify unmet needs, this would enable the development of unified European guidelines that truly meets the needs of head and neck survivors across Europe.

Following this report the *Make Sense* campaign and ECPC propose that this working group is established to develop these new head and neck cancer survivorship guidelines, with the hope to launch them in 2019.

Event organised by **ECPC** and the *Make Sense* campaign, hosted by MEP **Lieve Wierinck**, Alliance of Liberals and Democrats for Europe (ALDE), Belgium.



## ABOUT ECPC

ECPC was set up in 2003, and works for a Europe of equality, where all European cancer patients have timely and affordable access to the best treatment and care available, throughout their life. ECPC believes that cancer patients are the most important partners in the fight against cancer and against all the cancer-related issues affecting our society. ECPC works for the recognition of cancer patients as partners in their own healthcare and invites policy makers, researchers, doctors and industry to work all together in this direction.

## ABOUT THE MAKE SENSE CAMPAIGN

In 2013, the European Head and Neck Society (EHNS), a pioneering group of healthcare professionals, established the *Make Sense* campaign. The Campaign addresses a number of unmet needs in head and neck cancer, including disease awareness and understanding, signs and symptoms education, emotive support for patients, survivors and their caregivers, and building partnerships with governmental bodies and organisations. The ultimate aim of the Campaign is to increase awareness of this deadly disease and ensure better outcomes for patients.