

**NOT TO BE MADE PUBLIC BEFORE MONDAY SEPTEMBER 20**

## **NEW SURVEY REVEALS THE SCALE OF THE IMPACT HEAD AND NECK CANCER HAS ON SURVIVORS' WELLBEING AND THE ONGOING EFFECT OF THE COVID-19 PANDEMIC**

- Head and neck cancer survivors face a range of physical, social and professional challenges, with 80% of respondents indicating that head and neck cancer had negatively impacted their wellbeing
- The survey was completed by 229 individuals who had been treated for head and neck cancer across 12 countries (Belgium, Cyprus, France, Greece, Ireland, Italy, Israel, the Netherlands, Poland, Portugal, Turkey and the UK)
- Survey results coincide with the beginning of the *Make Sense* campaign's annual head and neck cancer awareness week, taking place September 20–24 across Europe

**MONDAY, SEPTEMBER 20:** A new survey initiated by the European Head and Neck Society (EHNS), as part of their *Make Sense* campaign, and the European Cancer Patient Coalition (ECPC), has uncovered the wide range of physical, social and professional effects that survivors of head and neck cancer across Europe face, and the drastic impact this is having on their emotional wellbeing, highlighting the urgent need for greater access to support services throughout Europe.

The vast majority of survey respondents (80%) indicated that head and neck cancer had negatively impacted their wellbeing, while the ongoing COVID-19 pandemic is further intensifying the negative effects that many survivors are experiencing; 51% of respondents reported that COVID-19 had a negative effect on their ability to access emotional support services. An analysis of results also suggests that those with easy access to a range of support methods tend to experience less of a negative impact on their wellbeing.

The sixth most common type of cancer in Europe, head and neck cancer has a devastating impact on those affected and is often diagnosed in advanced stages, leading to poorer outcomes. Survivors can experience a multitude of lifelong physical, emotional and lifestyle effects following treatment.

“The long-term impact of head and neck cancer on the wellbeing of survivors can often be overlooked, but the results of this survey demonstrate just how distressing this disease is for individuals far beyond initial diagnosis or treatment,” said Professor René Leemans, Chair of the *Make Sense* campaign and of the Department of Otolaryngology Head and Neck Surgery at the Amsterdam University Medical Center. “With the COVID-19 pandemic impacting how easily survivors can access support, it is vitally important we continue to listen to the changing needs of survivors and work to offer every individual the care and resources they deserve to live a fulfilled life.”

The results come at the start of the 9<sup>th</sup> annual head and neck cancer awareness week, taking place September 20–24, during which the *Make Sense* campaign is encouraging the general public to follow its [‘1for3’ rule](#) by learning the signs and symptoms of head and neck cancer and seeking early medical advice, via this year’s slogan ‘Stay head and neck cancer aware: don’t ignore the warning signs in COVID times.’

The survey’s findings showed emotional effects from a diagnosis of head and neck cancer were evident beyond the end of treatment, with approximately half of respondents noting they feared the future / a disease recurrence, as well as saying they experienced anxiety. Approximately one third of respondents also noted they experienced depression, anger and loneliness.

Physical symptoms were reported to have the biggest impact on wellbeing, with respondents noting their diagnosis negatively impacted speaking (48%), physical appearance (43%), eating/drinking (41%) and energy levels (40%). One survivor, from the UK, commented “I became introverted because of disfiguration to my neck and face”. Meanwhile, the professional/financial and social effects of head and neck cancer were reported to have a comparatively smaller, but still notable, impact on emotional wellbeing, with comments such as “I can’t stay out of the house long because I get tired quickly, this also prevents me from spending time with my family (and) my face-to-face friendship relationships have weakened a lot,” from one survivor in Turkey.

There were, however, some positive narratives revealed through the survey. The majority of respondents (81%) felt their family relationships had not been affected, more than two thirds found family and friends to be a helpful avenue for support, and half of survivors described the emotional support they have received as “excellent” or “good”. However, just under a quarter (23%) reported the support they had received to address their emotional wellbeing to be “poor” or “terrible”, illustrating a smaller, but significant, number of survivors may not be receiving the support they desperately need.

A key takeaway from the survey is the need to improve access to a range of support services for survivors throughout Europe. While many survivors reported that they have access to resources or services which they find helpful (such as reading materials, digital tools and peer-to-peer support groups), many of these remain sought-after for others: responses showed the most sought-after resources that are not available to some survivors were specialised nurses, peer to peer support groups and carer support resources.

“Rates of head and neck cancer are growing year-on-year, and the results of this survey detailing the life-changing impacts and emotional toll this disease can have, coupled with the unmet need for support, is deeply troubling.” said Jacqueline Daly, Secretary of ECPC Board. “Ensuring that resources and support are made equally and readily available for survivors across Europe is more important than ever.”

The *Make Sense* campaign is currently undertaking an ongoing project in conjunction with the EHNS to develop European-specific Survivorship Guidelines for head and neck cancer, with their launch anticipated later this year. Throughout this week, activities are also planned across Europe and on social media to raise awareness of head and neck cancer. To find out more about what is happening in your area, visit [makesensecampaign.eu](https://makesensecampaign.eu), and the Campaign’s [Twitter](#) and [Facebook](#) channels using the hashtag #StayHNCAware.

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### **About the survey**

All figures, unless otherwise stated, are from survey results collected by the *Make Sense* campaign. Total sample size was 229 with results gathered from adults who had been treated for head and neck cancer in 12 countries (Belgium, Cyprus, France, Greece, Ireland, Italy, Israel, the Netherlands, Poland, Portugal, Turkey and the UK). Fieldwork was undertaken between 8th June – 31st August 2021. The survey was carried out online and distributed to applicable respondents via email and public social media posts addressed to healthcare professionals, patient advocacy groups, and other relevant groups and individuals in the *Make Sense* campaign’s existing network, acting on behalf of the Campaign.

### **About Head and Neck Cancer**

Head and neck cancer is a way of describing any cancer that is found in the head or neck region, including the inside of the mouth and tongue ('oral cavity'), the throat ('pharynx') and the voice box ('larynx') and excluding the eyes, brain, ears or oesophagus. This type of cancer usually begins in the

squamous cells that line the moist, mucosal surfaces inside the head and neck: for example, inside the mouth, nose and throat.

### **About the *Make Sense* Campaign**

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. It will do this through:

- Education on disease prevention
- Driving understanding of the signs and symptoms of the disease
- Encouraging earlier presentation, diagnosis and referral

The *Make Sense* campaign is supported by Bristol Myers Squibb, Merck and MSD. More information about the campaign is available at <https://makesensecampaign.eu/>, on [Twitter](#) and on [Facebook](#).

### **About the EHNS**

The European Head and Neck Society (EHNS) is an international non-profit association based in Belgium. The EHNS is composed of individuals, national and multinational societies, and associated study groups oriented towards head and neck cancer research, training and treatment throughout Europe. Individuals from the rest of the world are also welcome to apply for membership. The intent of the EHNS is to promote exchange of knowledge in all aspects of head and neck neoplastic diseases and to promote the highest standards of research, education and training, disease prevention and patient care. For more information on the society, please visit: <http://www.ehns.org>.