

# European Journal of Palliative Care



THE JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE



10th Congress of the  
European Association  
for Palliative Care



## CONNECTING DIVERSITY

### Programme and abstracts

Budapest, Hungary, 7–9 June 2007



## Acknowledgements

We wish to express our appreciation for the support provided by:

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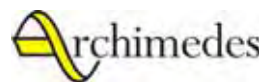
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### SILVER SPONSORS



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### SPONSORS





## CONNECTING DIVERSITY

10th Congress of the European Association for Palliative Care (EAPC)  
Budapest, Hungary, 7–9 June 2007

### PROGRAMME AND ABSTRACTS

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Istituto Nazionale dei Tumori  
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Published by **Hayward Medical Communications**,  
publishers of the *European Journal of Palliative Care*  
a division of Hayward Group plc, The Pines, Fordham Road, Newmarket CB8 7LG, UK.

Printed by Latimer Trend, UK



The High Patron of the EAPC 2007 Budapest Congress is **László Sólyom, President of the Republic of Hungary.**

Dear colleagues in palliative care,

On behalf of the European Association for Palliative Care (EAPC) and the Hungarian Hospice–Palliative Association, we welcome you to the 10th Congress of the EAPC. It has been an ambition for many years to host an EAPC congress in a Central or Eastern European country. We are therefore delighted to welcome you to Budapest!

Congress delegates from all parts of the world will have an opportunity to meet and share their knowledge and experience of palliative care. The congress programme reflects the challenging and fascinating diversities of palliative care. We will find out about delegates' personal experiences, their clinical practice and research, and their research methodology. All this will provide us with opportunities to learn from each other, discuss each others' work and take some inspiration back home for the benefit of our patients.

An important aspect of palliative care that will also form an essential part of the congress programme is the subject of policy and organisation. The 'Budapest commitment' is a tool to support palliative care development in each country through relevant goals defined by national associations. The Budapest commitment is an EAPC initiative, together with the International Association for Hospice and Palliative Care (IAHPC) and the Worldwide Palliative Care Alliance (WPCA).

The congress will be a wonderful opportunity to meet people, make new friends, learn from new perspectives and share what you know about caring for people at the end of their life.

Welcome to Budapest and enjoy the congress!



**Carl Johan Fürst**  
*Chair, Scientific Committee*



**Katalin Hegedűs**  
*Chair, Organising Committee*

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**Corry van Tol-Verhagen**, Netherlands  
**Elena Vvedenskaya**, Russia  
**Bernard Wary**, France  
**Yvonne Wengström**, Sweden

## SCIENTIFIC SESSIONS

### Plenary lectures

Plenary lectures cover key aspects of palliative care and its development, plus future challenges. The lectures include a plenary in memory of Virgilio Floriani, the Floriani Lecture, and an EAPC award lecture presented by a distinguished contributor to palliative care development.

### Parallel sessions

The parallel sessions will highlight a large number of important palliative care subjects.

### Plenary follow-up sessions

These will present different aspects of the plenary themes and give time for discussion.

### Workshops

These will be in a variety of formats, mostly interactive and sometimes with a limited number of participants (entry will be on a first come, first served basis).

### Free paper sessions

After a review of the submitted abstracts, those rated highest in terms of originality, relevance to palliative care, clarity and scientific standard have been selected for oral presentations.

### Morning 'meet the expert' sessions

The purpose of these sessions is to give participants the opportunity to meet experts of different fields of palliative care informally. The sessions are educational and interactive. Basic knowledge, new developments, and controversies in relation to clinical experience and scientific evidence, will be included.

### Guided poster tours

Posters will be assessed by a review panel over the three days of the congress. A selection of interesting posters will be presented and discussed during guided poster tours chaired by experts in palliative care.

### Paediatric palliative care

The congress programme is highlighting palliative care for children, and will include a morning 'meet the expert' session, a plenary lecture, parallel sessions and free paper sessions.

### ESMO accreditation

The congress will give ESMO members ten ESMO-MORA points, category 1.

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# Informal meetings

Informal meetings for specific interest groups will be held on Wednesday 6 June 2007 and throughout the three days of the congress. Most meetings will welcome interested delegates.

