



**PSYCHOSOZIALE ARBEITSGEMEINSCHAFT IN DER  
PÄDIATRISCHEN ONKOLOGIE UND HÄMATOLOGIE (PSAPOH)**  
AG in der Gesellschaft für pädiatrische Onkologie und Hämatologie (GPOH)

AWMF- Leitlinie Register Nr. 025/002

Entwicklungsstufe 3

Psychosocial Care in  
Paediatric Oncology and Haematology

ABRIDGED VERSION

2019

Hildegard M. Schröder<sup>1</sup>, Susanne Lilienthal<sup>2</sup>, Beate M. Schreiber-Gollwitzer<sup>3</sup>, Barbara Grießmeier<sup>4</sup>,  
Birte Hesselbarth<sup>1</sup>, Iris Lein-Köhler<sup>5</sup>, Alexandra Nest<sup>6</sup>, Liesa J. Weiler-Wichtl<sup>7</sup> und Ulrike Leiss<sup>7</sup>

<sup>1</sup> Universitätsklinikum Schleswig-Holstein, UKSH Campus Lübeck, Klinik für Kinder- und Jugendmedizin, Pädiatrische Onkologie und Hämatologie, <sup>2</sup> Universitätsklinikum Hamburg-Eppendorf, Klinik und Poliklinik für Pädiatrische Hämatologie und Onkologie, <sup>3</sup> Klinikum Dritter Orden München, Sozialpädiatrisches Zentrum, Zentrum für chronische Erkrankungen und Entwicklungsförderung, <sup>4</sup> Universitätsklinikum Frankfurt, Klinik für Kinder- und Jugendmedizin, Schwerpunkt Onkologie, Hämatologie und Hämostaseologie, <sup>5</sup> Universitätsklinikum des Saarlandes, Klinik für Pädiatrische Onkologie und Hämatologie, <sup>6</sup> Klinikum der Universität München, Dr. von Haunersches Kinderspital, Abteilung für Pädiatrische Hämatologie, Onkologie, Hämostaseologie und Stammzelltransplantation, <sup>7</sup> AKH und Medizinische Universität Wien, Universitätsklinik für Kinder- und Jugendheilkunde, Klinische Abteilung für Neonatologie, Pädiatrische Intensivmedizin und Neuropädiatrie - Neuroonkologie

On behalf of: Gesellschaft für Pädiatrische Onkologie und Hämatologie



Sponsored by:

DLFH - Deutsche Leukämie- Forschungshilfe -  
Aktion für krebskranke Kinder e.V.



ÖKKH - Österreichische  
Kinder-Krebs-Hilfe



## Members of the panel of experts 2008/2013

Dr. med. Carola Bindt, *Hamburg*, Dr. phil. Gerlind Bode, *Bonn*, Dipl.-Soz.-Päd. Maren Bösel, *Heidelberg*, Dipl.-Soz.-Päd. Ralf Braungart, *Stuttgart*, Dr. med. Gabriele Calaminus, *Düsseldorf/Münster*, Dipl.-Psych. Viola Diesselhorst, *Berlin*, Prof. Dr. med. Alain di Gallo, *Basel*, Prof. Dr. med. Rudolf Erttmann, *Hamburg*, Dipl.-Theol., Dipl.-Soz.-Päd. Renate Fischer, *Greifswald/Berlin*, Prof. Dr. med. Henning Flechtner *Magdeburg*, Carola Freidank, MA, Kranken- und Kinderkrankenpflegerin *Hannover*, Barbara Grießmeier, MA, Dipl.-Musiktherapeutin, *Frankfurt*, Prof. Dr. med. Michael Günter, *Tübingen*, Ute Hennings, Dipl.-Musiktherapeutin, *Hamburg*, Prof. Dr. med. Dr. phil. Uwe Koch, *Hamburg*, Dipl.-Psych. Sigrid Kochendörfer, *Tübingen*, Dr. rer. nat. Ulrike Leiss, *Wien*, Dipl.-Psych. Susanne Lilienthal, *Hamburg*, Dipl.-Soz.-Päd. Stephan Maier, *Schönwald*, Dipl.-Rehabilitationspädagogin Anne-Christin Minetzke-Gruner, *Berlin*, Dipl.-Päd. Dorothee Mundle, *Tübingen*, Dr. med. Dirk Schnabel, *Berlin*, Dipl.-Psych. Beate M. Schreiber-Gollwitzer, *München*, Dipl.-Päd. Hildegard M. Schröder, *Lübeck*, PD Dr. phil., Dipl.-Psych. Andrea Schumacher, *Münster*, Dr. phil., Dipl.-Psych. Rainer Thiel, *Hamburg*, Dr. med. Gabriele Wevers-Donauer, *Homburg-Saar*, Gunda Wiedenbruch, Erzieherin *Göttingen*.

## Members of the panel of experts 2019:

Dipl.-Soz.-Päd. Ralf Braungart, *Stuttgart*, Dr. med. Gabriele Calaminus, *Bonn*, Dipl.-Psych. Viola Diesselhorst, *Berlin*, Prof. Dr. med. Alain di Gallo, *Basel*, Dipl.-Soz.-Päd., Erzieherin Sonja Eßmann, *Münster*, Prof. Dr. med. Henning Flechtner *Magdeburg*, Carola Freidank, MA, Kranken- und Kinderkrankenpflegerin *Hannover*, Barbara Grießmeier, MA, Dipl.-Musiktherapeutin *Frankfurt*, Dipl.-Psych., Dipl.-Theol. Birte Hesselbarth, *Lübeck*, Anita Kienesberger, MA, *Wien*, Dr. phil. Ria Kortum, *Bonn*, Dipl.-Psych. Iris Lein-Köhler, *Homburg-Saar*, Dr. rer. nat. Ulrike Leiss, *Wien*, Dipl.-Psych. Peggy Lüttich, *Heidelberg*, Dipl.-Soz.-Päd. Stephan Maier, *Schönwald*, Prof. Dr., Dipl.-Psych. Anja Mehnert-Theuerkauf, *Leipzig*, Dipl.-Päd. Dorothee Mundle, *Tübingen*, Dipl.-Psych. Alexandra Nest, MSc, *München*, Dr. scient. med. Thomas Pletschko, *Wien*, Mag. Carina Schneider, *Wien*, Dipl.-Psych. Beate M. Schreiber-Gollwitzer, *München*, Dipl.-Päd. Hildegard M. Schröder, *Lübeck*, PD Dr. phil., Dipl.-Psych. Andrea Schumacher, *Münster*, Dr. scient. med. Liesa J. Weiler-Wichtl, *Wien*.

## Participating scientific associations:

- Psychosoziale Arbeitsgemeinschaft in der Gesellschaft für Pädiatrische Onkologie und Hämatologie (PSAPOH)
- Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH)
- Arbeitsgemeinschaft für Psychoonkologie (PSO) in: Deutsche Krebsgesellschaft (DKG)
- Deutsche Arbeitsgemeinschaft für Psychosoziale Onkologie (dapo)
- Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie, Psychosomatik und Psychotherapie e.V. (DGKJP)
- Deutsche Gesellschaft für Sozialpädiatrie und Jugendmedizin (DGSPJ)
- Gesellschaft für Neuropsychologie Österreich (GNPÖ)
- Konferenz onkologischer Kranken- und Kinderkrankenpflege (KOK) in: Deutsche Krebsgesellschaft (DKG)
- German Paediatric Oncology Nurses Group (GPONG)
- Bundesarbeitsgemeinschaft Künstlerische Therapien (BAG KT)

## Participating organisations:

- Deutsche Leukämie-Forschungshilfe - Aktion für krebskranke Kinder e.V. - Dachverband (DLFH)
- Deutsche Kinderkrebsstiftung (DKKS)
- Österreichische-Kinder-Krebshilfe (ÖKKH)

Scientific advisers 2008:

Dr. phil. Birgit Watzke, Dr. phil. Wiebke Kluth, Kai Kossow, Prof. Dr. med. Dr. phil. Uwe Koch, Institut und Poliklinik für Medizinische Psychologie, Universitätsklinikum Hamburg-Eppendorf

Scientific advisers for the updated version 2013/2019\*:

Dr. rer. nat. Ulrike Leiss (Univ. Ass. post-doc), Mag. Doris Lamplmair\*, Mag. Anna Müller\*, Mag. Lisa Laussner\*, Universitätsklinik für Kinder- und Jugendheilkunde, Medizinische Universität Wien<sup>1</sup>

Advice and mediation:

Prof. Dr. med. Hans-Konrad Selbmann, Tübingen, Prof. Dr. med. Ina Kopp, Marburg, Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (AWMF)

Coordinators and Editors:

Dipl.-Päd. Hildegard M. Schröder  
Systemische Familientherapeutin  
Pädiatrische Psychoonkologin  
ehem. Universitätsklinikum Schleswig-Holstein,  
UKSH Campus Lübeck  
Klinik für Kinder- und Jugendmedizin

[Schroeder.Hildegard@outlook.de](mailto:Schroeder.Hildegard@outlook.de)

Dr. Ulrike Leiss  
Klinische und Gesundheitspsychologin  
(*Kinder-, Jugend-, Familienpsychologie; Klinische Neuropsychologie*), Pädiatrische Psychoonkologin  
Univ. Klinik für Kinder- und Jugendheilkunde,  
Medizinische Universität Wien

[ulrike.leiss@meduniwien.ac.at](mailto:ulrike.leiss@meduniwien.ac.at)

Acknowledgement:

We would like to express our sincere thanks to the *Deutsche Leukämie-Forschungshilfe – Aktion für krebskranke Kinder e.V. – Dachverband (DLFH)* and the *Österreichische Kinder-Krebs-Hilfe (ÖKKH)*. The support of both made it possible to carry out the comprehensive 2019 update.

Translation: Moya Irvine

First version: 2008, First update: 2013

Current version: 2019

---

<sup>1</sup> In addition, special thanks is due to Mag. Angelika Holzer, Mag. Stephanie-Dominique Karigl, Mag. Katja Keiblinger, Mag. Iris Kickinger, Kerstin Krottendorfer, MA, Mag. Neeltje Obergfell and Mag. Oliver Bousek for their cooperation on the evidence evaluation of current literature.

## Contents

1	INTRODUCTION /BACKGROUND	5
1.1	Development of psychosocial care	5
1.2	Goals and areas of responsibility in psychosocial care	6
2	STRUCTURE AND FRAMEWORK	7
2.1	Definition of psychosocial care	7
2.2	Basic principles of psychosocial care	7
2.3	Organisation and structure	7
2.4	Quality assurance and documentation	8
3	STRESS FACTORS AND RESOURCES	8
3.1	Stressors related to disease	8
3.2	Non-disease-related stressors	10
3.3	Personal and social resources	11
4	DIAGNOSTICS	12
4.1	Psychosocial diagnostics in clinical care	12
4.2	Psychosocial diagnostics in oncological treatment studies	12
5	LEADING SYMPTOMS AND INDICATION	14
5.1	Reactions to a severe stressor: Differential diagnostics	14
5.2	Reactions to a severe stressor: Leading symptoms and indication	16
5.3	Indication for basic or intensified psychosocial care	17
5.3.1.	<i>Indication for basic psychosocial care</i>	17
5.3.2.	<i>Indication for intensified psychosocial care</i>	17
6	THERAPY / INTERVENTIONS	18
6.1	Basic versus intensified care	18
6.2	Phase-specific psychosocial interventions	20
6.3	Evidence-basing of the effectiveness of selected psychosocial interventions	22
7	FOLLOW-UP CARE AND REHABILITATION	22
7.1	Responsibilities of psychosocial follow-up care	23
7.2	Current provisions and structures in psychosocial follow-up care	24
	CONCLUDING REMARKS	25
	REFERENCES	26

---

<i>Appendix A:</i>	<i>Guideline report on the creation of the guideline and the updates of 2013 and 2019 incl. evidence tables, declaration of interests of all participants</i>
<i>Appendix B:</i>	<i>Sources of the examination methods (tests, questionnaires etc.)</i>
<i>Appendix C:</i>	<i>Index of online resources</i>
<i>Appendix D:</i>	<i>Index of other standards, position papers, consensus papers and recommendations</i>

**Note:** Literature sources in the following document are cited in accordance with American Psychological Association APA (6th ed.) guidelines. Appendix A-D is to be found at: <http://www.awmf.org/leitlinien/detail/II/025-002.html>

# 1 INTRODUCTION / BACKGROUND

## 1.1 Development of psychosocial care

Today, psychosocial care is a standard part of treatment in paediatric oncology and haematology, and in Germany, has a more than 30-year background of experience from which concepts and structures for everyday practice have been developed (*Creutzig, Jürgens, Herold, Göbel, & Henze, 2004*). Today, medical advances in the treatment of malignant diseases in childhood and adolescence make recurrence-free survival possible for 80% of all patients (*Berthold, Bode, Böcker, Christaras, & Creutzig, 2006; Creutzig et al., 2002; Gatta, 2014*). The basis for the high rates of cure for children and adolescents is extremely intensive treatment, usually associated with serious physical side effects. In addition, the consolidation of treatment centres into national or international treatment networks, as within the GPOH, has also proved to be a factor in this success (*Rossig et al., 2013*).

