

CHILDHOOD CANCER AND DISABILITY: THE IMPORTANCE OF EARLY DETECTION, TREATMENT AND SUPPORT

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Survival and a high quality of life following a cancer diagnosis is possible in all income settings and various actions can be undertaken to promote early detection of cancer to prevent death and disability and improve the access of cancer patients to ongoing treatment, care and support.

What is the relationship between cancer and disability?

There have been significant advances in cancer treatment over the last 50 years. This has meant that childhood cancer is highly curable, with 80% cure rates of children diagnosed with cancer in high income countries. However, despite these advances, survival rates are much lower in LMICs and are estimated to range from 5-60% across settings. Common contributing factors to death and disability as a result of cancer include late detection and diagnosis, lack of knowledge of signs and symptoms of cancer in families and among health workers, weak referral networks, limited or unavailability of diagnostic equipment and cancer medicines, the inability of families to pay for treatment and care and high abandonment rates.



Alia is a 4 year old girl diagnosed with advanced retinoblastoma. While her parents noticed that she had a white pupil for at least one year, it was not brought to medical attention. When the disease progressed to an advanced stage, she was diagnosed and treated. However, Alia lost her vision in one eye.

Hacettepe University Cancer Institute, Turkey

While many children with cancer recover from their treatment, others may experience lifelong health problems such as damaged organs, slow or stunted growth, loss of vision and disabilities. Children who are diagnosed late and/or there is a delay between diagnosis and therapy may be particularly at risk of disability and late effects. For example, retinoblastoma is a curable disease with preservation of the eye possible with early diagnosis, however, many children are treated too late to avoid removal of the eye. "Commonly, patients are treated with eye ointments first before being referred for correct treatment. Children should not lose their eyes because of retinoblastoma but this is common in our setting due to delays in diagnosis and accessing correct treatment" says the Director of Tumaini la Maisha in Tanzania.

Living with cancer related disabilities

Children who are diagnosed with a non-communicable disease such as cancer can and should be enabled to live full and productive lives. As these case studies demonstrate, children with cancer related disabilities seek to rejoin school and engage in social and leisure activities, including sport. Consequently, in addition to early detection and timely treatment of cancer, it is important that children receive ongoing support from the health system and community based programmes to assist them to reintegrate into school and social life following cancer treatment.

Include children living with cancer in the health and development agenda

Persons living with disabilities include childhood cancer survivors!

As articulated in the Convention on the Rights of the Child, article 24 “State parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. State parties shall strive to ensure that no child is deprived of his or her right of access to such health care services”.

The Convention on the Rights of Persons with Disabilities defines disability as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” The Convention includes adults and children and also promotes the right to the highest attainable standard of health in addition to other rights related to full and equal participation in society.

In 2011, Heads of State and Government adopted the Political Declaration on the Prevention and Control of NCDs, which inter alia,

Jejomar is 7 years old and was admitted to hospital after being hit by a motorcycle and fracturing his left leg. Despite treatment, two months after the accident he still could not walk. His family noticed a mass in the same leg and took Jejomar back to the district hospital. After several tests, Jejomar was diagnosed with Acute Lymphoblastic Leukemia (ALL) and chemotherapy was advised. His parents, however, could not afford the cost of treatment and so he returned home untreated. Jejomar was taken to various faith healers but his condition worsened and the mass in his left leg grew bigger. He was finally brought to the Philippine Children’s Medical Centre where he is now in his fourth month of chemotherapy. Although Jejomar is now in clinical remission and is greatly looking forward to going back to school and playing with his friends, he still cannot walk and may never be able to walk normally.

Philippine Children’s Medical Center, My Child Matters Project, Philippines

Eduardo is 15 years old and was admitted to hospital with a mass in his right leg. The mass was growing rapidly, but before being taken to the hospital, he visited a traditional healer for massage therapy. Due to the advanced disease at diagnosis, it was not possible to salvage his limb and an amputation was performed. Eduardo received chemotherapy and adjusted himself to his disability. Although Eduardo now uses prosthesis and is continuing with his studies and practising sports, for every child like him there are many more with similar disabilities after cancer treatment who never find the strength in themselves to even attempt living a normal life. All these children need to have systems in place to give meaning to their lives and make them feel productive and capable.

Hospital Escuela Universitario, My Child Matters Project, Honduras

recognises the intimate relationship between NCDs and disabilities and calls on Member States to provide rehabilitation services within the spectrum of services for addressing NCDs.

Childhood cancer must therefore be addressed as part of discussions on mainstreaming disability in the global post 2015 development agenda as well as in relation to post 2015 health goals and targets. All people, including children, living with disabilities as a result of non-communicable diseases such as cancer, must be visible in health and development policies and programmes, including internationally agreed development goals and strategies. In order to reduce the likelihood of cancer related disability, early detection of cancer in children must be integrated into health programmes including at primary health level.

SOME KEY ACTIONS

- Promote early detection through public awareness of signs and symptoms of childhood cancer
- Integrate knowledge and awareness of signs of symptoms of childhood cancer into the training of health providers, including at primary health care level to promote early detection and referral
- Support the treatment costs of children diagnosed with cancer including providing social support to parents to promote adherence to treatment
- Provide support to families to enhance the quality of life of children with cancer through setting up childhood cancer family groups and support networks
- Support the health and development needs of children with cancer related disabilities



The UICC Childhood Cancer Programme (ChiCa) seeks to raise global awareness of childhood cancers and increase the proportion of children surviving cancer in low- and middle- income countries. The My Child Matters (MCM) initiative, launched in 2005, aims to reduce inequities in childhood cancer survival in low and middle income countries. Supported by the Sanofi-Esprit Foundation, MCM involves an innovative partnership with UICC for high level advocacy to help improve outcomes of childhood cancers worldwide. Since 2005, My Child Matters has provided support to 51 hospitals and NGOs in 33 countries through grass-roots projects.

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