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**Wednesday** **Budapest II. Hall – Building A**  
**10.00–17.00** **European Palliative Care Research Collaborative EPCRC**  
EPCRC group by invitation  
Stein Kaasa *Norway*

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**Wednesday** **Building B**  
**13.00–17.30** **Development of palliative care – commitments for change:  
The Budapest commitment  
A joint initiative by the EAPC in collaboration with the IAHPC  
and the WPCA**  
All interested are welcome  
Chair: Lukas Radbruch EAPC  
Co-chairs: Kathy Foley IAHPC, David Prail WPCA, Carl Johan Fürst EAPC

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<b>Welcome and introduction</b>	Lukas Radbruch
<b>A map of palliative care in Europe</b>	Carlos Centeno and David Clark
<b>Steps towards palliative care development</b>	Frank Ferris
Drug availability – narcotics	Willem Scholten
Drug availability – the essential list	Liliana de Lima
Policy	Urska Lunder and Kathy Foley
Education	José Pereira
Quality	Xavier Gomez
Research	Lukas Radbruch
<b>Budapest commitments on different levels:</b>	Carl Johan Fürst
<b>Proposal and introduction to discussion</b>	

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Break

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Discussion in groups on commitments and priorities  
Reports from the groups on paper/memory stick  
Chairs and speakers as group chairs

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**Wednesday** **Building B**  
**16.00–18.30** **Physiotherapists' meeting**  
Physiotherapists  
Unni Vidvei Nygaard *Norway*

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**Thursday** **Paris Hall – Building A**  
**15.30–16.30** **International family carer research collaboration meeting**  
By invitation  
Peter Hudson, Sheila Payne *UK*

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**Thursday** **Venice Room – Building C**  
**15.30–16.30** **Palliative care in long-term facilities – a research approach**  
All interested are welcome  
Katherine Froggatt *UK*

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<b>Friday</b> 10.00–11.00	<b>Intellectual disabilities – inaugural meeting</b> All interested are welcome Linda McEnhill <i>UK</i>	<b>Paris Hall – Building A</b>
<b>Friday</b> 10.00–11.00	<b>Palliative care and older people</b> All interested are welcome Paul Cann, Nick Pahl <i>UK</i>	<b>Venice Room – Building C</b>
<b>Friday</b> 12.45–13.45	<b>Social workers’ meeting</b> Social workers Pam Firth <i>UK</i>	<b>Brussels Hall – Building A</b>
<b>Friday</b> 15.00–16.30	<b>World Federation of Neurology Research Group meeting</b> All interested are welcome Raymond Voltz <i>Germany</i>	<b>Venice Room – Building C</b>
<b>Friday</b> 15.00–16.30	<b>The story so far – EAPC Paediatric Taskforce</b> All interested are welcome Richard Hain <i>UK</i>	<b>Paris Hall – Building A</b>
<b>Saturday</b> 13.00–14.00	<b>ECEPT General Assembly</b> ECEPT members Wojciech Leppert <i>Poland</i>	<b>Budapest I. Hall – Building A</b>

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# Programme planner – Thursday 7 June

Time	Plenary Hall	Budapest I. Hall Building A	Budapest II. Hall Building A	Aachen Hall Building C	The Hague Hall Building C	Palermo Hall Building C	Geneva Hall Building A	London Hall Building C	Barcelona Hall Building C	Bergen Hall Building C	Brussels Hall Building A	Paris Hall Building A	Venice Room Building C
09.00–10.00	Opening ceremony and EAPC Award												
10.00–10.30	Plenary 1												
10.30–11.30	Poster viewing and Coffee												
11.30–13.00		Policy in Palliative Care – Steps for Improvement (Joint EAPC/IAHPC session)	Palliative Care and People with Intellectual Disabilities	Complementary Therapy	Oral Problems – Assessment and Treatment	Palliative Care in Nursing Homes – European Perspectives	Pain	Development of Palliative Care in Europe	Family and Bereavement	Assessment – Needs and Measures			
13.00–14.30	Lunch/Guided poster tour (13.15–14.15)												
14.30–15.00	Plenary 2												
15.00–15.30	Plenary 3												
15.30–15.40	EAPC News 1												
15.40–16.30	Poster viewing and Coffee												
16.30–18.00		Hydration – Attitudes and Practice	A Change of Perspective – from Risk to Resilience	Depression in Palliative Care: The Key Questions and the EPCRC Research Agenda	The Needs and Care of Patients with Neurological Diseases	Fundraising – The Resource Alliance (Joint EAPC/Help the Hospices)	Symptoms	Ethical Issues	The Diversity of Palliative Care	Oral History			
18.00–18.15	Break												
18.15–20.15	Welcome reception on the Danube												

