

Supporting Children, Adolescents and Young Adults (CAYA) through the cancer pathway and beyond



Irish Cancer Society

Pre-Budget Submission 2022



Many aspects of treatment and care for CAYA with cancer work well; however, there is much that we can do to support and improve the quality of life for this community. The Irish Cancer Society would like to assert the need for quality support structures built around CAYA and their families across the cancer care pathway so that CAYA and their family can thrive in life beyond cancer. Budget 2022 should deliver on quality of life priorities for children, adolescents and young adults with cancer, survivors, and their families, through the following actions:

1 Recognise the Costs of Cancer to Patients and their Families

- Provide funding for grants to parents/guardians, or up to the age of 18 for adolescents who are responsible for their own care, to cover non-medical expenses as a result of their treatment needs.
- Extend Carers' Allowance and Domiciliary Care Allowance to parents/guardians whose child is treated in hospital for longer than 13 weeks, in recognition of the fact that children must be accompanied. Similarly, entitlements for Domiciliary Care Allowance must be extended to parents/guardians of 16 and 17 year olds.
- Establish and fund a CAYA specific public psycho-oncology support hub-and-spoke service (covering the entire cancer care pathway).
- Provide funding to public hospitals to waive car parking charges for parents of children/adolescents

2 Supporting better outcomes from care

- Invest funding in age-appropriate, multi-disciplinary care for adolescents and young adults
- Foster mechanisms to enable more health and social care professionals at all career stages, across different disciplines, to participate in research activities to improve outcomes for CAYA living with and beyond cancer.
- Dedicate resources for the continuous monitoring of the workforce capacity to ensure sufficient staffing for adolescent and young adult oncology services.
- Ringfence and provide a predictable funding stream for clinical trials to ensure that children, adolescents and young adults can access clinical trials to support an improvement in outcomes.
- Provide new funding to develop a world-class cancer genetics service.

- Enhance funding to extend access to a special needs assistant for survivors of childhood and adolescent cancer who need it.
- Provide a lifelong medical card to survivors of childhood and adolescent cancer.
- Ringfence funding for survivors of childhood and adolescent cancer through the full implementation of the Priority Actions outlined in the NCCP's health needs assessment in survivorship after childhood cancer (Barrett et al. 2018)

Building Palliative Care Capacity

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- Provide funding for delivery of age-appropriate palliative services for children and young adults with untreatable cancers in their local community.

3 Supporting quality of life beyond cancer

- Extend publicly funded fertility preservation services to children and adolescent cancer patients as well as access to fertility preservation post-treatment for those who require it.
- Fund the Model of Care for Infertility, with dedicated funding available to adult survivors of CA cancer to access fertility treatments such as in-vitro fertilisation (IVF) and intrauterine insemination (IUI).

The recommendations in the Irish Cancer Society pre-budget submission which relate to CAYA are supported by the following organisations:



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