



# **Childhood Cancer**

## **Guidelines for**

### **Standards of Treatment & Care**

**Adopted by SIOP, Porto, September 2002**

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## **1. Definitions**

For the purposes of this document, the following definitions apply:

“**Childhood cancer**” is intended to encompass children and adolescents under 21, unless other criteria are set within the member country.

“**Parent**” means parent or guardian.

“**Family**” means parents, patient, siblings, and grand parents, or the family as perceived by the parents and patients.

“**Professional**” means someone providing one of a range of childhood cancer therapy and support services.

## **2. The purpose of these guidelines**

Every child has the basic right to life, and not to be discriminated against. Parents should also be supported in helping their children achieve these rights. These rights are stated in the UN Convention (Section 4).

This document sets guidelines on what families of children with cancer might expect in terms of treatment (dealing with the illness) and care (support with the social and psychological impact of the illness).

How well families are supported will be substantially affected by their cultural and economic circumstances. In some countries, the priority will be to improve access to diagnosis and treatment to reduce the level of preventable death. In other countries where there is adequate access to treatment and survival rates are good, the priority will be to reduce the psychosocial impact of the illness. *At all stages, though, families need information and psychosocial support.*

The Standards (Section 7) set out the fundamental expectations for each stage in the treatment and care process. A family *at any one of these stages* might expect these levels of support. Section 8 provides details of where to access best practice information.

The Standards provide a framework for family and patient-centred support. For a country where most children are not diagnosed, enacting Article 1 (on diagnosis) is likely to be the most pressing need. But even the most developed countries may not be able to achieve the optimum standards at every stage of treatment & care. For example, children with cancer may benefit from a parent being able to take full time care of the child, yet for parents everywhere there may be little or no job security in these circumstances.

***These Articles, therefore, provide a checklist to assess what is currently provided, where the priority for improvement lies, and guidelines for making these improvements.***

## **3. Who should use this document?**

This document is intended to provide guidance to those who can *make or advocate* positive change to improve standards of treatment and care for children with cancer. *Professional and family groups* working in this field are therefore the primary audience.

The document is also intended as a guide *to individual professionals and family members* who wish to understand the stages of treatment and care, and to advocate change where it is needed.

Finally, the document is intended as an aid *to other bodies* seeking a basic understanding of the

needs in childhood cancer, and who wish to contribute to improving treatment and care everywhere in the world.

#### **4. The UN Convention on the Rights of the Child**

The UN Convention on the Rights of the Child is a key source document in assessing what the expectations of child with cancer should be. The convention states amongst others:

Article 3 – Parties (to the convention) shall ensure the health care of children conforms to standards established by competent authorities.

Article 6 – Every child has the inherent right to life.

Article 17 – Parties shall ensure access to information aimed at promoting health.

Article 18 – Working parents have a right to benefit from child-care facilities.

Article 24 – children have the right to enjoy the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

Article 26 – Every child has the right to benefit from social security, including social insurance (in accordance with their national law).

Article 28 – Every child has the right to education.

Articles 42 to 45 – Parties undertake to examine progress on this convention and report to the UN every two years, and to make their reports widely known to the public in their own countries.

#### **5. Preamble**

Around 250,000 children worldwide get cancer each year. In developed countries, most children are diagnosed and have access to treatment. Up to 70% of them may be cured. In less developed countries many children do not even get diagnosed, or have no access to treatment. 80% of the world's children fall into this category. As a result some 200,000 children with cancer die each year. But with equal access to treatment, over 100,000 of those deaths might be avoidable.

One of the tasks of the ICCPO and SIOP (as international organisations representing families and professionals) is to help families and other carers understand what they should expect as the most basic elements of treatment and care of children with cancer. These expectations cover four areas:

##### **Access to treatment**

All children should have the right to diagnosis and locally appropriate treatment. We must help local doctors and other health workers identify childhood cancer before its too late. Specialist treatment centres should be accessible and appropriately resourced for children and adolescents. Diagnosis must be clearly communicated, allowing families to make informed decisions, and creating a partnership between the family and professionals. And treatment should be explained, the alternatives discussed, and families helped to make decisions based on a complete understanding of the situation.