The disease- and treatment-related stressors are associated with a high degree of suffering for young patients and their relatives. They can lead to traumatisation, psychological illness and considerable loss of quality of life. The patients' physical, social, emotional and cognitive development is endangered. For the whole family, the diagnosis of cancer in childhood and adolescence means a prolonged and extreme emotional situation focused on the life-threatening nature of the disease. It gives rise to profound changes in family life and is accompanied by a considerable degree of psychosocial stress for the whole family.

The individual psychological and social pressures are reflected in a range of publications and personal accounts of those affected. The experiences of former patients and their relatives play an important role in the process of developing psychosocial concepts. The complexity of the pressures on the patient and his relatives requires care that integrates psychological, social and art therapy services, and also cooperates with the clinic's school and pastoral care service.

The complexity of the stressors experienced by patients and their relatives requires multiprofessional psychosocial care in close cooperation with professionals from the fields of medicine, nursing, physiotherapy, ergotherapy, speech therapy, hospital pastoral care and the clinic's school as well with external teams providing support.

In German-speaking countries a range of experience-based treatment concepts for various areas of care have been developed (e.g. *Di Gallo, 2004; Schreiber-Gollwitzer, Schröder, & Niethammer, 2002; Topf, Trimmel, Vaschalek, Felsberger, & Gadner, 1994*), and a model for standardised care (*Kusch, Labouvie, Jager, & Bode, 1997; Labouvie, 2005*) and a national guideline (*H. M. Schröder et al., 2006*) have been drawn up over the past years. At the international level, from 1993 onwards, guidelines and recommendations on a broad spectrum of psychosocial topics have been continually developed through a committee of the SIOP (*Société Internationale d'Oncologie Pédiatrique*) and other organisations (e.g. *Association of Oncology Social Work (AOSW), 2012; Canadian Association of Psychosocial Oncology, 2010; SIOP - Working Committee on Psychosocial Issues in Pediatric Oncology. (Guidelines: 1993-2004)/and ICCPO, 2002*). In the Anglo-American world, various concepts of care for children with cancer and their families have been created (u.a. *Bearison & Mulhern, 1994; M. M. Lauria, Hockenberry-Eaton, Pawletko, & Mauer, 1996*). The common basis for all these concepts is orientation towards the family, the strengthening of resources and resistance, and multiprofessional supportive therapy oriented to the process of the disease.

A 2015 systematic review (*Wiener, Viola, Koretske, Perper, & Paenaude, 2015*) gives an overview of 27 different standards, guidelines and consensus statements that were published in relevant literature databases (MEDLINE and PubMed) between 1980 and 2013.

Subsequently, a group of psychosocial experts from the USA set out to define updated, consensus- and evidence-based standards for psychosocial care. As a result, interdisciplinary specialists from the field of paediatric oncology together with representatives of parents' organisations, published 15 evidence-based standards within the framework of the *Psychosocial Standards of Care Project* relating to various topics in psychosocial care (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015 as well as following articles in *Pediatric Blood Cancer 2015, Volume (62)*).

The development of medical and psychosocial follow-up care and transitional concepts for former child and adolescent cancer sufferers has gained increasing importance in recent years. Results of studies on late effects and quality of life point to physical, emotional, cognitive and social consequences of the disease and treatment for a proportion of patients. Psychosocial problems are also evident among parents and siblings. Specific psychosocial follow-up care services are particularly necessary for high-risk groups, such as patients with brain tumours and patients who need a radical operation or a stem-cell transplant (see chapter 7 and unabridged version of the guideline).

## 1.2 Goals and areas of responsibility in psychosocial care

Important goals and areas of responsibility of psychosocial care in everyday clinical practice are:

### **Support in coping with the disease**

- Counselling and support for patients and families in a persistent stress situation
- Encouragement of a functional, age- and development-appropriate adaptation to the disease
- Strengthening the resources, competence and autonomy of the patient and the family
- Treatment and support in acute crises and in the palliative situation
- Promotion of the greatest possible health-related quality of life and psychological health

### **Ensuring therapy and cooperation**

- Promoting compliance with the implementation of medical treatment
- Strengthening familial competence in the emotional and social care of the patient
- Organisational help for the care of the patient at home

### **Treatment of specific symptoms**

- Symptom-oriented interventions in case of emotional, behavioural and other problems

### **Social counselling and support/ organisation of follow-up care**

- Information and counselling aimed at securing the family's socioeconomic basis
- Help in applying for benefits/entitlements
- Initiation and coordination of supportive measures, help with finding financial aid
- Application for and initiation of in-patient rehabilitation
- Counselling aimed at the reintegration of the patient in kindergarten, school and vocational training
- Arranging continuing outpatient supportive measures and therapies

### **Prevention**

- Avoidance of secondary and concomitant mental illness in the patient and relatives
- Avoidance of social isolation and difficulties and also excessive familial strain
- Avoidance of social, emotional and cognitive late effects/developmental disorders

## 2 STRUCTURE AND FRAMEWORK

### 2.1 Definition of psychosocial care

Psychosocial care in paediatric oncology and haematology<sup>2</sup> encompasses all the clinical and scientific research activities concerning the evaluation and treatment of individual, psychological, familial, social and social welfare/entitlement issues relevant to the disease and their influence on coping. It also includes the development of concepts aimed at the ongoing improvement of treatment.

Psychosocial care in paediatric oncology and haematology is conducted in cooperation with the medical and nursing treatment team. The emphasis is on promoting the resources of the patient and family during the course of the disease, during therapy, follow-up care and, if the need arises, during dying, death and (anticipatory) mourning. The basis for this is a supportive and informative relationship with the children, families and the social environment. It is oriented towards the physical, emotional, social and developmental potential of sick children and adolescents and their social environment, taking individual styles and ability to cope and adjust into account.

Psychosocial care is characterised by defined basic principles, structural-organisational (pre)conditions, and conditions of quality assurance and documentation that are supported by various national and international concepts. It is carried out by specialists from a range of professions (*Grießmeier, B., Venker-Treu, S., & Kusch, M., 2003*), requires a clearly defined allocation of responsibilities and ongoing interdisciplinary communication within the team. The psychosocial staff perform specific activities according to their professional qualifications. In addition, there are interdisciplinary, overlapping areas of responsibility.

### 2.2 Basic principles of psychosocial care<sup>3</sup>

- Holistic approach to treatment
- Preventive approach to treatment
- Family orientation
- Centred on the individual
- Resource-oriented
- Supportive therapy
- Process orientation towards course of disease
- Interdisciplinary cooperation
- Maintenance of basic ethical attitudes

### 2.3 Organisation and structure<sup>3</sup>

- Psychosocial care as a standard element in paediatric oncology and haematology
  - Psychosocial service as an integral part of medical treatment and follow-up care
  - Basic care for all patients/families with intensified care as required
  - Availability and general accessibility to psychosocial care services

---

<sup>2</sup> Further on in the text, this field is often referred to by the abbreviated term “paediatric oncology”.

<sup>3</sup> Chapters 2.2, 2.3 and 2.4. summarise the basic principles, structural-organisational conditions and those for quality assurance and documentation. A more detailed presentation and the evidence on which these principles and structures are based can be found in the unabridged version of the guideline.

- Conditions regarding personnel, time, premises and administration
  - multidisciplinary psychosocial team
  - clearly defined clinical and administrative tasks
  - staffing oriented towards need for care
  - premises that ensure privacy
  - funding for patient information, play and therapy materials, tests, questionnaires (see chapter 4)
  - well-equipped play room
  - age-appropriate activities for children and adolescents

## 2.4 Quality assurance and documentation<sup>3</sup>

- Qualifications of psychosocial staff
  - Staff with specialist training as: psychologists, social education workers / social workers, educators, art and music therapists, play specialists, teachers, pastors
  - Interdisciplinary knowledge of diseases, stress reactions, disease concepts etc.
  - Ability to build up relationships based on trust and to deal with crisis situations etc.
- Ongoing training and supervision
- Documentation of status and process
- Evaluation and research
  - Updating of care standards
  - Networking/linking clinical-somatic and psychosocial research

## 3 STRESS FACTORS AND RESOURCES

Oncological diseases have psychological and social implications. In the patient and also in the family, these are determined by the type and character of the individual disease-specific physical and emotional stressors. In addition, non-disease-related secondary stressors of one or more family members, such as unfavourable sociocultural or psychosocial conditions, can make coping with disease and treatment more difficult (*e.g. Caplin et al., 2017; Hürter, 1990; Kazak, 1992; Kusch, Labouvie, Fleischhack, & Bode, 1996*).

### 3.1 Stressors related to disease

Stress factors related to disease comprise all the conditions and demands that arise from the disease and the therapy. Table 1 gives an overview of the stressors that in clinical experience play a major role for child and adolescent patients, their siblings, parents and other relatives.



Table 1: Stressors related to disease

Stressors	Concretisation
<b>Psychosocial stressors resulting from the shock of the diagnosis and (acute) crises (during the whole course of the disease)</b>	
<ul style="list-style-type: none"> <li>● Confrontation/dealing with the diagnosis and prognosis, life-threatening/incurable nature of the disease and an uncertain disease process</li> </ul>	
<ul style="list-style-type: none"> <li>● Fear of late effects resulting from the disease and therapy</li> </ul>	
<ul style="list-style-type: none"> <li>● Sudden change in the circumstances of the family</li> </ul>	
<ul style="list-style-type: none"> <li>● Critical situation in the patient, parents or siblings</li> </ul>	
<ul style="list-style-type: none"> <li>● Where appropriate, dealing with recurrence or progression</li> </ul>	
<ul style="list-style-type: none"> <li>● Where appropriate, dealing with the palliative treatment situation</li> </ul>	
<b>Psychosocial stressors due to medical-diagnostic measures</b>	
<ul style="list-style-type: none"> <li>● Experience of stressful, frightening and painful medical examinations</li> </ul>	<ul style="list-style-type: none"> <li>- punctures</li> <li>- diagnostic imaging</li> <li>- taking of blood samples inter alia</li> </ul>
<ul style="list-style-type: none"> <li>● Ongoing check-ups during and after treatment</li> </ul>	
<b>Psychosocial stressors due to medical-therapeutic measures/treatment</b>	
<ul style="list-style-type: none"> <li>● Dealing with necessary treatment procedures</li> </ul>	<ul style="list-style-type: none"> <li>- operation, chemotherapy, radiotherapy, stem cell transplant</li> <li>- decisions on the course of therapy (e.g. change in assignment to risk group)</li> </ul>
<ul style="list-style-type: none"> <li>● Experiencing stressful, frightening and painful medical-therapeutic measures</li> </ul>	<ul style="list-style-type: none"> <li>- taking tablets</li> <li>- mouth care</li> <li>- preparation for surgery</li> <li>- invasive procedures inter alia</li> </ul>
<ul style="list-style-type: none"> <li>● Restrictions to lifestyle (of the whole family) due to the treatment regime and the necessity for the long-term restructuring of everyday life</li> </ul>	<ul style="list-style-type: none"> <li>- reorganisation of everyday family life</li> <li>- strain on the parents' relationship</li> <li>- strain on siblings</li> <li>- interruption of education</li> <li>- increased financial expense</li> <li>- organisational problems</li> <li>- existential economic hardships</li> <li>- threat of job loss inter alia</li> </ul>
<ul style="list-style-type: none"> <li>● Parents' ongoing concern and multiple stressors</li> </ul>	<ul style="list-style-type: none"> <li>- emotional overload</li> <li>- chronic exhaustion etc.</li> </ul>
<ul style="list-style-type: none"> <li>● Impairment of age-appropriate development due to the changed life situation</li> </ul>	<ul style="list-style-type: none"> <li>- loss of autonomy and self-esteem</li> <li>- feelings of guilt</li> <li>- social isolation</li> </ul>
<b>Psychosocial stressors due to side effects and consequences of the disease and medical therapy</b>	
<ul style="list-style-type: none"> <li>● Physical impairment or changes due to the side effects of the medical therapy</li> </ul>	<ul style="list-style-type: none"> <li>- infections</li> <li>- nausea</li> </ul>

	<ul style="list-style-type: none"> <li>- hair loss</li> <li>- Cushing</li> <li>- cachexia</li> <li>- pain</li> <li>- fatigue</li> <li>- disturbed sleep</li> <li>- need for intensive care</li> <li>- taking tablets for the therapy of persistent side effects inter alia</li> </ul>
<ul style="list-style-type: none"> <li>• Radical surgical procedures associated with loss of function</li> </ul>	<ul style="list-style-type: none"> <li>- amputations inter alia</li> </ul>
<ul style="list-style-type: none"> <li>• Emotional or cognitive problems due to the disease or medical therapy</li> </ul>	<ul style="list-style-type: none"> <li>- change in experience and behaviour</li> <li>- emotional instability</li> <li>- limitation of physical performance</li> <li>- dealing with loss of skills and abilities</li> <li>- loss of physical integrity</li> <li>- coping with a changed body image inter alia</li> </ul>
<ul style="list-style-type: none"> <li>• Persistent physical, emotional or cognitive (late-) effects of the disease; fear of lasting impairments relevant to personality</li> </ul>	<ul style="list-style-type: none"> <li>- growth disturbances</li> <li>- fatigue</li> <li>- limitation of cognitive performance</li> <li>- limitation of fertility inter alia</li> </ul>
<ul style="list-style-type: none"> <li>• Insecurity in the reintegration/re-orientation phase</li> </ul>	
<ul style="list-style-type: none"> <li>• Fear of recurrence/progression</li> </ul>	

### 3.2 Non-disease-related stressors

Non-disease-related stressors (Table 2) are factors that are not explained by the disease or the necessity of the treatment or did not originally arise in the context of the disease. They result – mostly before the onset of the disease – from the familial, personal or socioeconomic conditions of the patient and their family. They can constitute a significant risk factor with regard to the demands of dealing with the illness.

Table 2: Non-disease-related stressors

Stressors	Concretisation
<ul style="list-style-type: none"> <li>• Socioeconomic stress factors</li> </ul>	<ul style="list-style-type: none"> <li>- unemployment</li> <li>- financial difficulties</li> <li>- single-parent family</li> <li>- housing problems</li> </ul>
<ul style="list-style-type: none"> <li>• Language and cultural problems, legal uncertainties</li> </ul>	<ul style="list-style-type: none"> <li>- unclear residency status</li> <li>- unclear housing situation</li> <li>- social dislocation</li> <li>- lack of language skills</li> </ul>
<ul style="list-style-type: none"> <li>• Lack of social support and family cohesion</li> </ul>	
<ul style="list-style-type: none"> <li>• Dysfunctional coping strategies and unfavourable health behaviour</li> </ul>	
<ul style="list-style-type: none"> <li>• Problematic parenting style</li> </ul>	
<ul style="list-style-type: none"> <li>• Pre-existing development disturbances or deficits</li> </ul>	
<ul style="list-style-type: none"> <li>• Pre-existing somatic or mental illness of the patient or relatives</li> </ul>	
<ul style="list-style-type: none"> <li>• See further Z-diagnoses in ICD-10</li> </ul>	

### 3.3 Personal and social resources

Resources are the positive potential the patient and family bring to the process of coming to terms with the life-threatening disease and its treatment. They are of major importance to patients in helping them to deal with this extraordinary situation. Coping with disease is an active process which includes the utilisation of existing resources and also the development of new behaviours and additional resources. In the context of preventive aspects of psychosocial care, the strengths and competencies of the children, adolescents and young adults affected and their relatives are supported, taking their previous individual problem-solving strategies into account.

Since the 1980s, research has concentrated increasingly on questions of resilience, and individual and social resources that contribute towards the ability to remain emotionally healthy despite stressful circumstances. Based on a variety of theoretical concepts such as coping, stress resistance, protective factors, invulnerability and resilience, numerous studies have described factors that promote child development and coping with critical life events. Social support within and outside the family, positive self-perception, sense of coherence, optimism, hope and a beneficial parenting climate are among the resources identified as having a protective effect on coping successfully with disease (*Bettge & Ravens-Sieberer, 2003; Germann et al., 2015; Howard Sharp et al., 2017; Howard Sharp et al., 2015*).

Stable coping factors, both short and long-term, have been found in the majority of families of young cancer patients (*Kazak et al., 2003; Kupst, 1992*). The following factors are among those that have been identified as promoting coping: (see for example *Grootenhuis & Last, 1997; Kazak et al., 1997; Patenaude & Kupst, 2005; Toffalini, Veltri, & Cornoldi, 2015; Turner, Hutchinson, & Wilson, 2018; Van Schoors et al., 2017; Willard, Hostetter, Hutchinson, Bonner, & Hardy, 2016; Turner, Hutchinson, & Wilson, 2018*).

Table 3: Protective factors: personal and social resources

Personal Resources	Social Resources
<ul style="list-style-type: none"> <li>● Optimistic attitude, hope</li> <li>● Positive experience of working through disease and death</li> <li>● Favourable disease concepts</li> <li>● Favourable coping strategies               <ul style="list-style-type: none"> <li>○ active problem-solving</li> <li>○ fighting spirit</li> <li>○ search for information</li> <li>○ distraction strategies</li> <li>○ self-encouragement</li> <li>○ openness towards contacts</li> <li>○ creativity</li> </ul> </li> <li>● Positive self-perception</li> <li>● Feeling of self-efficacy (i.e. confident of ability to cope with situations/challenges etc. using own competencies)</li> <li>● Psychological stability</li> <li>● Religiosity and sense of a greater meaning</li> </ul>	<ul style="list-style-type: none"> <li>● Cohesion of family members</li> <li>● Reliable emotional connections</li> <li>● Socially well integrated family</li> <li>● Open communication within the family</li> <li>● Emotionally positive and secure parent-child relationship</li> <li>● Competent parenting style</li> <li>● Family adaptability</li> <li>● Secure economic and legal status</li> <li>● Ability to seek and accept social support</li> </ul>

In addition, the following **protective factors** are of central importance for the **siblings** of children and adolescents with an oncological/haematological disease:

- open and honest communication about the disease (*Eiser & Havermans, 1994*),
- adequate information about the disease and treatment (*Houtzager, Grootenhuis, & Last, 1999; Zegaczewski, Chang, Coddington, & Berg, 2016; Zeltzer et al., 1996*) and
- involving siblings in the process of the disease and patient care.

The complex interaction of demands, stress factors and resources is the basis for the individual and familial process of adapting to the disease and its consequences, and for subsequent psychosocial development. It is fundamental for the psychosocial treatment plan.

## 4 DIAGNOSTICS

### 4.1 Psychosocial diagnostics in clinical care

Psychosocial diagnostics serve to evaluate individual stressors and to identify coping and adjustment strategies available to the sick child, adolescent or young adult and their social environment. Psychosocial diagnostics can include the taking of a thorough history and exploration and/or the use of standardised tests/questionnaires and/or behaviour observation. Particularly in contact with children, adolescents and young adults with cancer, great stress should be placed on the consideration of both methodical and ethical standards, such as transparency and orientation towards daily life and the patients' resources. This should be reflected in the choice of tests in order to record not only possible weaknesses but also everyday strengths (*see for example Leiss, 2011*).

Psychosocial diagnostics form the basis for the further planning of psychosocial treatment and can at the same time promote team communication concerning the psychosocial treatment needs of individual families. These **basic diagnostics**, which are described in detail in table 4, should be conducted routinely as early as possible at the beginning of therapy (*cf. e.g. A. S. Kunin-Batson et al., 2016*), during the course of treatment (in the case of long-term therapy in particular), at the conclusion of intensive therapy and in follow-up care.

The inclusion in the diagnostic process of the perceptions of all those concerned (e.g. through self-assessment by the children/adolescents and external assessment by parents and teachers) is of great importance for a meaningful intervention plan. In principle, differentiated diagnostics are preferable to the use of screening methods. At the beginning of therapy especially, but also at other critical points in time during the course of treatment (e.g. on transition to follow-up care), treatment needs should not be assessed exclusively by screening.

In addition to basic diagnostics, **specific, in-depth diagnostics** can be necessary, using appropriate standardised methods for the differentiated assessment of the relevant problem areas associated with the disease. In the case of certain risk factors such as brain tumours, ALL/AML or following certain forms of medical treatment or surgery (e.g. neurosurgery, radiotherapy of the central nervous system, intrathecal therapy, stem cell transplants), neuropsychological diagnostics are recommended as a central element of psychosocial care (*e.g. Boulet-Craig et al., 2018; Van Der Plas et al., 2018*).

### 4.2 Psychosocial diagnostics in oncological treatment studies

Psychosocial diagnostics are now an integral element in many international oncological treatment protocols and studies. According to the problems faced by patients and relatives, parameters on quality of life, for example, on participation or neurocognitive function are assessed and the findings included in the further development of medical treatment protocols.

Accordingly, within the PSAPOH framework, a battery of tests *for neuropsychological diagnostics in paediatric oncology and haematology (ND-POH)* was designed. This is recommended within the framework of the HIT treatment network and used in some GPOH therapy optimisation studies as accompanying study. Table 4 gives an overview of psychosocial basic diagnostics. The **examination dimensions** and recommended **examination methods** concerning in-depth diagnostics, available in **German-speaking countries**, are to be found in the unabridged version of the guideline or Appendix B.

Table 4: Psychosocial basic diagnostics

<b>BASIC DIAGNOSTICS</b>	
<b>INITIAL DIAGNOSTICS</b>	
<ul style="list-style-type: none"> <li>Initial contact on diagnosis</li> <li>Presentation of psychosocial care provision</li> <li>Start of diagnostic process</li> </ul>	
Examination dimension	Examination methods
<ul style="list-style-type: none"> <li>Psychosocial anamnesis                             <ul style="list-style-type: none"> <li>sociodemographic data</li> <li>history of disease</li> <li>patient's and family's anamnesis</li> <li>evaluation of resources</li> <li>disease-dependent and -independent stressors</li> <li>coping with the disease</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>anamnesis and exploration</li> <li>resource - and stress profile (<i>Schreiber-Gollwitzer &amp; Schröder, 2012</i>)</li> <li>parental stress inventory (<i>Tröster, 2010</i>)</li> <li>family genogram</li> </ul>
→ Complementary diagnostics (patient) on suspicion of developmental/psychological abnormalities or disturbances	<ul style="list-style-type: none"> <li>in-depth diagnostics; if necessary, consultation of specialist psychologist/psychiatrist and taking the assessment of other therapeutic specialists into account</li> </ul>
→ Complementary diagnostics (family) on suspicion of social conflict situation	<ul style="list-style-type: none"> <li>in-depth exploration of socioeconomic situation; consultation with social work specialists</li> </ul>
<b>ONGOING DIAGNOSTICS</b>	
<ul style="list-style-type: none"> <li>Phase-specific and disease-oriented (in particular during long-term therapy)</li> <li>In critical situations (e.g. medical complications)</li> <li>In transition situations (e.g. preparing for a transplant)</li> </ul>	
Examination dimension	Examination methods
<ul style="list-style-type: none"> <li>Coping with disease, compliance</li> <li>Motivation for therapy</li> <li>Phase-specific issues</li> <li>Overall family stress</li> <li>Psychological findings of the child/ adolescent/ young adult</li> </ul>	<ul style="list-style-type: none"> <li>repetition of elements of the initial diagnostics or in-depth diagnostics</li> <li>if necessary, in-depth diagnostics</li> </ul>
<ul style="list-style-type: none"> <li>Diagnostics for the initiation of in- or out-patient rehabilitation measures</li> </ul>	<ul style="list-style-type: none"> <li>detailed psychosocial exploration of patient and care givers, psychosocial referral report/opinion (e.g. on neuro-psychological diagnostics; special referral reports from rehabilitation clinics)</li> </ul>
<b>DIAGNOSTICS AT THE CONCLUSION OF INTENSIVE THERAPY and in the course of FOLLOW-UP CARE</b>	
Examination dimension	Examination methods
<ul style="list-style-type: none"> <li>Status survey of:                             <ul style="list-style-type: none"> <li>psychosocial situation</li> <li>adjustment to disease (patient and family)</li> <li>home care situation</li> <li>child's/adolescent's/ young adult's psychological findings</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>repetition of elements of initial diagnostics</li> </ul>
<ul style="list-style-type: none"> <li>Assessment of support needs for reintegration in everyday life/kindergarten/school/workplace</li> </ul>	<ul style="list-style-type: none"> <li>in-depth exploration of individual conditions and environmental factors relating to participation in everyday life</li> <li>in-depth diagnostics, where necessary consultation with psychology/education specialists</li> </ul>
→ Complementary diagnostics (patient) on suspicion of inadequate adaptation to the disease, behavioural- or emotional abnormalities or disturbances, fatigue, pain, sleep disturbances, abnormal eating behaviour	<ul style="list-style-type: none"> <li>in-depth diagnostics, where necessary, consultation with psychological/psychiatric specialists</li> </ul>
→ Complementary diagnostics (patient) in case of neuropsychological impairments	<ul style="list-style-type: none"> <li>in-depth diagnostics, where necessary, consultation with psychological/psychiatric specialists</li> </ul>

## 5 LEADING SYMPTOMS and INDICATION

### 5.1 Reactions to a severe stressor: differential diagnostics

The indication for psychosocial interventions is based on significant psychological and social burdens on the patient and their family. These burdens can lead to a range of reactions of varying degrees. The trauma of a life-threatening disease presents itself as an intense experience of discrepancy between the threatening situation and individual coping capacities, associated with feelings of helplessness and defenceless abandonment (G. Fischer & Riedesser, 1999).

The reaction of a child, their parents, siblings and other relatives to a severe, life-threatening illness should not principally be interpreted as a psychological disturbance, but depending on the intensity of the symptoms, it can turn into one.

In paediatric oncology we therefore usually refer to adequate stress reactions, i.e. those that are appropriate to the event or occurrence that caused them with regard to expression and intensity- as distinct from the pathological stress reactions and adjustment disorders in terms of ICD 10 (Dilling, 2004). Persistent stress reaction (B. Schreiber-Gollwitzer & Gollwitzer, 2007) is defined as follows:

*Subjective suffering and emotional disturbance as a reaction to extraordinary mental or physical stress. With regard to the severity of the stress, the reaction is adequate in expression and intensity. The reaction includes symptoms of depressive mood, anxiety, despair, withdrawal or also aggressive or expansive behaviours, social behaviour problems and psychosomatic problems, which do not fulfil the criteria for a disorder in accordance with ICD 10, but nevertheless present a considerable need for psychosocial intervention. A temporary relief from or revival of symptoms, possibly in a different form, and usually due to the course of the disease, can occur, but is always linked to the event that caused it or the stressor.*

In the Anglo-American world these forms of reaction are also referred to as “emotional distress” (Bultz & Carlson, 2006; NCCN - National Comprehensive Cancer Network, 2007). Other models refer to the concept of “chronic sorrow” (see for example Ahlström, 2007).

Even if this *persistent stress reaction* does not constitute a pathological event in the narrow sense, there is often a considerable need to take action and give support due to the severity and intensity of the subjective pain and decreased level of functioning. The assessment of the appropriateness of the reaction, taking into account the severity of the burden on the one hand, and on the other hand the subjective perception of stress and knowledge of the personal characteristics of the patient, is fundamental. (A. D. Cox, 1994; Resch, 1999).

The following figure 1 makes the diagnostic distinction between persistent stress reactions and the acute stress reaction and adjustment disorders of ICD 10.

Decision tree for differential diagnosis of reaction to a severe stressor or adjustment disorder

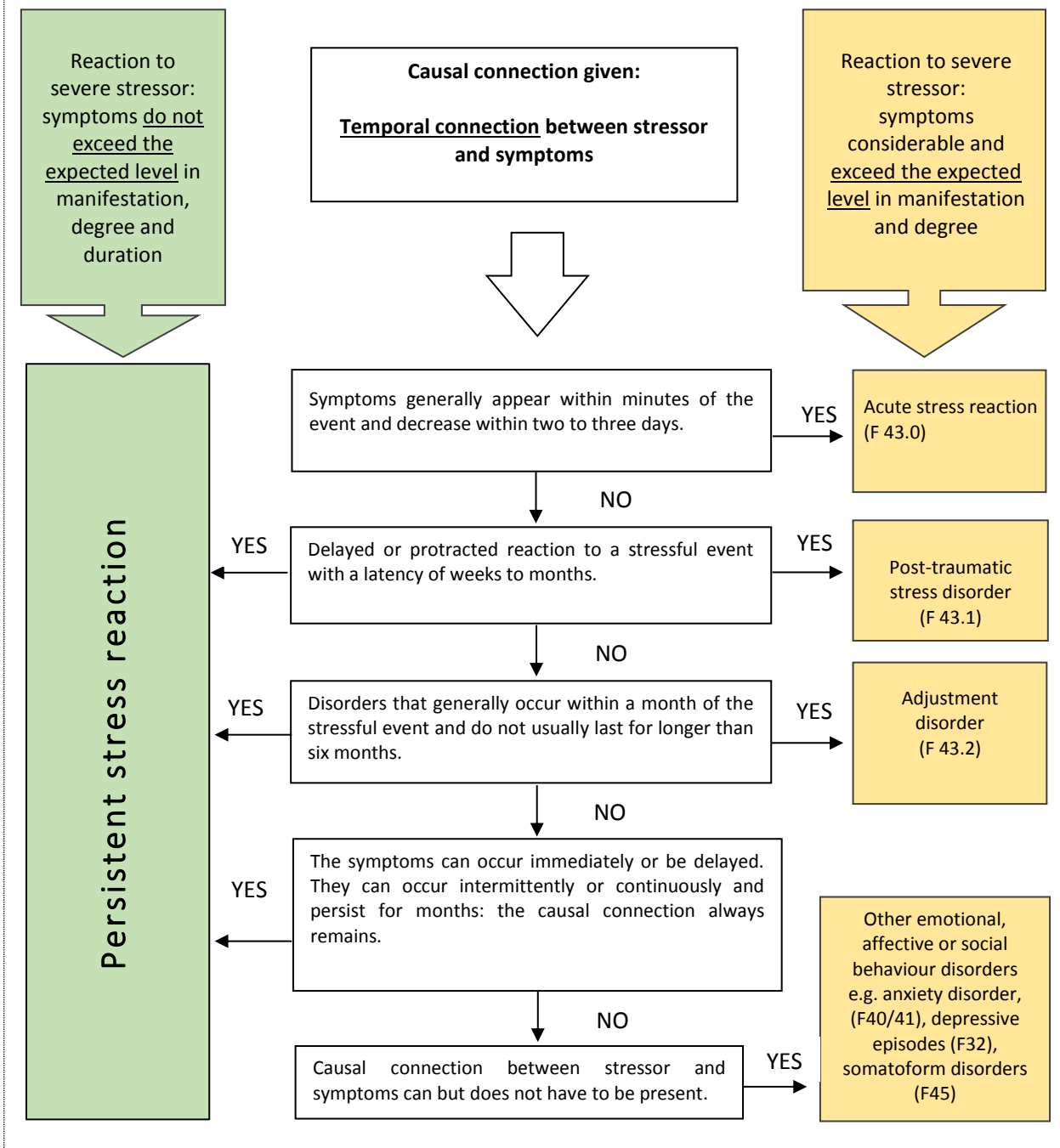


Figure 1: Diagnostic decision tree (B. Schreiber-Gollwitzer & Gollwitzer, 2007)

## 5.2 Reactions to a severe stressor: Leading symptoms and indication

Alongside the indication for the treatment of the patient, there is also an indication for the social pedagogic and/or psychological support of the relatives within the framework of family-oriented psychosocial care. This is based on the crucial importance of parental support for the implementation of treatment and the disease adaptation of the patient (Vance & Eiser, 2004).

The indication for *social pedagogic care of the family* is primarily given in social conflict situations, to secure the parental functions of protection and support for patients and siblings, and to maintain the family's socioeconomic basis during treatment (Kazak, 1992; Pelletier & Bona, 2015; see chapter 3). The indication for *supportive psychological care of relatives* is given in the case of emotional problems and a high level of psychological stress in coping with the disease and treatment. It is also necessary in the case of unfavourable coping mechanisms and interaction disorders which can place a serious strain on the patient.

The leading symptoms for psychosocial interventions are signs of dysfunctional disorders and problems, and those which affect the emotional, cognitive, behavioural or familial functioning. They can be seen as a concomitant, comorbidity or as consequences of the disease. In particular, they include:

- Behavioural problems and changes
- Emotional problems (anxiety symptoms, depressive symptoms etc.)
- Developmental problems or disturbances
- Compliance problems (e.g. in dealing with medical requirements)
- Body image problems due to visible and non-visible body changes
- Cognitive problems (attention and concentration problems etc.)
- Somatoform reactions (e.g. appetite disorders, sleep disturbances etc.)
- Social isolation due to prolonged stays in hospital (e.g. for SCT)
- Social conflict situations, problematic life circumstances
- Interaction problems (communication problems between family members etc.)
- Unfavourable individual and familial mechanisms for coping with disease
- Other marked changes in behaviours and reactions

The distinction between an adequate and an excessive reaction of the patient to a severe stressor is not always clear. The guidelines for child and adolescent psychiatry (*Deutsche-Gesellschaft-fuer-Kinder-und-Jugendpsychiatrie-psychosomatik-und-psychotherapie*) contain treatment paths for different disorders which should be taken into consideration in the planning of psychosocial treatment (see Appendix C)

The most important disorders in ICD-10 to be taken into account in psychosocial care are:

- Acute stress reaction (e.g. threatened decompensation, crisis reaction) (F43.0)
- Posttraumatic stress disorder (e.g. chronic traumatisation) (F43.1).
- Adjustment disorders (regressive, aggressive or depressive reaction) (F43.2)
- Emotional disorders with separation anxiety (F93.0)
- Fatigue syndrome (cf. F 48.0)
- Depressive episode (F32)
- Phobic disorders and other anxiety disorders (F 40/41)
- Compulsive disorders (F 42)
- Dissociative disorders (F44)
- Somatoform disorders (F45)
- Combined disorders of social behaviour and emotions (F92)
- Personality and behavioural disorder due to disease, damage or functional disorder of the brain (F07)
- other symptoms



### 5.3 Indication for basic or intensified psychosocial care

The findings obtained in the diagnostic process lead to an assessment of the intensity of psychosocial care needed.

#### 5.3.1 Indication for basic psychosocial care

---

The indications for basic psychosocial care are primarily disease- and treatment-related stressors, referred to as disease-related stressors. Stressors that are not related to the disease, rated as less serious in degree, can constitute a further indication (see 5.3.2, and also 3.1 und 3.2).

A need for intensified psychosocial care can also arise within the framework of basic care at critical points during the course of the disease and treatment.

#### 5.3.2 Indication for intensified psychosocial care

---

Indications for intensified care are increased disease-related primary stressors (unfavourable prognosis, complications, recurrence, among others.) and comprehensive or considerable stressors in several non-disease-related secondary areas. The adjustment capability of the patient and family can for example be affected due to limited psychosocial resources, unfavourable sociocultural conditions etc., or there may be substantial secondary psychological stressors in the sense of emotional disturbances of the sick child, adolescent or young adult or one or more members of the family.

The following is a list of risk groups that require intensified care in clinical practice due to extreme stress factors (before and during therapy).

- patients with a poor or unclear prognosis
- patients with recurrence
- patients in critical situations (e.g. in intensive care)
- patients in palliative care
- patients with brain tumours
- patients who need radical surgery
- patients who receive a stem cell transplant (SCT)
- patients undergoing long-term therapies and/or whose disease takes a chronic course
- patients with cancer predisposition syndrome
- patients with psychological problems or additional illnesses
- adolescent and young adult patients
- parents of children who receive a cancer diagnosis in early childhood
- single parents
- low-income families/families with an unemployed parent
- families in which a member is mentally or physically ill
- families who have travelled from outside the country for medical treatment
- families with language difficulties

## 6 THERAPY / INTERVENTIONS

Psychosocial interventions should be oriented towards the current state of health of the patient and their relatives. They are aimed at achieving direct relief and practical help for the patient and relatives, and securing a long-term stabilising and preventive effect. They are phase-specific and can be planned according to the course of the disease and the therapy. On the other hand, acute changes in the course of the disease can occur, and the psychosocial worker should react flexibly and immediately to these.

The following procedures and methods are used to implement the goals of psychosocial care:

- **Information, orientation aid** / 9-401.1 Familien- Paar- und Erziehungsberatung<sup>4</sup>
- **Psychosocial diagnostics** / 1-901 (Neuro-) psychologische u. psychosoziale Diagnostik
- **Supportive therapy**<sup>5</sup> / 9-401.3 Supportive Therapie
- **Crisis intervention** / 9-401.5 Integrierte Psychosoziale Komplexbehandlung
- **Social welfare counselling and support** / 9-401.0 Sozialrechtliche Beratung
- **Family and couples counselling, parental guidance** / 9-104.1 Familien- Paar- und Erziehungsberatung
- **Preparation, follow-up and support for medical measures** / 9-500 Patientenschulung
- **Educating patients and relatives / psychoeducation** / 9-500 Patientenschulung
- **Clinical-psychological treatment** (e.g. training of social and emotional competence) / 9-401.3 Supportive Therapie
- **Neuropsychological therapy** / 9-404 Neuropsychologische Therapie
- **Relaxation techniques** (e.g. breathing techniques, autogenic training, progressive muscle relaxation, imagination ) / 9-401.3 Supportive Therapie
- **Psychotherapy** (e.g. conversational therapy, behavioural therapy, systemic therapy, hypnotherapy, depth psychology) / 9-41 Psychotherapie
- **Play and creative pedagogy** / 9-401.3 Supportive Therapie
- **Creative arts therapy** (e.g. music- and art therapy) / 9-401.4 Künstlerische Therapie
- **Palliative support** / 8-982 Palliativmedizinische Komplexbehandlung
- **Planning and initiation of outpatient and inpatient follow-up care and rehabilitation** / 9-401.2 Nachsorgeorganisation
- **Organisation of reintegration into school and workplace** / 9-401.2 Nachsorgeorganisation
- **Coordination of inpatient and outpatient psychosocial care** / 9-401.2 Nachsorgeorganisation

Two approaches are outlined below, describing the timing, intensity and target groups of psychosocial interventions: (1) the difference between *basic* and *intensified care* and (2) the *phase-specific model of psychosocial interventions*

### 6.1. Basic versus intensified care

All paediatric oncology patients should receive basic psychosocial care (see also chapter 5, Indication). In cases of great psychosocial stress and multiple risk factors coupled with limited psychosocial resources, intensified care according to the indication should be provided (see chapter 5.3.2).

---

<sup>4</sup> The OPS codes in the DRG system relevant for billing in Germany, with which the respective interventions are recorded, are given in italics. In Austria, the LKF system (Austrian DRG system) is used.

<sup>5</sup> "Supportive therapy" is understood to mean a therapeutic procedure focused on the current health problems of patients and their families. It is of varying duration and focusses on the psychological processing of the diagnosis and the course of the disease, on coming to terms with the disease, its side effects and the necessary treatment as well as the familial, individual, academic, social and job-related problems that result.

An individual treatment plan is drawn up. Interventions in this area are higher-frequency and continuous. They can concentrate on varying aspects of care (Schreiber-Gollwitzer, B.M., Schröder, H.M. et al., 2003). The degree of stress is subject to considerable fluctuation and is recorded continuously during the course of treatment.

Outreach psychosocial care is given throughout all phases of treatment, particularly at the beginning of treatment and in crisis situations. An offer of care is made within a short timeframe.

Interventions of basic versus intensified care are outlined in tables 5 and 6.

Table 5: Interventions of basic psychosocial care


<b>Basic care</b> should comprise...	
<p><b>Diagnosis</b></p>  <p><b>End of therapy</b></p>	<ul style="list-style-type: none"> <li>• Initial contact immediately after diagnosis/admission</li> <li>• Crisis intervention</li> <li>• Psychosocial anamnesis (during the first 4 weeks)</li> <li>• Psychosocial (differential) diagnostics and planning of treatment</li> <li>• Social and psychological counselling</li> <li>• Family and couples counselling, parental guidance</li> <li>• Practical orientation aids; organisational support in daily life</li> <li>• Psychoeducative measures</li> <li>• Supportive therapy: promotion of ability to cope with treatment situations, functio laesa or disablement; measures for coping with pain; promotion of social contacts; mobilisation of individual resources</li> <li>• Ongoing diagnostics oriented towards the specific disease</li> <li>• Individual and group art- and music therapy</li> <li>• Play and creative pedagogy</li> <li>• Measures aimed at distraction, relaxation and pleasure</li> <li>• Physical- and exercise therapy</li> <li>• Rehabilitation counselling and organisation</li> <li>• Final interview at the end of intensive therapy, transition to follow-up care</li> <li>• Counselling relating to reintegration into daily life, kindergarten, school and workplace</li> <li>• Initiation/coordination of psychosocial follow-up care</li> </ul>

Table 6: Interventions in intensified care

<b>Intensified care</b> should comprise...	
<ul style="list-style-type: none"> <li>• higher-frequency basic-care interventions</li> <li>• individualised, more complex setting</li> </ul>	<ul style="list-style-type: none"> <li>• further interventions:               <ul style="list-style-type: none"> <li>- clinical-psychological treatment</li> <li>- neuropsychological therapy</li> <li>- psychotherapy</li> <li>- palliative support</li> </ul> </li> </ul>

## 6.2 Phase-specific psychosocial interventions

Psychosocial interventions should be oriented towards individual needs, which can change according to different phases in the disease and treatment. Acute changes require flexible and immediate response by the psychosocial worker.

In all phases, it can become necessary to adapt the care strategy to meet current needs in the sense of *crisis intervention*<sup>6</sup>.

The following summarised explanations are oriented towards day-to-day clinical observations. A more comprehensive outline is given in the unabridged version of the guideline.

### A. Diagnosis phase / Beginning of therapy

- Psychosocial diagnostics: Assessment of family burdens and resources and current need for support
- Supportive therapy: Support in dealing with the diagnosis, help in shifting focus from fear of death towards struggle for life, help with development to a realistic assessment of disease, promotion of adjustment to disease, empathic acceptance, reassurance and listening
- Help in the form of information and orientation: Material dealing with disease, treatment and consequences of treatment for the patient and relatives, information on support groups, charities etc., information for teachers and fellow students of patient and siblings
- Social welfare counselling and support: Help with reorganising everyday life, employment situation and financing household/basic needs; if necessary, involvement of social services

### B. Treatment phase

- Supportive therapy: Encouragement, strengthening focus on healthy aspects, help in activating emotional and social resources, motivation for active cooperation, clarifying fantasies about disease and treatment, reducing anxieties and uncertainty, support in maintaining social contacts during treatment
- Help in the form of information and orientation: age-appropriate information, preparation for and follow-up after operations, radiotherapy, SCT, etc. (brochures, books, videos etc.), special counselling for adolescents regarding fertility etc., establishing contact with parents an patients in similar situation to provide encouragement, support of contact to self-help groups (e.g. parent organisations, survivors), charities etc.
- Social welfare counselling and support: Help with organising outpatient home care, coordination of different provisions for support, help with obtaining medical aids, organisation of home and clinic tuition
- Artistic therapies: Activities aimed at promoting emotional expression
- Family and couples counselling, parental guidance: Help in dealing with the patient and his siblings, strengthening ability to communicate and autonomy in the family

---

<sup>6</sup> Crisis intervention is defined here as the acute, temporary care of people in case of drastic events or states that are experienced as traumatic or threatening and that can cause a massive change in life. According to *Sonneck, Kapusta, Tomandl, & Voracek (2016)* crisis intervention is to be distinguished from measures of acute psychiatry and comprises all the actions that can help the person involved to cope with their current difficulties. "Negative social, mental and medical consequences which are immanent as maladjustment or psychological breakdown in every crisis can thus be prevented."

As general principles of crisis intervention the authors include a rapid beginning of treatment, the activity of the helper, flexible methods, focus on the current situation, involving the social environment, the adequate relief of emotional pressure and interprofessional cooperation.

- Psychotherapy: Measures aimed at reducing fear of medical treatment and emotional stress, promotion of a positive body image and autonomy, particularly in adolescents
- Play and creative pedagogy: Making the clinic stay more comfortable, using play to process it, diversion, relaxation, building up trust

### C. Remission phase / Follow-up care

- Supportive therapy: Help in case of fear of late effects or recurrence, development of protection from feelings of guilt, support to help parents regain energy, help in coping with disability, organisation of appropriate therapeutic programmes, supporting the development of a positive view of the future
- Social welfare counselling and support: Organisation of rehabilitation to reduce physical and emotional exhaustion in the patient and family members (family oriented, neurological etc.)
- Family and couples counselling, parental guidance: Strengthening the patient's self-responsibility, helping to reduce the special role of the sick child, support for reintegration of the patient in kindergarten, school, vocational training and employment, encouraging the integration of disease-related experiences into the personal life story
- Psychotherapy: Promotion of age-appropriate emotional processing of the disease trauma and physical effects, building up the patient's confidence and trust in their abilities, reduction of anxiety and adjustment disorders in the patient and relatives

### D. Recurrence phase/ Progression

- Supportive therapy: Building up motivation and confidence, promotion of coping mechanisms, concentration on life in spite of changed prognosis, development of an appropriate future perspective, help and encouragement, confirmation of what has been achieved
- Social welfare counselling and support: intensified social support to ease the family's burden
- Family and couples counselling, parental guidance: Reduction of parental feelings of guilt, help in maintaining the social network for the patient, special focus on the situation of siblings, promotion of open communication
- Artistic therapies: Expression of feelings, experience of strengths and capabilities
- Psychotherapy: Support in dealing with fear of death and dying
- Play and creative pedagogy: creative and play activities, activation, promotion of sense of achievement, pleasure and relief from distress

### E. Palliative phase / Death and dying

- Supportive therapy: Help with planning the last phase of life, strengthening parents' protection function, providing space for anticipatory grief
- Social welfare counselling and support: Promotion of a supportive network for home care, organisation of outpatient care in the home, if necessary, hospice
- Artistic therapies: finding child-appropriate forms of leave-taking, finding expression for fantasies and imagination
- Palliative support: Support in coping with fear, loss, pain and grief, interdisciplinary, culturally appropriate care, support during dying, home visits, follow-up care of grieving families, organisation of contact to centres for grieving relatives

### 6.3 Evidence-basing of the effectiveness of selected psychosocial Interventions<sup>7</sup>

In order to establish the scientific foundation for the effectiveness of psychosocial care **interventions** for child/adolescent cancer patients and their relatives, a systematic literature research was carried out for the 2008 guideline and the first update in 2013. In addition, evidence rating in accordance with the recommendations of the *Centre for Evidence Based Medicine, Oxford* and the *Ärztliches Zentrum für Qualitätssicherung (Medical Centre for Quality Assurance)* was conducted. In order to be rated as conclusive, the studies had to fulfill minimum criteria with regard to sample size, randomisation, blinding, validity and other aspects.

For the period from 2013 to 2014, standards of the “*Psychosocial Standards of Care Project for Childhood Cancer*” and the studies contained in them are included (*Wiener, Kazak, et al., 2015*).

A systematic literature search was again carried out for the 2015-2018 period. Studies with a *high* evidence level and clinical importance were considered in the guideline (therefore: *systematic reviews or meta-analyses of controlled studies, randomised controlled studies, non-randomised controlled studies*). The GRADE system was used to rate the quality of the evidence and strength of the recommendation (*see for example G. Langer et al., 2012*). Details of the literature research and review can be found in the guideline report (appendix A); the studies themselves are described in the unabridged version of the guideline. The presentation of the evidence is oriented toward the following *goals* of the interventions.

- interventions regarding information, orientation aids and communication (chap. 6.3.1)
- interventions regarding emotional and social support (chap. 6.3.2)
- interventions aimed at reducing fatigue and improving fitness (chap. 6.3.3)
- interventions regarding support in practical and financial issues (chap. 6.3.4)
- interventions aimed at ensuring therapy and cooperation, and in case of specific symptoms within the framework of medical measures (chap. 6.3.5)
- interventions regarding prevention and rehabilitation (chap. 6.3.6)

## 7 FOLLOW-UP CARE AND REHABILITATION

Alongside the main focus on acute care, the development of medical and psychosocial follow-up and transition concepts for former child and adolescent cancer patients has gained increasing importance.

Findings from studies of late effects and quality of life point to physical, emotional, cognitive and social consequences of the disease and treatment for a proportion of patients (*Calaminus, Weinspach, Teske, & Göbel, 2007; Friend, Feltbower, Hughes, Dye, & Glaser, 2018; Michel, Rebholz, von der Weid, Bergstraesser, & Kuehni, 2010; Moyer et al., 2012*).

There is an urgent need for specific psychosocial follow-up care provision, in particular for groups at risk of late effects (e.g. children and adolescents after tumours of the central nervous system, acute lymphatic leukaemia (ALL) or stem cell transplants).

An overview by Signorelli et al. (2017) also makes clear that child and adolescent cancer survivors who are included in a follow-up care setting have a better health and education status. The authors therefore conclude that there is a necessity for life-long follow-up care and continuous information about late effects.

---

<sup>7</sup> Detailed explanations are to be found in the guideline report at: <http://www.awmf.org/leitlinien/detail/II/025-002.html>

## 7.1 Responsibilities of psychosocial follow-up care

Psychosocial care is an established part of intersectoral, multidisciplinary follow-up care and accompanies children and adolescents with cancer and their families long after the end of therapy.

The beginning of follow-up care depends on the clinical picture and the treatment associated with it: sometimes follow-up care begins after surgery, sometimes at the end of a long course of intensive therapy, although the intensity of the treatment does not define the degree of follow-up care needed. Children and adolescents who have a short treatment phase can have a great need for follow-up care due to treatment-related late effects. In any case, follow-up care topics (e.g. possible late effects) should be included in the psychosocial treatment plan early on. Thus, final psychosocial diagnostics and counselling should be conducted in the acute clinic and support the transition to follow-up care.

The initiation, coordination and implementation of psychosocial follow-up care includes the following aspects:

- Psychosocial follow-up within the framework of multidisciplinary follow-up care
- Monitoring psychosocial development trajectory
- Early planning and coordination of outpatient and inpatient rehabilitation
- Networking with outpatient and inpatient follow-up care institutions and providers (regional and national)
- Counselling on dealing with possible late effects
- Preparation and organisation of targeted support measures for cognitive and other late effects
- Support in coping with fear of recurrence and progression
- Measures to aid social, school and workplace integration
- Measures to prevent psychosomatic, emotional and social late effects
- Preparation for the transition to long-term follow-up care in adulthood
- Organisation of rehabilitation measures and other provisions for grieving relatives

Patients with neuropsychological late effects also have a special need for interventions that focus not only on learning difficulties, but also on aspects of emotional and social resource enhancement (*Barrera & Schulte, 2009; Bruce et al., 2012; Butler, Sahler, et al., 2008*).

Parents and siblings also have clear psychosocial problems (*Kazak et al., 2004; Kusch et al., 1999; Meyler, Guerin, Kiernan, & Breatnach, 2010; Prchal & Landolt, 2009; Taieb, Moro, Baubet, Revah-Levy, & Flament, 2003; Van Dongen-Melman, 1995*) that require therapeutic measures dependent on their needs.

Specific aspects of stress and the associated needs of adolescents and young adults (AYAS) after cancer in childhood and adolescence give rise to special challenges in their follow-up care, too (*Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG), 2006; Larsson, Mattsson, & von Essen, 2010; Quinn, Goncalves, Sehovic, Bowman, & Reed, 2015; Seitz, Besier, & Goldbeck, 2009*). This also applies to the rising number of adolescents and young adults with significant physical and mental health risks after cancer in childhood or adolescence (*Krull et al., 2010; Schultz et al., 2007; Zebrack, Mills, & Weitzman, 2007*).

## 7.2 Current provisions and structures in psychosocial follow-up care<sup>8</sup>

### **(1) Outpatient follow-up care/ outpatient rehabilitation**

Nationally and internationally, there are widely differing concepts for the implementation of psychosocial outpatient follow-up care. Alongside various, mostly multiprofessional and interdisciplinary models for follow-up care in the first 5-10 years after diagnosis (often referred to as acute or short-term follow-up care), which are primarily located in treating clinics, in recent years, clinical experience and numerous research findings have made it abundantly clear that there is an additional need for linked-up, multiprofessional concepts in long-term follow-up care. A successful transition to long-term care for adults plays a central role here.

An overview of follow-up care services or projects in Germany, Austria and Switzerland is available online and given in appendix C.

### **(2) Inpatient follow-up care: family oriented rehabilitation, rehabilitation for adolescents and young adults, neurological rehabilitation**

The implementation of specific inpatient rehabilitation measures for families, adolescents and young adults is an integral part of the treatment concept in paediatric oncology and haematology. Psychosocial aspects are of great importance in these measures (*H. Häberle, Schwarz, & Mathes, 1997; H. Häberle, Weiss, Fellhauer, & Schwarz, 1991; Inhestern et al., 2017; Leidig, Maier, Niethammer, Niemeyer, & Rau, 2001; Mathes, 1998*). Patients with severe neurological and neuropsychological deficits receive treatment in inpatient neurological rehabilitation units.

### **(3) Seminars, camps und mentoring projects**

Additional options for promoting the process of coping with the disease and psychosocial reintegration have been established with information events for patients with a range of symptoms, family seminars and seminars for young adults (*Kröger, 2005; Kröger & Lilienthal, 2001*). Moreover, free-time and vacation camps support the exchange of experiences between patients and siblings of all age groups.

Mentoring programmes and other services offered by 'survivors' organisations are aimed at strengthening the exchange of information and experiences among those affected.

Grief seminars are offered for parents and siblings of children who have died.

An overview of current services in Germany, Austria and Switzerland is available online and can be found in appendix C.

### **(4) Information materials**

There is a wealth of age-specific information material covering different topics in follow-up care for children, adolescents and young adults with cancer and their relatives. Special follow-up care brochures have been created for some disease pictures. Other central topics are, for example, *school reintegration* and *driving ability* with and after a brain tumour. A collection of German-language materials and their availability on the internet is given in appendix C.

---

<sup>8</sup> A collection of current follow-up care provisions (for all subitems) including addresses for German-speaking countries can be found under: <https://www.kinderkrebsinfo.de/nachsorgeangebote>



Some guides and brochures from English-speaking countries are also recommended (*Edwards, Marshall, & Haeems, 2015; Keenie, Hobbie, & Ruccione, 2012, see also appendix A; Larcombe, Eiser, Davies, & Gerrard, 2007, 2015, 2018*); however, there is no guarantee of completeness here or in appendix C.

**Summing up**, it must be noted that the needs of survivors must still be assessed as greater than the current provision, despite the numerous initiatives and concepts that have been implemented in many places.

*Tallen et al. (2015)* also note in their review that more evidence-based knowledge and also competence and strategies are needed to cater for the individual physical and psychosocial needs of survivors and enable them to experience a high quality of life and participation in society. Accordingly, aspects of follow-up care should also be central elements in the training and further training of paediatric oncology personnel (*see for example Shapiro et al., 2016*).

## CONCLUDING REMARKS

In the context of the holistic treatment concept in paediatric oncology and haematology, psychosocial care supports humanitarian aspects in patient care (*J.C. Holland & Lewis 2001*) and thus contributes significantly to the improvement of the quality of life, patient satisfaction and promoting the health of individual family members.

Psychosocial support of patients and their relatives is the expression of an ethical commitment (*Labouvie & Bode, 2006*) in view of the serious impact of the cancer and treatment on the life context and life perspective of the child/adolescent.

Psychosocial treatment measures also help to avoid psychological and social late effects and the resulting costs, and are therefore relevant in the health policy context (*Calaminus, 2000; Carlson & Bultz, 2003; Janicke & Hommel, 2016; Schumacher, 2004*).

Further research is needed for the quality development of care concepts, which are based on a continuing process of integrating research findings and clinical expertise. Research is needed for example on the effectiveness of specific interventions for quality of life and emotional adjustment, and the identification of risk factors regarding psychosocial reintegration.

The guideline presented here is intended to serve the drafting of quality standards and the guaranteeing of psychosocial care for children, adolescents and young adults with cancer and their families. It is meant as a contribution towards greater transparency and as a practical guide. The overall aim is to support the further development and specification of good clinical practice in paediatric oncology and haematology.

*The S3- guideline "Psychosocial Care in Paediatric Oncology and Haematology" by PSAPOH/GPOH is published as an unabridged version and with additional literature to individual chapters including diagnostic procedures at <http://www.awmf.org/leitlinien/detail/ll/025-002.html>. The unabridged version was agreed in consensus with the panel of experts. This text is an adapted version.*

## References

- Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG). (2006). Closing the gap: Research and cancer care imperatives for adolescents and young adults with cancer. Retrieved from <https://www.cancer.gov/types/aya/research/ayao-august-2006.pdf>
- Ahlström, G. (2007). Experiences of loss and chronic sorrow in persons with severe chronic illness. *Journal of Nursing and Healthcare of Chronic Illness*, 16(3a), 76-83.
- Association of Oncology Social Work (AOSW). (2012). Standards of practice in oncology work. Retrieved from <http://www.aosw.org/docs/StandardsOfPractice.pdf>
- Barrera, M., & Schulte, F. (2009). A group social skills intervention program for survivors of childhood brain tumors. *Journal of Pediatric Psychology*, 34(10), 1108-1118. doi:10.1093/jpepsy/jsp018
- Bearison, D. J., & Mulhern R.K. (Eds.). (1994). *Pediatric psychooncology: Psychological perspectives on children with cancer*. New York: Oxford University Press.
- Berthold, F., Bode, G., Böcker, A., Christaras, A., & Creutzig, U. (2006). Maßnahmen zur Qualitätssicherung für die stationäre kinderonkologische Versorgung. *Klinische Pädiatrie*, 118, 293-295.
- Bettge, S., & Ravens-Sieberer, U. (2003). Schutzfaktoren für die psychische Gesundheit von Kindern und Jugendlichen - empirische Ergebnisse zur Validierung eines Konzepts. *Gesundheitswesen*, 65, 167-172.
- Boulet-Craig, A., Robaey, P., Laniel, J., Bertout, L., Drouin, S., Krajinovic, M., . . . Lippe, S. (2018). DIVERGT screening procedure predicts general cognitive functioning in adult long-term survivors of pediatric acute lymphoblastic leukemia: A PETALE study. *Pediatric Blood and Cancer*, 65(9), e27259. doi:10.1002/pbc.27259
- Bruce, B. S., Newcombe, J., & Chapman, A. (2012). School liaison program for children with brain tumors. *Journal of Pediatric Oncology Nursing*, 29(1), 45-54. doi:10.1177/1043454211432296
- Bultz, B. D., & Carlson, L. E. (2006). Emotional distress: the sixth vital sign-future directions in cancer care. *Psycho-Oncology*, 15(2), 93-95. doi:10.1002/pon.1022
- Butler, R. W., Sahler, O. J., Askins, M. A., Alderfer, M. A., Katz, E. R., Phipps, S., & Noll, R. B. (2008). Interventions to improve neuropsychological functioning in childhood cancer survivors. *Developmental Disabilities Research Reviews*, 14(3), 251-258. doi:10.1002/ddrr.33
- Calaminus, G. (2000). Lebensqualität in der Pädiatrischen Onkologie. In U. Ravens-Sieberer & C. Alarcos (Eds.), *Lebensqualität und Gesundheitsökonomie in der Medizin*. Landsberg: Ecomed Verlag.
- Calaminus, G., Weinspach, S., Teske, C., & Göbel, U. (2007). Quality of survival in children and adolescents after treatment for childhood cancer: the influence of reported late effects on health related quality of life. *Klinische Pädiatrie*, 219(3), 152-157. doi:10.1055/s-2007-973846
- Canadian Association of Psychosocial Oncology. (2010). Standards of psychosocial health services for persons with cancer and their families. Retrieved from <http://www.capo.ca/pdf/CAPOstandards.pdf>
- Caplin, D. A., Smith, K. R., Ness, K. K., Hanson, H. A., Smith, S. M., Nathan, P. C., . . . Oeffinger, K. C. (2017). Effect of population socioeconomic and health system factors on medical care of childhood cancer survivors: A report from the Childhood Cancer Survivor Study. *Journal of Adolescent and Young Adult Oncology*, 6(1), 74-82. doi:10.1089/jayao.2016.0016
- Carlson, L. E., & Bultz, B. D. (2003). Benefits of psychosocial oncology care: Improved quality of life and medical cost offset. *Health and Quality of Life Outcomes*, 1, 8.
- Cox, A. D. (1994). Child and adolescent Psychiatry - modern approaches. In M. Rutter, E. Tayler, & L. Hersov (Eds.), *Diagnostic Appraisal* (pp. 22-33). Blackwell, London, Paris, Melbourne, Vienna.
- Creutzig, U., Jürgens, H., Herold, R., Göbel, U., & Henze, G. (2004). Concepts of the society of paediatric oncology and haematology (GPOH) and the german competence network in paediatric oncology and haematology for the quality controlled development in paediatric oncology. *Klinische Pädiatrie*, 216(6), 379-383. doi:10.1055/s-2004-832383
- Di Gallo, A. (2004). Kinderpsychoonkologie. In P. Imbach & T. Kühne (Eds.), *Kompendium Kinderonkologie* (pp. 300-324). Heidelberg: Springer Verlag.
- Dilling, H., Mombour, W., & Schmidt, M.H. (Hrsg). (2004). *Internationale Klassifikation psychischer Störungen (ICD-10 V). Klinisch-diagnostische Leitlinien*. (5 ed.). Bern: Huber.

- Edwards, L., Marshall, L., & Haeems, G. (2019). Returning to school. A teacher's guide for pupils with brain tumours, during and after treatment. 3<sup>rd</sup> edition. Retrieved from <https://www.cerebra.org.uk/help-and-information/guides-for-parents/returning-to-school-a-teachers-guide-for-pupils-with-brain-tumours-during-and-after-treatment/>
- Fischer, G., & Riedesser, P. (1999). Lehrbuch der Psychotraumatologie (Vol. 2). München: Ernst Reinhardt Verlag.
- Friend, A. J., Feltbower, R. G., Hughes, E. J., Dye, K. P., & Glaser, A. W. (2018). Mental health of long-term survivors of childhood and young adult cancer: A systematic review. *International Journal of Cancer*, *143*(6), 1279-1286. doi:10.1002/ijc.31337
- Germann, J. N., Leonard, D., Stuenzi, T. J., Pop, R. B., Stewart, S. M., & Leavey, P. J. (2015). Hoping is coping: A guiding theoretical framework for promoting coping and adjustment following pediatric cancer diagnosis. *Journal of Pediatric Psychology*, *40*(9), 846-855. doi:10.1093/jpepsy/jsv027
- Grootenhuis, M. A., & Last, B. F. (1997). Adjustment and coping by parents of children with cancer: A review of the literature. *Supportive Care in Cancer*, *5*(6), 466-484.
- Häberle, H., Schwarz, R., & Mathes, L. (1997). Familienorientierte Betreuung bei krebskranken Kindern und Jugendlichen. *Praxis der Kinderpsychologie und Kinderpsychiatrie*, *46*, 405-419.
- Häberle, H., Weiss, H., Fellhauer, S., & Schwarz, R. (1991). Familienorientierte Nachsorge als Maßnahmen der Rehabilitation und sekundären Prävention für krebskranke Kinder und ihre Familien. *Klinische Pädiatrie*, *203*(4), 206-210.
- Holland, J. C., & Lewis, S. (2001). *The human side of cancer: Living with hope, coping with uncertainty*. New York: Harper Collins Publishers.
- Houtzager, B. A., Grootenhuis, M. A., & Last, B. F. (1999). Adjustment of siblings to childhood cancer: A literature review. *Supportive Care in Cancer*, *7*(5), 302-320.
- Howard Sharp, K. M., Willard, V. W., Barnes, S., Tillery, R., Long, A., Phipps, S., . . . Grayson, N. H. (2017). Emotion socialization in the context of childhood cancer: Perceptions of parental support promotes posttraumatic growth. *Journal of Pediatric Psychology*, *42*(1), 95-103. doi:10.1093/jpepsy/jsw062
- Howard Sharp, K. M., Willard, V. W., Okado, Y., Tillery, R., Barnes, S., Long, A., & Phipps, S. (2015). Profiles of connectedness: Processes of resilience and growth in children with Cancer. *Journal of Pediatric Psychology*, *40*(9), 904-913. doi:10.1093/jpepsy/jsv036
- Hürter, A. (1990). Psychische und soziale Belastungen und der Wunsch nach professioneller Hilfe bei verschiedenen chronischen Erkrankungen. Krankheitsverarbeitung bei Kindern und Jugendlichen. In I. Seiffge-Krenke (Ed.), *Jahrbuch der medizinischen Psychologie*. Berlin: Springer.
- Inhestern, L., Beierlein, V., Krauth, K. A., Rolfes, U., Schulte, T., Berger, D., . . . Bergelt, C. (2017). [Burden of Parents of Pediatric Cancer Patients in Pediatric-oncological Rehabilitation]. *Prax Kinderpsychol Kinderpsychiatr*, *66*(3), 179-193. doi:10.13109/prkk.2017.66.3.179
- Janicke, D. M., & Hommel, K. A. (2016). Introduction to special section on the cost-effectiveness and economic impact of pediatric psychology interventions. *Journal of Pediatric Psychology*, *41*(8), 831-834. doi:10.1093/jpepsy/jsw033
- Kazak, A. E. (1992). Social context of coping with childhood illness: Family systems and social support. In A. LaGreca, L. Siegel, J. Wallander, & C. Walker (Eds.), *Stress and Coping in Child Health*. (pp. 262-278). New York: Guilford Press.
- Kazak, A. E., Alderfer, M., Rourke, M. T., Simms, S., Streisand, R., & Grossman, J. R. (2004). Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *Journal of Pediatric Psychology*, *29*(3), 211-219.
- Kazak, A. E., Barakat, L. P., Meeske, K., Christakis, D., Meadows, A. T., Casey, R., . . . Stuber, M. L. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting and Clinical Psychology*, *65*(1), 120-129.
- Kazak, A. E., Boyer, B. A., Brophy, P., Johnson, K., Scher, C. D., Covelman, K., & Scott, S. (1995). Parental perceptions of procedure-related distress and family adaptation in childhood leukemia. *Child Health Care*, *24*(3), 143-158. doi:10.1207/s15326888chc2403\_1
- Kazak, A. E., Cant, M. C., Jensen, M. M., McSherry, M., Rourke, M. T., Hwang, W. T., . . . Lange, B. J. (2003). Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed pediatric oncology patients. *Journal of Clinical Oncology*, *21*(17), 3220-3225. doi:10.1200/JCO.2003.12.156
- Keenie, N., Hobbie, W., & Ruccione, K. S. (2012). *Childhood cancer survivors: A practical guide to your future*. (3rd ed.). Bellingham: Childhood Cancer Survivors.
- Kröger, L. (2005). *Lebensqualität krebskranker Kinder, krebskranker Erwachsener und deren Angehörigen: Ergebnisse der ambulanten Nachsorge und Rehabilitation*. Lengrich: Pabst Science Publishers.

- Kröger, L., & Lilienthal, S. (2001). Vernetzung stationärer und ambulanter Versorgung krebskranker Kinder und deren Familien in Hamburg. Eine Bilanz nach 10 Jahren. *PSAPOH-Journal*, 4(1), 27-31.
- Krull, K. R., Huang, S., Gurney, J. G., Klosky, J. L., Leisenring, W., Termuhlen, A., . . . Hudson, M. M. (2010). Adolescent behavior and adult health status in childhood cancer survivors. *Journal of Cancer Survivorship*, 4(3), 210-217. doi:10.1007/s11764-010-0123-0
- Kunin-Batson, A., Lu, X., Balsamo, L., Graber, K., Devidas, M., Hunger, S. P., . . . Kadan-Lottick, N. S. (2016). Prevalence and predictors of anxiety and depression after completion of chemotherapy for childhood acute lymphoblastic leukemia: A prospective longitudinal study. *Cancer*, 122(10), 1608-1617. doi:10.1002/cncr.29946
- Kupst, M. J. (1992). Long-term family coping with acute lymphoblastic leukemia in childhood. In A. LaGreca, L. Siegel, J. Wallander, & C. Walker (Eds.), *Stress and Coping in Child Health* (pp. 242-261). New York: Guilford Press.
- Kusch, M., Labouvie, H., Fleischhack, G., & Bode, U. (1996). *Stationäre psychologische Betreuung in der Pädiatrie*. Weinheim: Psychologie Verlagsunion.
- Kusch, M., Labouvie, H., Jager, R. S., & Bode, U. (1997). Psychology of patient management: evaluation and quality assurance of psychosocial management in pediatric oncology. *Gesundheitswesen*, 59(2), 87-94.
- Kusch, M., Labouvie, H., Langer, T., Winkler von Mohrenfels, U., Topf, R., & et al. (1999). *Psychosoziale Folgen von Krebs im Kindes- und Jugendalter: Empirisch fundierte Erkenntnisse und begründbarer rehabilitativer Bedarf*. Landau: Verlag Empirische Pädagogik.
- Labouvie, H. (2005). Psychosoziale Betreuung krebskranker Kinder und ihrer Familien. Evaluation und Optimierung einer Versorgungskonzeption. In Deutsche-Leukämie-Forschungshilfe - Aktion für Krebskranke Kinder e.V. (Ed.): Wir 3.
- Labouvie, H., & Bode, G. (2006). Psychosoziale Unterstützung von Patienten und ihren Angehörigen. In H. Gadner, G. Gaedicke, C. Niemeyer, & J. Ritter (Eds.), *Pädiatrische Hämatologie und Onkologie*. Heidelberg: Springer Verlag.
- Langer, G., Meerpohl, J. J., Perleth, M., Gartlehner, G., Kaminski-Hartenthaler, A., & Schunemann, H. (2012). [GRADE guidelines: 1. Introduction - GRADE evidence profiles and summary of findings tables]. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswes*, 106(5), 357-368. doi:10.1016/j.zefq.2012.05.017
- Larcombe, I., Eiser, C., Davies, H., & Gerrard, M. (2007, 2015, 2018). Welcome back! A guide for teachers helping children and young people returning to school after a diagnosis of cancer. Retrieved from <https://www.cclg.org.uk/publications/School/Welcome-back!/WLCMBACK>
- Larsson, G., Mattsson, E., & von Essen, L. (2010). Aspects of quality of life, anxiety, and depression among persons diagnosed with cancer during adolescence: a long-term follow-up study. *European Journal of Cancer*, 46(6), 1062-1068. doi:10.1016/j.ejca.2010.01.021
- Leidig, E., Maier, S., Niethammer, D., Niemeyer, C., & Rau, J. (2001). Positionspapier zur familienorientierten Rehabilitation bei krebskranken Kindern. Retrieved from [http://www.katharinenhoehe.de/fileadmin/downloads/reh-antrag/Katha\\_Positionspapier\\_familien\\_Reha.pdf](http://www.katharinenhoehe.de/fileadmin/downloads/reh-antrag/Katha_Positionspapier_familien_Reha.pdf)
- Leiss, U. (2011). Neuropsychological assessment and intervention in pediatric neuro-oncology. *Memo-Magazine of European Medical Oncology*, 3(11), 2. doi:10.1007/s12254-011-0314-z
- Mathes, L. (1998). *Programmevaluation der stationären, familienorientierten Rehabilitation und Entwicklung eines Qualitätssicherungssystems in der Rehabilitationsklinik Katharinenhöhe.*, Universität Heidelberg, Heidelberg.
- Meyler, E., Guerin, S., Kiernan, G., & Breatnach, F. (2010). Review of family-based psychosocial interventions for childhood cancer. *Journal of Pediatric Psychology*, 35(10), 1116-1132. doi:10.1093/jpepsy/jsq032
- Michel, G., Rebholz, C. E., von der Weid, N. X., Bergstraesser, E., & Kuehni, C. E. (2010). Psychological distress in adult survivors of childhood cancer: the Swiss Childhood Cancer Survivor study. *Journal of Clinical Oncology*, 28(10), 1740-1748. doi:10.1200/JCO.2009.23.4534
- Moyer, K. H., Willard, V. W., Gross, A. M., Netson, K. L., Ashford, J. M., Kahalley, L. S., . . . Conklin, H. M. (2012). The impact of attention on social functioning in survivors of pediatric acute lymphoblastic leukemia and brain tumors. *Pediatric Blood & Cancer*, 59(7), 1290-1295. doi:10.1002/pbc.24256
- NCCN - National Comprehensive Cancer Network. (2007). Distress management. Practice Guidelines in Oncology. Retrieved from [www.nccn.org/professionals/physician\\_gls](http://www.nccn.org/professionals/physician_gls)
- Patenaude, A. F., & Kupst, M. J. (2005). Psychosocial functioning in pediatric cancer. *Journal of Pediatric Psychology*, 30(1), 9-27.
- Pelletier, W., & Bona, K. (2015). Assessment of financial burden as a standard of care in pediatric oncology. *Pediatric Blood and Cancer*, 62 Suppl 5, S619-631. doi:10.1002/pbc.25714

