



# Long-term survivors of childhood cancer: cure and care—the Erice Statement (2006) revised after 10 years (2016)

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## Abstract

**Purpose** The number of persons who have successfully completed treatment for a cancer diagnosed during childhood and who have entered adulthood is increasing over time, and former patients will become aging citizens.

**Methods** Ten years ago, an expert panel met in Erice, Italy, to produce a set of principles concerning the cure and care of survivors of childhood and adolescent cancer. The result was the Erice Statement (Haupt et al. Eur J Cancer 43(12):1778–80, 2007) that was translated into nine languages. Ten years on, it was timely to review, and possibly revise, the Erice Statement in view of the changes in paediatric oncology and the number and results of international follow-up studies conducted during the intervening years.

**Results** The long-term goal of the cure and care of a child with cancer is that he/she becomes a resilient and autonomous adult with optimal health-related quality of life, accepted in society at the same level as his/her age peers. “Cure” refers to cure from the original cancer, regardless of any potential for, or presence of, remaining disabilities or side effects of treatment. The *care* of a child with cancer should include complete and honest information for parents and the child.

**Conclusions and implication for cancer survivors** Some members of the previous expert panel, as well as new invited experts, met again in Erice to review the Erice Statement, producing a revised version including update and integration of each of the ten points. In addition, a declaration has been prepared, by the Childhood Cancer International Survivors Network in Dublin on October 2016 (see Annex 1).

**Keywords** Childhood cure · Childhood care · Health · Quality of life

## Introduction

The number of persons who have successfully completed treatment for a cancer diagnosed during childhood and who have entered adulthood is increasing over time, and former patients will become aging citizens.

Ten years ago, an expert panel met in Erice, Italy, to produce a set of principles concerning the cure and care of survivors of childhood and adolescent cancer. The result was the Erice Statement [1]. The Erice Statement was translated into nine languages and can be found in the PanCare website (<https://www.pancare.eu/en/erice/>). PanCare is a multidisciplinary pan-European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side effects of the treatment of children and adolescents with cancer.

Ten years on, it was timely to review, and possibly revise, the Erice Statement in view of the changes in paediatric oncology and the number and results of international follow-up studies conducted during the intervening years. Some

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members of the previous expert panel, as well as new invited experts, met again in Erice to review the Erice Statement, producing a revised version including update and integration of each of the ten points.

## Methods

Sixty-five paediatric cancer experts (representing paediatric oncologists, psychologists, nurses, epidemiologists and survivors) from 17 European countries (with four additional experts from North America) met again in Erice, Sicily, from November 1 to 3, 2016, as part of the semi-annual PanCare meeting ([www.pancare.eu](http://www.pancare.eu)). The ten points reflect what the group considers essential in childhood cancer survivors' cure and care.

Over a single session, ten experts addressed each of the ten points of the statement, followed by a question and answer session with the audience. Though there are some changes in the ten points, their number remains unchanged. Also, the "goal" included in the original statement is unchanged.

## Results

### The goal of the cure and care of childhood cancer—the statement

The long-term goal of the cure and care of a child with cancer is that he/she becomes a resilient and autonomous adult with optimal health-related quality of life, accepted in society at the same level as his/her age peers.

