# CREATEYOURFUTURE E-ZINE 01



CHILDHOOD CANCER



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#### Welcome to the Create Your Future E-Zine

We are very happy that you are interested in the very first edition of our electronic magazine focusing on childhood cancer and its consequences for young survivors entering the labour market.

This E-Zine is produced by the project team of Create your Future, a project funded by the European Union's Erasmus+ Programme. We are a group of professionals from childhood cancer associations, educators, career counsellors, and project managers from Bulgaria, Austria, Spain and Greece. Our common aim is to support survivors from childhood cancer on their way into the labour market. To do so, we develop career counselling approaches which reflect the specific challenges of childhood cancer survivors. We also aim to sensitize employers for the potential of these young people, and to inform the general public about this socially important issue.

This E-Zine is one of the channels through which we want to reach out. Five editions of the E-Zine are planned until May 2017, each of them focusing on a different aspect of childhood cancer and its implications for survivors' career pathways. The magazine consists of short, informative articles.

If you want to share something with us within the Create your Future E-Zine just let us know, by simply sending an email to a.dimitrova@catro.com.

To be informed about the release of coming E-Zine editions and of the other project activities of Create your Future please visit our website www.createyourfuture-eu.org.

We very much look forward to getting in touch with you to help our important cause!





## Surviving Childhood Cancer: Facts & Figures

Childhood Cancer is very different from cancer in adults. Not only in terms of the types of cancer that affect different age groups but also in terms of the effect of anticancer treatments on growing children and adolescents. Luckily, the treatment of childhood cancer is one of oncology's great success stories. When diagnosed early enough, and treated with the appropriate protocols, nowadays approximately 70% to 80% of childhood cancers are curable. This is a huge increase since the mid-1970s, when the 5-year survival rate was about 58%.

However, survival rates for most childhood cancers vary widely across cancer types. The most common types of cancer diagnosed in children and adolescents are leukemia, brain and central nervous system tumors, lymphoma, rhabdomyosarcoma, neuroblastoma, Wilms tumor, bone cancer, and gonadal (testicular and ovarian) germ cell tumors.

Find out more about childhood cancer types and how common childhood cancer is worldwide in our next e-zine. Sign up here: J.Ziegler@dieberater.com

### Now that treatment is over...

What is often forgotten is that the intense effort to care for and cure a child with cancer does not end with survival. Once the cancer treatment is complete even more challenges await for cancer survivors. Trying to find their way back into society, job and school after leaving the hospital successfully is a long journey which very often also means to abandon original career plans due to the disease and its late and long term effects.

After cancer treatment many childhood cancer survivors feel that although they are happy it's over, they also wonder about what comes next. There is a lot of support during the illness, but after treatment there are new questions and concerns to address. Many people look forward to returning to work or education after finishing cancer treatment. Working can provide opportunities to reconnect with colleagues and friends, focus on something other than cancer and most importantly start settling back into a regular routine and lifestyle.

#### Back to School & Work after Cancer

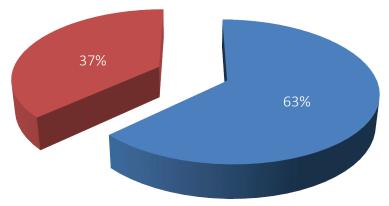
Even though most survivors' wish of resuming their normal life is huge, cancer and its treatment sometimes have a serious impact on people's ability in going back to a normal life, affecting not only work but also education and social life: Long-term survivors of childhood cancer have higher risk factors for poor educational attainment, less than optimal employment status, and interpersonal relationship issues. Cancers and treatments that result in impairment to the CNS (central nervous system), particularly brain tumors, or that impact sensory functioning, such as hearing loss, are associated with greater risk for undesirable social outcomes, as are emotional health problems and physical disability (CCSS 2009). Research also shows that psychological distress in Adolescent and Young Adult Survivors concerns every fifth childhood cancer survivor. This indicates a greater need for monitoring and follow-up care related to psychological health in childhood cancer survivors (Min Ah Kim, Jaehee Yi: 2013).

