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.

Fiona Smith, RCN (United Kingdom) /Frauke Leupold, BeKD e.V. (Germany) / Ingrid Hankes Drielsma, V&VN (Netherlands)
When we discuss **paediatric palliative care (PPC)** we refer to the **definition of the World Health Organization** (WHO 1998 & 2002) which was adopted by IMPaCCT:

- **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.
IMPaCCT: standards for paediatric palliative care in Europe
IMPaCCT recommends that these standards be implemented in all European countries!

The key principles of “IMPaCCT: 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.

Fiona Smith, RCN (United Kingdom) / Frauke Leupold, BeKD e.V. (Germany) / Ingrid Hankes Drielsma, V&VN (Netherlands)
... 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
... International Meeting for Palliative Care in Children, Trento (IMPaCCT)

Result:

... a united document for Europe

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

Fiona Smith, RCN (United Kingdom) / Frauke Leupold, BeKD e.V. (Germany) / Ingrid Hankes Drielsma, V&VN (Netherlands)
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

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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)

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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)

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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

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Organisation of services (II)

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

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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

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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

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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

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• 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

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• Professional resources from the child’s own community are utilised if appropriate.
  \[\text{[AT, DE, DK, GB, NL, SE]}\]  
  \[6\]

• Expert paediatric palliative care support and advice are available to the child and family **24 hours a day, 365 days a year.**
  \[\text{[DE, GR, NL, SE]}\]  
  \[4\]

• The care **team ensures continuity of care** at home, in the hospital and in a hospice through planning, sharing strategies and objectives.
  \[\text{[AT, DE, DK, GB, GR, NL, SE]}\]  
  \[7\]

• The direct caretakers provide **psychosocial support and supervision.**
  \[\text{[AT, DE, DK, GB, GR, NL, SE]}\]  
  \[7\]
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

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<table>
<thead>
<tr>
<th>Ethical and legal rights of children in paediatric palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equal access PPC</td>
</tr>
<tr>
<td><strong>YES</strong> (AT, BE, DE, DK, GR, NL, NO, SE)</td>
</tr>
<tr>
<td><strong>NO</strong> (FI, GB, HR, PT, TR)</td>
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<tr>
<td>8</td>
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<td>5</td>
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<tr>
<td>Standard for communication and decision making</td>
</tr>
<tr>
<td><strong>YES</strong> (BE, DE, GB, NL, PT, SE)</td>
</tr>
<tr>
<td><strong>NO</strong> (AT, DK, FI, GR, HR, NO, TR)</td>
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<tr>
<td>6</td>
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<td>7</td>
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</tbody>
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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

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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

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• 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

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• 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 ...

Yes

(NL, UK) 2

No

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

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