##### **Emotional support**

Emotional support must be available. Retaining their parental role, and establishing a partnership with professionals is key to the parents of a child diagnosed with cancer. This means being able to stay with the child in hospital and taking an active role in treatment and care. Formal and informal

programmes operating at family and individual levels should help people cope with the stress of a life threatening illness.

### **Social support**

No family should suffer economic hardship as a result of their child's illness. We believe that wherever possible families should have access to economic support, to minimise the financial impact of treatment and care. Parents should not have to choose between caring for their child and continuing employment on which the family depends. Where possible, there should be compensation schemes or employment protection. No child, or sibling should suffer in education and support should be offered to minimise the impact.

### **Reintegration into society**

It is essential that families receive support both during and post-treatment to help them re-integrate into society. This means support in education and employment, and support when a child lives through cancer. There should be no discrimination against families or children in later life because of the illness and its effects. Those who have suffered the loss of a child should have ongoing access to professional and peer group support.

## **6. Key elements of treatment & care**

The main expectations described in the preamble can be sub-divided into key elements of treatment and care – the cancer journey. *The Standards in section 7 set out the basic expectations for each stage:*

*Implicit is that families should have access to information throughout the process.*

- Speed of diagnosis
- Specialist treatment centres
- Understanding diagnosis
- Understanding treatment
- Welfare
- Employment
- Education
- The role of the family
- Coping with treatment
- Continuity of care
- Peer support
- Reintegration
- Relapse
- Coping with loss
- Late effects & long term follow up
- Symptom control

From a treatment perspective, the keys stages are:

- Referral
- Diagnosis
- Treatment
- Surveillance
- Survival
- Death

## **7. Standards**

### **1 – Speed of diagnosis**

1. There should be educational programmes in place to *help local doctors and primary health workers* identify childhood cancer and refer cases to treatment centres.
2. There should be programmes in place to *educate families and the wider public* about the symptoms of cancer.

### **2 – Specialist treatment centres**

1. Children and adolescents should be treated in *units designed for them*.
2. These Units should *specialise in childhood cancer and belong to a multi-centre group*, collaborating at regional, national or international level.
3. These Units should be staffed by a *multi-disciplinary* team and resourced to the highest attainable standard with the purpose of *improving survival and quality of care*.

### **3 – Understanding diagnosis**

1. All communication with families should be implemented in a way that helps to *establish a partnership* between the family and professionals.
2. Diagnosis should be explained so as to allow families to make *informed decisions*.

### **4 – Understanding treatment**

1. Treatment options should be explained in a way that enables the family to give *informed consent*.
2. Explanation should include *prognosis, and whether this differs materially* from outcomes in other locations to which families have realistic access.
3. *Participation in clinical trials should be explicit and appropriate consent obtained*.

### **5 – Economic Support**

1. Families should have access to *economic support* designed to alleviate the financial impact of treatment & care. This might be provided through government, insurance, a range of support groups, or some mix of these.

### **6 – Employment**

1. Parents should not have to choose between continuing employment on which their family economy depends and looking after their child during life-threatening illness.
2. *Employment* should have a level of *protection* or compensation to allow families if they wish to provide full-time care for a child with life-threatening illness.

### **7 – Education**

1. *Education should be encouraged to continue as normally* as the illness permits for both the child and siblings.
2. *Additional support should be provided* to offset and minimise the impact of treatment.
3. Support should be provided to assist re-entry into education.
4. All children, and their siblings, should have the right to continuing educational achievement for which appropriate provision is required.