# Friday 8 June – Programme planner

Time	Plenary Hall	Budapest I. Hall Building A	Budapest II. Hall Building A	Aachen Hall Building C	The Hague Hall Building C	Palermo Hall Building C	Geneva Hall Building A	London Hall Building C	Barcelona Hall Building C	Bergen Hall Building C	Brussels Hall Building A	Paris Hall Building A	Venice Room Building C
08.00–08.45				Opioid – How to Rotate	Self Management of Symptoms	Emergencies in PC			The Role of Religion in PC	Paediatric Palliative Care	Fundraising – Meet the Expert		PHD Education – a European Perspective
08.45–09.00	Break												
09.00–09.30	Plenary 4												
09.30–10.00	Plenary 5												
10.00–10.10	EAPC News 2												
10.10–11.00	Poster viewing and Coffee												
11.00–12.30	'Beyond Words' – Creating Relationships in Unique Ways	Pain: Clinical Challenges and the EPCRC Research Agenda	Paediatric Palliative Care	Palliative Care and Oncology Collaboration in University and Local Hospitals (Joint EAPC/ESMO session)	Archimedes session – Fighting the fire: meeting the challenges of BTCP	Palliative Care in the Elderly	Video presentations	Teams and Team Working – Conflict, Supervision and Management	Education in Palliative Care	Bridging the Gap between Oncology and Palliative Care: an Interactive Educational Tool	Wound Care Part 1 – Practical Approach to Wound Care		The Family Focused Grief Therapy (11.00–12.30)
12.30–14.00	Lunch	Mundipharma Symposium (12.45–13.45)											The Family Focused Grief Therapy (continued) (13.00–14.30)
14.00–14.25	Plenary 6												
14.25–14.35	EAPC News 3												
14.35–15.00	Plenary 7												
15.00–16.30		Cephalon Symposium (15.15–16.15)	Guided poster tour (15.10–16.15) and Coffee										
16.30–18.00	The Existential Dimension	Cachexia in Cancer Patients: Inevitable or Treatable? Research Proposals from the EPCRC	Developing a Common Language – towards Consensus Based Quality Palliative Care	National Associations meeting (Joint EAPC/Help the Hospices)	Family and Bereavement	Communicating in Palliative Care	Video presentations	Research – Patient and Staff Perspective	Paediatric Palliative Care	Bridging the Gap between Oncology and Palliative Care: an Interactive Educational Tool	The story so far – EAPC Paediatric Taskforce (informal meeting)		World Federation of Neurology Research Group meeting (informal meeting)
18.00–18.15	Break												Absolute Attention – Using Music at the End of Life – an Informative and Practical Workshop
18.15–19.30		EAPC General Assembly											

# Programme planner – Saturday 9 June

Time	Plenary Hall	Budapest I. Hall Building A	Budapest II. Hall Building A	Aachen Hall Building C	The Hague Hall Building C	Palermo Hall Building C	Geneva Hall Building A	London Hall Building C	Barcelona Hall Building C	Bergen Hall Building C	Brussels Hall Building A	Paris Hall Building A	Venice Room Building C
08.00–08.45					Quality of Life – a Valuable Concept in PC	Nutrition	Constipation – European Guidelines	Education – Adult Learning	Communication	The Dead Body – Cultural Competence	User Involvement	Fundraising – Meet the Expert	Volunteers
08.45–09.00	Break												
09.00–09.25	Plenary 8												
09.25–09.35	EAPC News 4												
09.35–10.00	Plenary 9												
10.00–11.30	Guided poster tour (10.15–11.15) and Coffee												
11.30–13.00		Molteni Symposium (10.15–11.15)	Palliative Sedation – an Update	From Basic Education to Specialist Training – EAPC Task Forces on Education	Communication (Joint EAPC/POS session)		The Diversity of Palliative Care 2	The Organisation of Palliative Care Services	AIDS – Challenges for Palliative Care (Epidemiology Resources and Organisation of Care etc)	The Dead Body – Cultural Competence	Video presentations	Wound Care Part 2 – Demonstration and Practice	
13.00–14.00		ECEPT General Assembly											
14.00–15.00			Sleep and Fatigue – Two Tiring Symptoms	The Liverpool Care Pathway – Development, Implementation, Evaluation and International Experience	The Budapest Commitment – the Final List of Priorities	Facets of PC Delivery – 'My Own Palliative Service' (Reimbursement, Some Statistics; eg Length of Stay and Case mix, Quality Control)	New Perspectives on Palliative Care Education	Review and Critique of a Scientific Paper	Symptoms in Palliative Care 2	Policy	Palliative Care – Non Cancer	The Diversity of Palliative Care 3	
15.00–15.15	Break												
15.15–15.45	Plenary 10												
15.45–16.15	Plenary 11 – Floriani Lecture												
16.15–16.45	Closing ceremony												