Surgical procedures often create considerable defects accompanied by dysfunction and even disfigurement, and radiation therapy can cause significant morbidity and unique tissue management problems. Speech, motor and cognitive functioning can all be adversely affected. Additionally, cancer as a life-threatening disease increases people's stress level, and they may need more social support. Regarding the social perception of the effects of treatment survivors, both young and old, often feel lonely and not understood by others. T hey want understanding for their chronic fatigue and other long-term effects.

The figures: a study by Howard et al. (2014)

63%\* of the survivors in a study by Howard et al. (2014) experienced social isolation over time as they grew through childhood, adolescence and young adulthood.

\*The research involved 30 childhood cancer survivors altogether.



<sup>4</sup> Erasmus+





A serious disease such as childhood cancer leaves nobody untouched. Cancer and especially its treatment (chemotherapy, radiation and surgery) very often result in long-term side effects called late effects. These late effects may arise even years after the treatment and part of these late effects very often are disabilities. The range of possible late effects is huge and also varies according to the type of cancer. Statistics suggest that more than two-thirds of childhood cancer survivors experience late effects.

Especially survivors of brain and central nervous system tumor (CNS) very often experience late effects. As the nervous system of children and adolescents is still very sensitive and maturing, the tumor and its treatment might lead to physical, cognitive or psychological disorder. Late effects also depend on the size of the tumor, its location and the intensity of the treatment. Late effects of brain tumor for example include disturbances of equilibrium or trembling of the hands, lack of concentration or a change in personality.

Tumors directly located at the spinal cord may lead to paraplegia, a retinoblastoma may lead to a loss of an eye. Radiotherapy of the abdomen may lead to a deformation of the skeleton and bone tumor may make amputation necessary. Other late effects may be heart problems, fatigue, hearing impairment, visual impairment, lack of memory, motoric impairment are possible late effects.

This shows that survivors of childhood cancer suffering from late effects are by no means a homogeneous group! However, what they do share are the limitations and restraints that they experience as a result of cancer and cancer treatment, and the associated barriers they face in returning to a 'normal' modern life, characterised by speed, time pressure and a pressure to perform; a life that is full of stairs and narrow streets.

# In our next e-zine you will find information on:

- What causes childhood cancer?
- How common is childhood cancer?
- How to live with late effects?









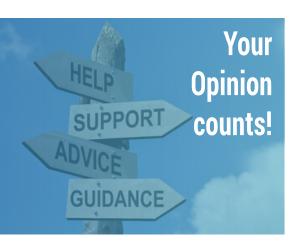
With Create your Future we want to provide childhood cancer survivors with individual career support in order to help them find a career perspective which is realistic, takes into account the health restrictions, but – most importantly - also builds on and enhances existing strengths and competences.

In Create your Future a bunch of experts from across Europe come together to develop a comprehensive career counselling programme for childhood cancer survivors that takes into account the special needs, stresses and strains of the target group. Additionally, a training curriculum for adult educators, who want to provide career counselling to survivors, is being devoloped.

We don't only want to share with you our thoughts, we are also very interested in what you have to say! If you want to share something with us within the Create your Future E-zine just let us know. Simply send us an e-mail with your idea for an article to a.dimitrova@catro.com and we will get back to you as soon as possible.

Your article can evolve around anything related to childhood cancer. Before starting your article please get in contact with us and we will let you know the details for publishing your article in our E-zine.





The Create Your Future E-zine is very reader-oriented. For us this means we want to improve our E-zine with each issue. Therefore we would be happy to receiving your feedback on our articles.

If you have a topic you are very interested in, just let us know too; we will write an article about it and incorporate it in one of our next E-zines.

For any suggestions, questions or feedback we are available under this email-address: a.dimitrova@catro.com

This project is funded by the European Commission and will be implemented in Bulgaria, Austria, Spain and Greece.