### **8 – The role of the family**

1. Parents should be encouraged by professionals to retain their full *parental role* during treatment and care, especially in decision taking.
2. Parents should be advocates for their children.
3. This should include the right to stay with the child in hospital and to take an *active role* in the treatment and care process.
4. The family and professional *partnership* should be emphasised, with all working in the best interests of the child.

### **9 – Coping with treatment**

1. There should be formal programmes of *psychosocial support* provided by professionals as

- an integral part of treatment.
2. This should include specific programmes providing support individually for *parents, patients, siblings, and the wider family*.

#### **10 – Peer support**

1. Families should have access to peer groups who can provide a range of support, including *emotional, economic and social support*, individually or collectively, to parents, patients, siblings, and the wider family.
2. Professionals and established peer groups should support the *setting up of peer groups* where they do not exist.
3. Some support programmes will benefit from combined input *from professionals and families working together*.

#### **11 – Continuity of care**

1. Care should be recognised as being required during, and beyond treatment, to assist reintegration; and provided as appropriate.

#### **12 – Reintegration**

1. Families should receive support during and post-treatment to help *reintegration* into society.
2. *Survivorship programmes* should help ensure the long-term rehabilitation of patients.
3. Patients and families should *not be discriminated against* in terms of education, employment or insurance.
4. Survivors should be encouraged to establish *networks* to help support future childhood cancer patients, and input to future psychosocial care programmes.

#### **13 - Relapse**

1. Treatment options should be explained that take account of the child's anticipated quality of life.
2. Appropriate support should be given to the family to cope with further treatment and/or the prospect of palliative care.

#### **14 – Coping with loss**

1. Families who suffer loss of a child should be provided with *professional support* during and post-treatment.
2. There should be *peer-run emotional support groups*, specialising in child loss.

#### **15 – Late effects and long term follow up**

1. Potential late-effects should be fully explained to families, including the child.
2. Programs should be in place to support patients, and their families, who suffer late effects of treatment.
3. Programs should be in place to provide long-term follow up as a means of supporting families and to help improve treatment and care for future patients and their families.

#### **16 – Symptom Care**

1. At all stages of the child's treatment, special attention should be paid to symptom control, especially pain.

## **8. Appendix - “Best practice”**

*This final section contains examples of how each Standard can be applied in practice. The material mentioned can be found on the ICCCPPO web site ([www.icccppo.org](http://www.icccppo.org)) unless otherwise stated.*

*The lack of examples in some sections shows a need for additional examples to be provided where they exist, or for potential collaboration to be carried out between SIOP and ICCCPPO.*

### **1 – Speed of diagnosis**

Early Warning Signs - SACCSG

Referral Guidelines - Department of Health, UK ([www.gov.uk](http://www.gov.uk))

### **2 – Specialist treatment centres**

Recommendations for organisation of paediatric unit including psychosocial care - SIOP

Charter for children in hospital - SIOP

### **3 – Understanding diagnosis**

Guidelines on communication of diagnosis - SIOP

### **4 – Understanding treatment**

### **5 – Welfare**

### **6 – Employment**

### **7 – Education**

Guidelines for School and Education - SIOP

### **8 – The role of the family**

Guidelines for a Therapeutic Alliance - SIOP

### **9 – Coping with treatment**

Recommendations for organisation of paediatric unit including psychosocial care - SIOP

### **10 – Peer support**

You Are Not Alone - Source book for Support Groups [Candlelighters (USA)]

What a parent groups can provide - Mark Chesler, ICCCPPO

Articles on Parent and other Support Groups – ICCCPPO Web Site

### **11 – Continuity of care**

### **12 – Reintegration**

Guidelines for Care of Long-term Survivors - SIOP

### **13 - Relapse**

### **14 – Coping with loss**

Guidelines for Assistance of terminally ill children with cancer - SIOP

### **15 – Late Effects & long term follow up**

Guidelines for Care of Long-term Survivors - SIOP

### **16 – Symptom control**