

Removing care inequalities for teens and young adults with cancer

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Adolescents and young adults (AYA) with cancer are often missing out on age-appropriate specialist care owing to a lack of awareness of how their needs differ from those of children and older adults with cancer.

A newly released position paper from the AYA Working Group of ESMO and the European Society for Pediatric Oncology (SIOPE) defines a common vision for improving outcomes for AYAs with cancer in Europe. Its recommendations include cooperation between a diverse range of specialists involved in AYA care, development of services tailored to the needs of AYAs with cancer, and specific measures to get more patients in this age group into [clinical trials](#).

Each year, more than 150,000 people in Europe in the AYA age range of 15–39 years, and over 1.2 million worldwide, are diagnosed with cancer. This is equivalent to nearly 7% of all cancers.

S., a 21-year-old patient with a rhabdomyosarcoma of the trunk, recalls that when he finally received the correct diagnosis, he was told to travel to another city where there was the only specialized center for his rare cancer. "They told me that even at 21, I would be hospitalized in a pediatric oncology unit, because the only experts for my disease were there," he says.

"These patients are a unique group who inhabit a middle ground between the pediatric and the adult worlds of oncology, and their management is still a challenge," says Dr. Andrea Ferrari, Pediatric Oncology Unit, Fondazione IRCCS Istituto Nazionale Tumori, Milan, Italy, lead author of the paper and SIOPE Co-Chair of the joint ESMO/SIOPE AYA Working Group. "They may present with pediatric- or adult-type tumors and there is limited awareness both within the general population and the medical and scientific community that cancer can arise at this age. In addition, there is the serious problem of access to quality care and specially designed clinical trials, and last but not least the specific and complex psychosocial considerations in this age group. Together, these critical determining factors impact on treatment outcomes and optimal care for these patients," he says.

"There is an under-provision and inequity of cancer care offered to this group of patients: 'speaking the same language' and fostering professional collaboration are really key to finding common ground and building something which is tailored to the unique needs of these patients," says Emmanouil Saloustros, Department of Oncology, University Hospital of Larissa.

The ESMO/SIOPE position paper highlights the key challenges of AYA care as a lack of understanding of cancer biology in this group, limited availability of specialized centers with age-appropriate multidisciplinary care and poor access to clinical trials of novel therapies. It also suggests that modest improvements in survival in the AYA age group compared to children and [older adults](#) with cancer reflect inequalities in care.

The ESMO/SIOPE AYA joint working group is committed to supporting both medical and pediatric oncologists by increasing awareness of AYA patients' needs, encouraging the development of ad-hoc education and advocating for an increase in research capacities in tumor types. "Educating oncologists on the characteristics of the diseases in this age group is a first step," says Ferrari. "It is similarly important to raise awareness beyond the medical communities, because the knock-on effects of adolescents and [young adults](#) being diagnosed with cancer are far broader and longer term."

"When I had to move to another city, I had to give up everything—university, my girlfriend, my friends. I packed my luggage with a lot of fear, a little courage and a little determination, and also a lot of hope. And I left for this journey, with uncertain and limping steps," says S.

The working group calls for healthcare professionals from different disciplines, patient advocates and stakeholders to focus collectively on the specific challenges of AYA cancer, taking account of the changing

physical and psychosocial needs of patients in this age group.

The position paper also suggests that centralisation of care into dedicated and financially well-supported specialist AYA services and networks is needed to improve care and facilitate access to clinical trials of novel therapies for all eligible patients, with potential for improved outcomes for AYAs with cancer.

S. says: "It is important we can have a way to tell our stories. We feel we have an important responsibility; we are witnesses and together with our doctors, we want to make it known that teenagers and young adults can have [cancer](#) too, and they can be cured, but only if they receive the best treatment at the right time."

More information: Ferrari A, Stark D, Peccatori FA et al. Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE). *ESMO Open*. DOI: [10.1016/j.esmoop.2021.100096](https://doi.org/10.1016/j.esmoop.2021.100096) [www.annalsofoncology.org/article ... \(21\)00053-3/fulltext](https://www.annalsofoncology.org/article/S0959-6460(21)00053-3/fulltext)

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