# Events programme

Thursday 7 June 2007

## CONNECTING DIVERSITY

10th Congress of the  
European Association for Palliative Care

09.00–10.00	<b>Opening ceremony and EAPC Award</b> Chairs: Marilène Filbet (France) – Katalin Hegedűs (Hungary)	Plenary Hall
10.00–10.30	<b>Plenary 1</b> Chairs: Marilène Filbet (France) – Katalin Hegedűs (Hungary)	Plenary Hall
	1 <b>Connecting diversities to scale up palliative care in Africa</b> Faith Mwangi-Powell <i>Uganda</i>	
10.30–11.30	<b>Poster viewing and Coffee</b>	
	<b>Poster topics</b>	
	Assessment	218 – 274
	Complementary therapy	275 – 298
	Palliative Care in the Elderly	299 – 315
	Non Cancer	316 – 347
	Policy	348 – 372
	Service Organisation and Place of Care	373 – 473
11.30–13.00	<b>Follow-up session</b> <b>Policy in Palliative Care – Steps for Improvement</b> <b>(Joint EAPC/IAHPC session)</b> Chairs: Lukas Radbruch (Germany) – Kathleen Foley (United States)	Budapest I. Hall – Building A
	2 <b>Funding – needs, responsibility and availability</b> Mary Callaway <i>United States</i>	
	3 <b>Access to controlled medications: impact for millions</b> Willem Scholten <i>Switzerland</i>	
	<b>Drugs – the essential list</b> Liliana de Lima <i>United States</i>	
	4 <b>A National Policy – Does It Make A Difference?</b> Eugene Murray <i>Ireland</i>	
	<b>Research – the Venice declaration</b> Liliana de Lima <sup>1</sup> , Lukas Radbruch <sup>2</sup> <sup>1</sup> <i>United States</i> <sup>2</sup> <i>Germany</i>	
11.30–13.00	<b>Parallel session</b> <b>Palliative Care and People with Intellectual Disabilities</b> Chairs: Linda McEnhill (United Kingdom) – Stewart Todd (United Kingdom)	Budapest II. Hall – Building A
	5 <b>Palliative care and intellectual disability – exploring the knowledge of specialist palliative care providers in Kent</b> David Oliver <i>United Kingdom</i>	
	6 <b>“The Veronica Project”: An ethnographic study into the experiences of people with Intellectual Disabilities (ID) who have cancer (preliminary findings)</b> Irene Tuffrey-Wijne <i>United Kingdom</i>	
	7 <b>Palliative care for people with intellectual disability: lessons we have learned and challenges for the future</b> Karen Ryan <i>Ireland</i>	
	8 <b>Social resurrectionists: death in a disability context</b> Stuart Todd <i>United Kingdom</i>	
	9 <b>An assessment tool for the bereavement needs of people with Intellectual disabilities</b> Noelle Blackman <i>United Kingdom</i>	
11.30–13.00	<b>Parallel session</b> <b>Complementary Therapy</b> Chairs: Torkel Falkenberg (Sweden) – Susie Wilkinson (United Kingdom)	Aachen Hall – Building C
	10 <b>A Global Perspective – World Health Organization Strategies and Resolutions</b> Torkel Falkenberg <i>Sweden</i>	
	11 <b>Complementary Therapies – The evidence base</b> Susie Wilkinson <i>United Kingdom</i>	
	12 <b>Effects and evaluation of haptotherapy for chemotherapeutical treated palliative cancer patients</b> Adriaan Visser <i>The Netherlands</i>	

- 13 **Users Perspectives on Homeopathy: Oscillating between Treatment and Companionship**  
Petra Plunger *Austria*

**11.30–13.00 Parallel session** **The Hague Hall – Building C**

**Oral Problems – Assessment and Treatment**

Chairs: Andrew Davies (United Kingdom) – Martine De Vlieger (Belgium)

- 14 **Oral problems – assessment and treatment overview**  
Andrew Davies *United Kingdom*
- 15 **Oral Hygiene**  
Margaret Sweeney *United Kingdom*
- 16 **Intervention Possibilities in Cancer treatment Induced Mucositis and What about Guidelines**  
Fred Spijkervet *The Netherlands*
- 17 **Bisphosphonates and osteonecrosis**  
Florian Strasser *Switzerland*

**11.30–13.00 Parallel session** **Palermo Hall – Building C**

**Palliative Care in Nursing Homes – European Perspectives**

Chairs: Katherine Froggatt (United Kingdom) – Katharina Heimerl (Austria)

