

2021

HEAD AND NECK CANCER SURVIVOR SURVEY



#StayHNCAware

Assessing the physical, social and professional impacts of head and neck cancer on survivors

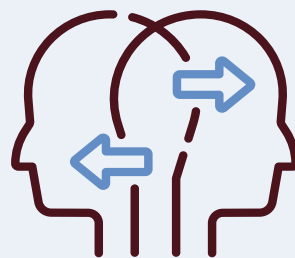
The European Head and Neck Society through its Make Sense campaign and the European Cancer Patient Coalition have conducted a survivor survey, assessing the impact of head and neck cancer on the physical, social and professional wellbeing of survivors, and the current availability of support resources.

The survey reveals that most survivors have experienced a negative impact on their overall wellbeing; the extent of this impact is magnified in cases where there is limited access to a range of support resources.



ABOUT THE SURVEY

229 respondents from 12 countries (Belgium, Cyprus, France, Greece, Ireland, Italy, Israel, the Netherlands, Poland, Portugal, Turkey and the United Kingdom)



EMOTIONAL WELLBEING

Survivors were impacted by a wide range of feelings – the most common were:

80%

of respondents said HNC had slightly or strongly negatively impacted their wellbeing

51%

A fear of the future/recurrence

49%

Anxiety/worry

28%

Depression

27%

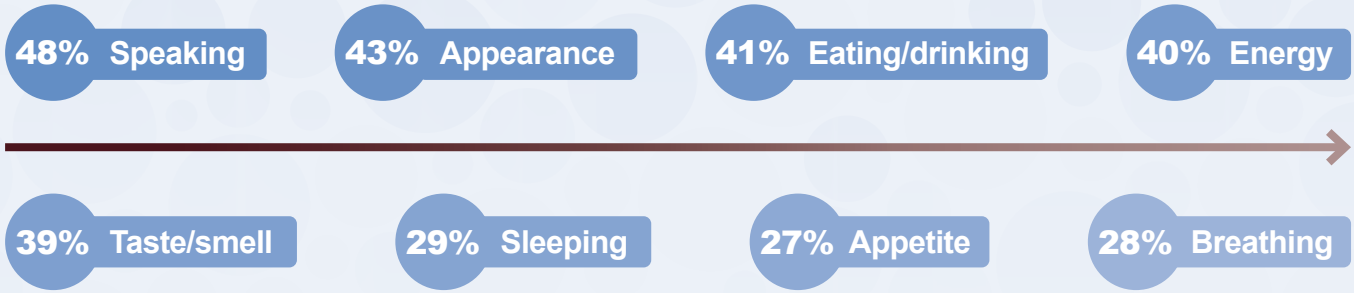
Anger

29%

Loneliness

PHYSICAL IMPACT

Physical symptoms were reported to have the biggest impact on wellbeing, with 48% of respondents reporting a negative impact. Areas where respondents noted a negative impact included:



SOCIAL AND PROFESSIONAL IMPACT

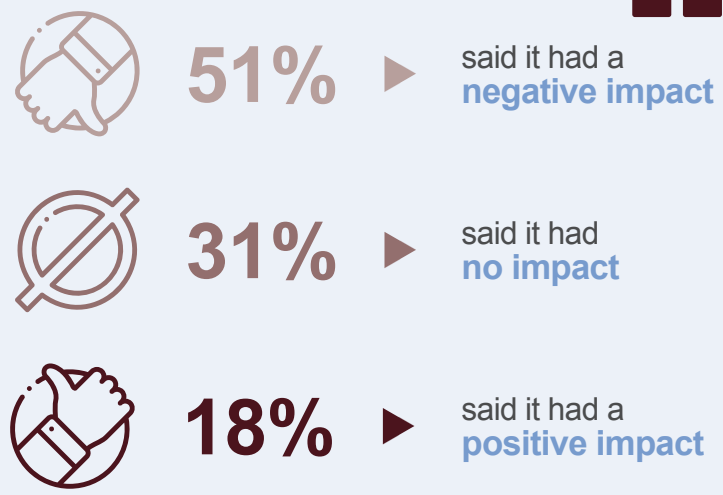


Comments from respondents revealed a variety of experiences

- 'Only one couple who we were close friends with seems reluctant to include me, the rest of my friends still treat me the same.'*
Survivor, UK
- 'After the treatment I started to work again, I ran my own business and I was working until retiring.'*
Survivor, Poland
- 'I do not work anymore. I was over 80% disabled.'*
Survivor, France
- 'Less mobility means I can do less and I become far more reliant on other people. I would be unable to live on my own.'*
Survivor, UK

IMPACTS OF COVID-19

When asked about the impact of COVID-19 on their ability to access emotional support services:



SUPPORT LANDSCAPE

Results indicated survivors were fortunate to benefit from an increasingly open culture when it comes to talking about emotional wellbeing:



68% found their family and friends to be a helpful support network



88% feel comfortable talking about their emotional wellbeing with their HCP



Many survivors have access to a range of resources that they find helpful including reading materials (**47%**), peer-to-peer support groups (**44%**) and digital tools (**42%**)



FURTHER SUPPORT NEEDED

50% of respondents rated the emotional wellbeing support they had received as “excellent” or “good” but the survey also revealed gaps where survivors would like further support:

41% would like support from specialised nurses and social workers

33% would like more resources for carer support

Some survivors would also like more access to peer-to-peer support groups (**33%**), digital tools for wellbeing management (**28%**) and support from mental health specialists (**27%**).

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 Belgium, Cyprus, France, Greece, Ireland, Italy, Israel, 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.

European support for the Make Sense campaign is provided by:

