

PNAE

**Paediatric Nursing Associations
of Europe**

Palliative nursing care of children and young people across Europe

Results of a postal survey in August 2016

*(presented at the 28th PNAE-meeting
in Paris/France on 8th December 2016)*

We are convinced that ...

- *... every child and young person has the right to expect good palliative care to be provided whether it is in a hospital setting or in a home environment.*
- *... all children and young people with life-limiting and terminal illness should receive the care they need.*

IMPACT: standards for paediatric palliative care in Europe

- When we discuss **paediatric palliative care (PPC)** we refer to the **definition of the World Health Organization (WHO 1998 & 2002)** which was adopted by IMPACT:
- *Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.*
- *It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.*
- *Healthcare providers must evaluate and alleviate a child's physical, psychological and social distress.*
- *Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*
- *It can be provided in tertiary care facilities, in community health centres and even in children's homes.*
- ...

Life-limiting illness is defined as a condition where premature death is usual, for example, Duchenne muscular dystrophy.

Life-threatening illness is one where there is a high probability of premature death due to severe illness, but there is also a chance of longterm survival to adulthood. For example, children receiving cancer treatment or admitted to intensive care after an acute injury.

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European Journal of Palliative Care



THE JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

IMPACT: standards for paediatric palliative care in Europe

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2007; 14(3)

IMPACT: standards for paediatric palliative care in Europe

IMPACT recommends that these standards be implemented in all European countries !

The key principles of “IMPACT: standards for paediatric palliative care in Europe” are our guideline to undertake a survey across Europe.

- We want to **identify if the minimum standards of palliative nursing care are implemented** across Europe as well as to identify good practice.
- The aim is to **establish good practice recommendations** to underpin the palliative nursing care of children and young people in all health care settings.

IMPACT: standards for paediatric palliative care in Europe

... in March 2006

... a group of healthcare professionals from Europe, Canada, Lebanon and the

USA

... met in Trento, Italy

... to discuss the current situation of paediatric palliative care in Europe

... **I**nternational **M**eeting for **P**alliative **C**are in **C**hildren, **T**rento (IMPACT)

Result:

... a united document for Europe

... defining and identifying **standards of care for children with life-limiting terminal illness**

Postal survey

13 countries responded (*December 2016*)

Key areas:

- *Organisation of services*
- *Paediatric Palliative care management*
- *Ethical and legal rights of children in paediatric palliative care*

Responses from ...

- Austria (AT)
- Belgium (BE)
- Croatia (HR)
- Denmark (DK)
- Finland (FI)
- Germany (DE)
- Greece (GR)
- Netherlands (NL)
- Norway (NO)
- Portugal (PT)
- Sweden (SE)
- Turkey (TR)
- United Kingdom (GB)

No responses from ...

- Armenia (AM)
- Cyprus (CY)
- Czech Republic (CZ)
- Estonia (EE)
- France (FR)
- Hungary (HU)
- Iceland (IS)
- Ireland (IE)
- Italy (IT)
- Lithuania (LT)
- Luxemburg (LU)
- Malta (MT)
- Poland (PL)
- Romania (RO)
- Republic Serbia (RS)
- Slovakia (SK)
- Slovenia (SI)
- Spain (ES)
- Switzerland (CH)

Organisation of services (I)

National Guidelines PPC exist

YES (DE, DK, GB, NL, NO, SE) **6**

NO (AT, BE, FI, GR, HR, PT, TR) **7**

Use of WHO Definition PPC

YES

(AT, BE, DE, DK, GB, GR, NL, NO, SE, TR) **10**

NO (FI, HR, PT) **3**

Guidelines on 3 levels of PPC

YES (BE, GB, NL, SE) **4**

NO (AT, DE, DK, FI, GR, HR, NO, PT, TR) **9**

Minimum core standards PPC

YES (AT, BE, DE, GB, GR, NL, SE, TR) **8**

NO (DK, FI, HR, NO, PT) **5**

Organisation of services Units of care

- **The unit of care is the child & family.** Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship
[AT, BE, DE, DK, GB, GR, NL, NO, SE, TR] 10
- **A full range of clinical and educational resources are available** for the child and family, in a format that is appropriate to age, cognitive and educational ability and within a suitable cultural context.
[BE, DE, DK, GB, NL, NO, SE] 7
- **The child and family are included in identifying the needs and priorities for care,** once given as much information as desired regarding disease and treatment options.
[AT, BE, DE, DK, GB, GR, NL, NO, SE, TR] 10

Organisation of services PPC teams (I)

PPC teams

YES (AT, BE, DE, DK, GB, GR, NL, SE) **8**

NO (FI, HR, NO, PT, TR) **5**

Family's care coordinator or key worker in PPC teams

YES (AT, BE, DE, GB, GR, NL, SE, TR) **8**

NO (DK, FI, HR, NO, PT) **5**

Paediatric Nurses

YES

(AT, BE, DE, DK, GB, NL, NO, SE, TR) **9**

NO (BE, FI, GR, HR, NO, PT) **6**

Special qualifications

YES (DE, NL, SE) **3**

NO

(AT, BE, DK, FI, GB, GR, HR, NO, PT, TR) **10**

Organisation of services PPC teams (II)

- *The care team recognises the **individuality of each child and family** and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm.*
[AT, DE, DK, GB, GR, NL, SE] 7
- *The palliative care team has **sufficient expertise** to address the physical, psychological, emotional, spiritual and social needs of the family.*
[AT, DE, DK, GB, GR, NL] 6
- *The skills and **services provided include a physician, nurse, social worker, child therapist or psychologist and a spiritual adviser.***
[AT, DE, DK, GB, GR, NL, SE] 7

Organisation of services PPC teams (III)

- *Professional resources from the **child's own community** are utilised if appropriate.*
[AT, DE, DK, GB, NL, SE] *6*
- *Expert paediatric palliative care support and advice are available to the child and family **24 hours a day, 365 days a year.***
[DE, GR, NL, SE] *4*
- *The care **team ensures continuity of care** at home, in the hospital and in a hospice through planning, sharing strategies and objectives.*
[AT, DE, DK, GB, GR, NL, SE] *7*
- *The direct caretakers provide **psychosocial support and supervision.***
[AT, DE, DK, GB, GR, NL, SE] *7*

PPCmanagement Pain and symptom management

Guidelines

YES (AT, DE, DK, GB, NL, NO, SE) **7**

NO (BE, FI, GR, HR, PT, TR) **6**

Assessment

YES (AT, BE, DE, DK, GB, GR, NL, PT, SE, TR) **10**

NO (FI, HR, NO) **3**

Protocols for adequate treatment

YES (AT, DE, GB, GR, NL, PT, SE, TR) **8**

NO (BE, DK, FI, HR, NO) **5**

Ethical and legal rights of children in paediatric palliative care

Equal access PPC

YES (AT, BE, DE, DK, GR, NL, NO, SE) **8**

NO (FI, GB, HR, PT, TR) **5**

Standard for communication and decision making

YES (BE, DE, GB, NL, PT, SE) **6**

NO (AT, DK, FI, GR, HR, NO, TR) **7**

Ethical and legal rights of children in paediatric palliative care

Evaluation of PPC

YES (BE, DE, NL, NO, PT, SE) **6**

NO (AT, DK, FI, GB, GR, HR, TR) **7**

Structured programme ... care management, respite care and family support

YES (GR, NL, SE) **3**

NO (AT, BE, DE, DK, FI, GB, HR, NO, PT, TR) **10**

Ethical and legal rights of children in paediatric palliative care

Funding of PPC services

- **Province Fund for PPC services (AT)** 1
- **Government (BE, DK, GB, GR, NL, NO, SE)** 7
- **Charitable donations (AT, BE, GB, GR)** 4
- **Health insurances (DE)** 1

Ethical and legal rights Communication and decision making (I)

- **An *honest and open approach* is the basis of all communication and is sensitive and appropriate to the child's age and understanding.**
[BE, DE, GB, NL, PT, SE] **6**
- **Parents are acknowledged as the primary caretakers and are centrally involved in the care and decisions involving their own child.**
[BE, DE, GB, NL, PT, SE] **6**
- **Information is provided for the parents, for the child and for the siblings according to age and understanding. The needs of other relatives are also addressed.**
[DE, GB, NL, PT, SE] **5**

Ethical and legal rights **Communication and decision making (II)**

- *Every child is given the **opportunity to participate in decisions** effecting his or her care, according to age and understanding.*
[GB, NL, PT, SE] 4
- *Situations posing a high risk of conflict are anticipated and **procedures for early communication, therapeutic interventions or ethics consultation** are established.*
[BE, GB, NL, PT, SE] 5
- *Every family is given the **opportunity of consultation with a paediatric specialist** who has particular knowledge of the child's condition, including the treatment and care options available.*
[BE, GB, NL, PT, SE] 5

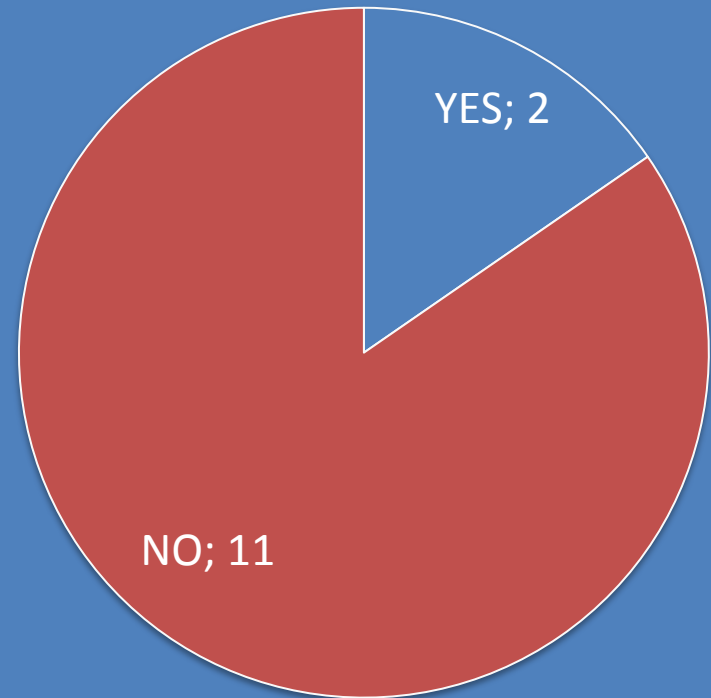
*All written standards of IMPaCCT
are met in the country ...*

No

*(AT, BE, DE, DK,
FI, GR, HR, NO, PT,
SE, TR)* **11**

Yes

(NL, UK) **2**



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