



The European Childhood Cancer Community calls for bold implementation of the European Care Strategy: Ensuring genuine support for young patients with life-threatening diseases, survivors and their family

Childhood Cancer International – Europe (CCI Europe) and the European Society for Paediatric Oncology (SIOP Europe) welcome the European Commission’s Communication on the European Care Strategy. This ambitious initiative aims at ensuring quality, affordable and accessible care services across Europe: goals that are supported by childhood cancer patients and healthcare professionals.

In addition, the Commission’s formal recognition of informal caregivers and the supportive measures aimed at enabling them to reconcile their caring responsibilities with their professional life are highly valued – indeed, childhood cancer has serious repercussions on families that must reorganise their lives to care for their sick child.

Childhood cancers affect over 35,000 children per year in Europe and are life-threatening. Parents have a fundamental role in caring for their child throughout the patient pathway. In addition, there are an estimated 500,000 childhood cancer survivors across Europe – a growing population that should be empowered and provided appropriate follow-up care models. Overall, childhood cancer represents a major health and societal burden in the EU.

In this light, CCI Europe and SIOP Europe would like to submit **six recommendations** that would significantly help children with cancer or another life-threatening disease, survivors and their families. We hope that these orientations can be reflected in the implementation efforts stemming from the current Communication as well as in its future revision as appropriate.

1. Explicit reference to children with a life-threatening disease and survivors

We would highly recommend an explicit inclusion of children “with a life-threatening disease, including cancer” in measures implementing the Communication on the European Care Strategy when it mentions “children in vulnerable situations or from disadvantaged backgrounds¹” in relation to early childhood education and the provision of continuous long-term follow up care.

Childhood cancer survivors should also be considered when referring to education and their access to long-term care.

2. Appropriate social protection for parents and caregivers of children with cancer

When a child is affected by a life-threatening disease such as cancer, the financial security of a family is frequently under threat as parents struggle between competing priorities: caring for their child, ensuring access to the best treatments, and sustaining a financial livelihood through their employment or other gainful occupation.

Hence, we would like to make the following proposals:

- Provide parent with an extraordinary leave for a duration equal to the treatment’s duration, with safeguards that ensure the security of their position in the workplace upon their return.
- Ensure an adequate financial compensation for the loss of informal carers’ salary or other income throughout the entire child’s treatment journey as well as for survivors experiencing difficulties in maintaining secure employment.

¹ This terminology notably includes children with disabilities, children at risk of poverty or social exclusion, children from homeless families, Roma children and those from minority groups, children with a migrant background, refugee children and children fleeing armed conflict (p. 7 of the Communication). The term “children with disabilities” doesn’t include children with diseases according to the definition of the UN Convention on the Right of Persons with Disabilities (CRPD) the Commission refers to on its website.



3. Affirmative support to patients and survivors' educational needs

All life-threatening diseases such as cancer interrupt a child's educational track, which results in repeated absences from school and challenges upon their return in class. Often, there is a strong communication and coordination problem between schools, families, and healthcare professionals.

These issues need to be adequately and specifically addressed in the implementation of the current European Care Strategy and we recommend that:

- Dedicated education facilities be provided for during the child's treatment: access to hospital schools but also remote classes for those children who are treated at home with individual educational support.
- Policies be adopted to enable a systematic and specific adaptation of sick children's curricula, including special conditions for their evaluation process, that would help facilitate their reintegration into school.

4. Long-term follow-up care and transition from childhood to adulthood for survivors

A substantial proportion of childhood cancer survivors experience worse health-related quality of life (QoL). They may be "lost" in the healthcare system once they become adults if transition from active treatment to long-term follow up (LTFU) care and from paediatric to adult care is not organised.

Healthcare providers in adult settings need to be informed about LTFU care and the importance of supporting survivors to take ownership of their care. The utilisation of the LTFU care guidelines and the Survivorship Passport model across Europe provides a clear pathway for high-quality survivorship care and should be encouraged.

5. Reinforced psychosocial support for patients, survivors and their informal carers

Due to the severe and life-threatening nature of cancer, there is a strong demand for integrating a distinct psychosocial support into the child's treatment and long-term follow-up care plans as well as in the support services for informal carers.

Therefore, robust referral pathways for psychosocial, psychiatric services and counselling should be established to refer patients, their caregivers, and survivors when necessary.

6. Synergies with European initiatives on childhood cancer (e.g., Europe's Beating Cancer Plan)

The European Care Strategy provides a unique opportunity to create synergies with many EU initiatives and legislations, such as Europe's Beating Cancer Plan and the Cross-Border Healthcare Directive, to ensure that childhood cancer patients and survivors live long, fulfilling lives and to further address the challenges faced by their families and caregivers.



ABOUT EUROPEAN CHILDHOOD CANCER ORGANISATIONS



Childhood Cancer International - Europe (CCI-E, or CCI Europe) represents childhood cancer parent and survivor groups as well as other childhood cancer organisations in Europe: 67 organisations in 34 European countries are members of CCI-E. CCI Europe works together with all relevant stakeholders for the same aim: help children and adolescents with cancer to be cured, with no - or as few as possible - long term health problems/late effects. (<https://ccieurope.eu/>)



The European Society for Paediatric Oncology (SIOPE, or SIOP Europe) is the single united European organisation representing all professionals working in the field of childhood cancers. With more than 2,500 members across 36 countries, SIOP Europe is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe. (www.siope.eu)