- Prchal, A., & Landolt, M. A. (2009). Psychological interventions with siblings of pediatric cancer patients: a systematic review. *Psycho-Oncology*, *18*(12), 1241-1251. doi:10.1002/pon.1565
- Quinn, G. P., Goncalves, V., Sehovic, I., Bowman, M. L., & Reed, D. R. (2015). Quality of life in adolescent and young adult cancer patients: a systematic review of the literature. *Patient Related Outcome Measures*, *6*, 19-51. doi:10.2147/PROM.S51658
- Resch, F. (1999). *Entwicklungspsychopathologie des Kindes- und Jugendalters. Ein Lehrbuch*. (Vol. 2). Weinheim: Psychologie Verlagsunion.
- Rossig, C., Juergens, H., Schrappe, M., Moericke, A., Henze, G., von Stackelberg, A., . . . Creutzig, U. (2013). Effective childhood cancer treatment: the impact of large scale clinical trials in Germany and Austria. *Pediatric Blood and Cancer*, *60*(10), 1574-1581. doi:10.1002/pbc.24598
- Schreiber-Gollwitzer, B., & Gollwitzer, K. (2007). Diagnostische und differenzialdiagnostische Abwägungen zur Einschätzung kindlicher Reaktionsweisen im Rahmen der psychosozialen Versorgung in der pädiatrischen Onkologie und Hämatologie. *Klinische Pädiatrie*, *219*(6), 372-379. doi:10.1055/s-2007-985872
- Schreiber-Gollwitzer, B. M., & Schröder, H. M. (2012). Ressourcen- und Belastungsprofil. Retrieved from [https://www.kinderkrebsinfo.de/fachinformationen/psapoh/drg\\_aktuelles/index\\_ger.html](https://www.kinderkrebsinfo.de/fachinformationen/psapoh/drg_aktuelles/index_ger.html)
- Schreiber-Gollwitzer, B. M., Schröder, H. M., Griebmeier, B., Labouvie, H., & Lilienthal, S. (2003). Quantitative and qualitative evaluation of psychosocial care for patients in pediatric oncology and hematology--a multicenter study on behalf of the PSAPOH. *Klinische Pädiatrie*, *215*(3), 171-176. doi:10.1055/s-2003-39377
- Schreiber-Gollwitzer, B. M., Schröder, H. M., & Niethammer, D. (2002). Psychosoziale Begleitung von Kindern und Jugendlichen mit malignen Erkrankungen. *Monatsschrift Kinderheilkunde*, *150*, 954-965.
- Schröder, H. M., Lilienthal, S., Schreiber-Gollwitzer, B. M., & Griebmeier, B. (2006). Psychosoziale Versorgung in der pädiatrischen Onkologie. *Kurzgefasste interdisziplinäre Leitlinien* (pp. 457-467): Deutsche Krebsgesellschaft e.V., Zuckerschwerdt Verlag.
- Schultz, K. A., Ness, K. K., Whitton, J., Recklitis, C., Zebrack, B., Robison, L. L., . . . Mertens, A. C. (2007). Behavioral and social outcomes in adolescent survivors of childhood cancer: a report from the childhood cancer survivor study. *Journal of Clinical Oncology*, *25*(24), 3649-3656. doi:10.1200/JCO.2006.09.2486
- Schumacher, A. (2004). Stellenwert der Psychoonkologie im neuen deutschen Gesundheitssystem. *Der Onkologe*, *10*, 98-102.
- Seitz, D. C., Besier, T., & Goldbeck, L. (2009). Psychosocial interventions for adolescent cancer patients: a systematic review of the literature. *Psycho-Oncology*, *18*(7), 683-690. doi:10.1002/pon.1473
- Shapiro, C. L., Jacobsen, P. B., Henderson, T., Hurria, A., Nekhlyudov, L., Ng, A., . . . Rowland, J. H. (2016). ReCAP: ASCO core curriculum for cancer survivorship education. *Journal of Oncology Practice*, *12*(2), 145, e108-117. doi:10.1200/JOP.2015.009449
- Signorelli, C., Wakefield, C. E., Fardell, J. E., Wallace, W. H. B., Robertson, E. G., McLoone, J. K., & Cohn, R. J. (2017). The impact of long-term follow-up care for childhood cancer survivors: A systematic review. *Critical Reviews in Oncology/ Hematology*, *114*, 131-138. doi:10.1016/j.critrevonc.2017.04.007
- SIOOP - Working Committee on Psychosocial Issues in Pediatric Oncology. (Guidelines: 1993-2004)/and ICCPO. (2002). Childhood cancer - Guidelines for standards of treatment & care. Retrieved from <http://www.iccipo.org/articles/psychosocial.html>, [http://www.iccipo.org/articles/standards\\_of\\_care.html](http://www.iccipo.org/articles/standards_of_care.html)
- Sonneck, G., Kapusta, N., Tomandl, G., & Voracek, M. (2016). *Krisenintervention und Suizidverhütung* (3rd ed.): UTB GmbH.
- Taieb, O., Moro, M. R., Baubet, T., Revah-Levy, A., & Flament, M. F. (2003). Posttraumatic stress symptoms after childhood cancer. *European Child & Adolescent Psychiatry*, *12*, 255-264.
- Tallen, G., Resch, A., Calaminus, G., Wiener, A., Leiss, U., Pletschko, T., . . . Rutkowski, S. (2015). Strategies to improve the quality of survival for childhood brain tumour survivors. *European Journal of Paediatric Neurology*, *19*(6), 619-639. doi:10.1016/j.ejpn.2015.07.011
- Toffalini, E., Veltri, A., & Cornoldi, C. (2015). Metacognitive aspects influence subjective well-being in parents of children with cancer. *Psycho-Oncology*, *24*(2), 175-180. doi:10.1002/pon.3622
- Topf, R., Trimmel, J., Vaschalek, K., Felsberger, C., & Gadner, H. (1994). Das Psychosoziale Betreuungskonzept der pädiatrischen Onkologie des St. Anna Kinderspitals. In: Österreichische Gesellschaft für Psychoonkologie (Ed.), *Jahrbuch der Psychoonkologie* (pp. 15-39). Wien: Springer.
- Tröster, H. (2010). Eltern-Belastungs-Inventar. Deutsche Version des Parenting Stress Index (PSI) von R. R. Abidin. Göttingen: Hogrefe.
- Turner, J. K., Hutchinson, A., & Wilson, C. (2018). Correlates of post-traumatic growth following childhood and adolescent cancer: A systematic review and meta-analysis. *Psycho-Oncology*, *27*(4), 1100-1109. doi:10.1002/pon.4577

- Van Der Plas, E., Erdman, L., Nieman, B. J., Weksberg, R., Butcher, D. T., O'Connor D, L., . . . Spiegler, B. J. (2018). Characterizing neurocognitive late effects in childhood leukemia survivors using a combination of neuropsychological and cognitive neuroscience measures. *Child Neuropsychology*, 24(8), 999-1014. doi:10.1080/09297049.2017.1386170
- Van Dongen-Melman, J. E. W. M. (1995). *On surviving childhood cancer. Late psychosocial consequences for patients, parents and siblings*. Alblasterdam: Haveka.
- Van Schoors, M., Caes, L., Knoble, N. B., Goubert, L., Verhofstadt, L. L., & Alderfer, M. A. (2017). Systematic review: associations between family functioning and child adjustment after pediatric cancer diagnosis: A meta-analysis. *Journal of Pediatric Psychology*, 42(1), 6-18.
- Vance, Y., & Eiser, C. (2004). Caring for a child with cancer - a systematic review. *Pediatric Blood and Cancer*, 42(3), 249-253. doi:10.1002/pbc.10440
- Wiener, L., Kazak, A. E., Noll, R. B., Patenaude, A. F., & Kupst, M. J. (2015). Standards for the psychosocial care of children with cancer and their families: An Introduction to the special issue. *Pediatric Blood and Cancer*, 62 Suppl 5, S419-424. doi:10.1002/pbc.25675
- Wiener, L., Viola, A., Kearney, J., Mullins, L. L., Sherman-Bien, S., Zadeh, S., . . . Lone Parent Study, G. (2016). Impact of caregiving for a child with cancer on parental health behaviors, relationship quality, and spiritual faith: Do lone parents fare worse? *Journal of Pediatric Oncology Nursing*, 33(5), 378-386. doi:10.1177/1043454215616610
- Willard, V. W., Hostetter, S. A., Hutchinson, K. C., Bonner, M. J., & Hardy, K. K. (2016). Benefit finding in maternal caregivers of pediatric cancer survivors: A mixed methods approach. *Journal of Pediatric Oncology Nursing*, 33(5), 353-360.
- Zebrack, B. J., Mills, J., & Weitzman, T. S. (2007). Health and supportive care needs of young adult cancer patients and survivors. *Journal of Cancer Survivorship*, 1(2), 137-145. doi:10.1007/s11764-007-0015-0
- Zegaczewski, T., Chang, K., Coddington, J., & Berg, A. (2016). Factors related to healthy siblings' psychosocial adjustment to children with cancer: An Integrative Review. *Journal of Pediatric Oncology Nursing*, 33(3), 218-227. doi:10.1177/1043454215600426
- Zeltzer, L. K., Dolgin, M. J., Sahler, O. J., Roghmann, K., Barbarin, O. A., Carpenter, P. J., . . . Sargent, J. R. (1996). Sibling adaptation to childhood cancer collaborative study: health outcomes of siblings of children with cancer. *Medical and Pediatric Oncology*, 27(2), 98-107. doi:10.1002/(SICI)1096-911X(199608)27:2<98::AID-MPO6>3.0.CO;2-O

<b>Versions-Nummer:</b>	<b>5.0</b>
<b>version number:</b>	
<b>Erstveröffentlichung:</b>	<b>01/1997</b>
<b>Initial release:</b>	
<b>Überarbeitung von:</b>	<b>12/2019</b>
<b>Revision of:</b>	
<b>Nächste Überprüfung geplant:</b>	<b>12/2024</b>
<b>Review planned:</b>	

**Versions-Nummer:** 5.0  
**version number:**

**Erstveröffentlichung:** 01/1997  
**Initial release:**

**Überarbeitung von:** 12/2019  
**Revision of:**

**Nächste Überprüfung geplant:** 12/2024  
**Review planned:**

The AMWF records and publishes the guidelines of the professional associations with the greatest possible care - yet the AMWF can not assume any responsibility for the accuracy of the content. **Espacially dosage information of the manufacturer must always be considered!**

Die AMWF erfasst und publiziert die Leitlinien der Fachgesellschaften mit größtmöglicher Sorgfalt - dennoch kann die AMWF für die Richtigkeit des Inhalts keine Verantwortung übernehmen. **Insbesondere bei Dosierungsangaben sind stets die Angaben der Hersteller zu beachten!**

authorized for electronic publication: AMWF online