1. "Cure" refers to cure from the original cancer (see "Note" below), regardless of any potential for, or presence of, remaining disabilities or side effects of treatment. The term "cured" can be used when discussing the survivors' status with them and in the larger society whereas the term "long-term survivor" should continue to be used in scientific research and related literature to alert physicians to potential sequelae that may require care and attention.
2. The *care* of a child with cancer should include complete and honest information for parents and the child (in an age- and culturally appropriate manner) regarding the diagnosis of the disease, its management and its curability. The communication of "cure" for an individual child or adolescent and his/her family should occur in the context of an agreed-upon decision made by the paediatric oncologist in charge, together with all persons involved, taking individual circumstances into consideration.
3. *Communication of risk* is difficult and challenging. Information about risk should be delivered to survivors and families in a language that is easily understood and in a positive light. Effective communication requires a high level of interpersonal skill. Survivors and families have the right to be fully informed in person and in writing about being cured, as well as about the remaining risks of non-cancer late effects, recurrence of the primary cancer or second primary cancers where applicable. After completion of treatment for the original cancer, it is the responsibility of the paediatric cancer unit (PCU) to provide the survivor and his/her parents with a summary of the characteristics of the cancer, of treatments received and of complications that may develop in the longer term as a result of the cancer or its treatment. The summary must be combined with suggestions on the type and timing of the follow-up evaluations to monitor the original cancer as well as possible late effects of the disease and its treatment. The survivorship passport (SurPass) provides access to personal clinical history and comprises (a) a database for safe storage of all the clinical data of European survivors, (b) a self-generated document connected to the database, which contains all details of the survivors' disease and treatment, (c) a website and a mobile app linked to the database, and (d) a brochure with recommendations for a personalized/tailored follow-up program.
4. There is an additional need for continuing *systematic follow-up* after cure for surveillance of potential long-term effects of the cancer or its treatment. To this end, every PCU should have a well-structured "long-term follow-up clinic" (LTFU) with care plans based on risk stratification and evidence-based guidelines and a multidisciplinary team including a key worker (coordinator) and other specialists, e.g. cardiologist, endocrinologist, medical (young adult) oncologist, radiotherapist, occupational adviser, plus other relevant specialists based on individual patient needs and risks.
5. In order to provide appropriate and definitive advice and support to long-term survivors, the PCU needs to have a LTFU database to support clinical care, as well as research initiatives and administrative needs. In prioritizing a *research agenda*, health care professionals should collaborate with survivors and their families and the study commissions responsible for the oncological front-line therapy. Potential research topics include (a) late effects evaluation and prevention, outcomes, risk factors (including genetics), surveillance, management and interventions; and (b) models of care (including transition).
6. Systematic efforts should be made during and after cancer treatment to *empower* the survivors and their families by making available age-appropriate information and strengthening their coping skills and strategies in dealing with their current and future concerns. Many survivors and their families face difficulties in coping with the

consequences of cure. By reinforcing their adjustment skills and strengthening their coping strategies, they can develop resilience that will help them to face and overcome, even more forcefully and confidently, future life challenges not only during transitions in the health care system but also in all aspects of life: in education, in work and in family life. We should not forget the socio-economic aspects of the psychosocial spectrum of outcomes. The coordinator, or case manager, of the LTFU clinic should be available for support not only during transition but throughout the survivor's journey.

7. The majority of survivors are relatively well adjusted, and many show extraordinary resilience. Compared to the general population, some survivors are at increased risk of *developing conditions* many years after treatment that need medical, psychological intervention or social services support. In addition, a subgroup of survivors is particularly vulnerable early in the course of survivorship and needs ongoing clinical and psychosocial support. The health care system must address these groups.
8. *Parents, survivors, siblings, partners* and other close family members should always be encouraged to play an active role in the discussion of plans for the future and in the design and implementation of psychosocial interventions. In addition, survivors and parents have an essential role to play in sharing information and life skills, helping to empower other survivors and parents, and in the design and implementation of future survivorship services. Parents, survivors and advocacy groups should be actively involved in the multidisciplinary health care team and research networks relating to late effects and childhood cancer in general.
9. The *general public* needs to be made aware that significant progress has been made over the past 40 years in the treatment of childhood cancers. This has resulted in many hundreds of thousands of survivors who are cured. This population increases every year. They also need to be more aware about the medical and psychosocial

challenges experienced by survivors. In order to enable survivors to reach their full potential as active members of society, survivors must have full and equal access to education, jobs, insurance and health care.

10. *Inequalities* of current treatment, long-term cure rates and quality of life after treatment, both within and between nations, based largely on differences in socioeconomic status, resource allocation and knowledge remain a challenge for the (inter)national community to address.

## Note

Identifying certain cure in an individual survivor is very difficult, but a practical population-based definition of cure that applies to any cancer is the time from diagnosis at which the risk of death from recurrence or metastatic spread of the original cancer becomes very small or negligible.

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## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** This article does not contain any studies with human participants or animals performed by any of the authors.

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