- 18 **Consultation and Involvement for Older Adults Living in Long Term Care Settings: An Action Research Study**  
Katherine Froggatt *United Kingdom*
- 19 **Palliative Care in Nursing Homes – the need for organization development**  
Katharina Heimerl *Austria*
- 20 **Nursing homes and hospice – needs fulfilled?**  
Friedemann Nauck *Germany*
- 21 **A Palliative Approach in Nursing Institutions: Background and Perspective**  
Elena Vvedenskaya *Russian Federation*

**11.30–13.00 Free paper session** **Geneva Hall – Building A**

**Pain**

Chairs: Per Sjøgren (Denmark) – Carla Ripamonti (Italy)

- 22 **The intravenous to oral milligram potency ratio of morphine**  
Wael Lasheen *United States*
- 23 **Intermittent cancer pain: clinical importance and classification**  
Wael Lasheen *United States*
- 24 **Managing skin irritation of Buprenorphine TTS (BUP TTS)**  
Johan Van den Eynde *Belgium*
- 25 **Nasalfent, a novel intranasal formulation of fentanyl, is rapidly effective and well-tolerated during treatment of breakthrough cancer pain**  
Geoffrey Davis *Canada*
- 26 **Validation study of the Doloplus scale in six languages**  
Bernard Wary *France*
- 27 **Palliative Sedation in an Acute Care Hospital: Policy, Ethics and Case Studies**  
Kelli Gershon *United States*

**11.30–13.00 Parallel session** **London Hall – Building C**

**Development of Palliative Care in Europe**

Chairs: Marilène Filbet (France) – Carlos Centeno (Spain)

- 28 **View from the Observatory**  
David Clark *United Kingdom*
- 29 **Palliative Care in Europe are moving forward**  
Carlos Centeno *Spain*
- 30 **Council of Europe Recommendation: the Purpose and the Impact**  
Natasa Milicevic *Serbia*

**11.30–13.00 Free paper session Barcelona Hall – Building C****Family and Bereavement**

Chairs: Barbara Monroe (United Kingdom) – Unnur Valdimarsdottir (Iceland)

- 
- 31 **The Social Worker in Palliative Medicine**  
Ruth Powazki *United States*
- 
- 32 **Emotional preparedness at the time of wives death predicts psychological morbidity for widowers 4–5 years after the loss – a population based follow-up**  
Arna Hauksdottir *Sweden*
- 
- 33 **Promoting Resilience through Bereavement by Connecting Diversity Notably by Connecting Flesh and Soul, Loss and Bliss**  
Hugues Cormier *Canada*
- 
- 34 **Palliative Care: The Economic Perspective for Families and Health Care System**  
Serge Dumont *Canada*
- 
- 35 **When a child loses his brother or sister: interest of dynamic peer support groups**  
Agnes Suc *France*

**11.30–13.00 Free paper session Bergen Hall – Building C****Assessment – Needs and Measures**

Chairs: Philippe Poulain (France) – Sheila Payne (United Kingdom)

- 
- 36 **Does recognition of the dying phase have an impact on interventions during the last three days of life?**  
Agnes Van der Heide *The Netherlands*
- 
- 37 **Defining Unbearable Suffering**  
Jaap Gootjes *The Netherlands*
- 
- 38 **Measuring pain and symptoms in resource-poor settings: a comparison of verbal, visual and hand scoring methods in Sub-Saharan Africa**  
Richard Harding *United Kingdom*
- 
- 39 **Delirium Observation Screening scale: its use in cancer patients after opioid change**  
Lia Van Zuylen *The Netherlands*
- 
- 40 **Predictive value of the prognostic inflammatory and nutritional index (PINI) in terminally ill cancer patients**  
Jean-Philippe Durand *France*
- 
- 41 **Use of the APCA African Palliative Outcome Scale (POS) improves nursing assessment of palliative care patients**  
Julia Downing *Uganda*

**13.00–14.30 Lunch**



13.15–14.15


**Nycomed Symposium**  
**Challenges in treating breakthrough pain**

Chair: Sebastiano Mercadante (Italy)

Budapest I. Hall – Building A

**Introduction**Sebastiano Mercadante *Italy***The “Art” of breakthrough pain treatment**Andrew Davies *United Kingdom***Challenges in breakthrough pain treatment**Stein Kaasa *Norway***Nasal fentanyl: A clinical pharmacological perspective**Ola Dale *Norway***Questions & Answers****13.15 – 14.15 Guided poster tour****Poster topics**

Assessment	218 – 274
Complementary therapy	275 – 298
Palliative Care in the Elderly	299 – 315
Non Cancer	316 – 347
Policy	348 – 372
Service Organisation and Place of Care	373 – 473

14.30–15.00

**Plenary 2**

Plenary Hall

Chairs: Rianne De Wit (The Netherlands) – Stein Kaasa (Norway)

**42 Resilience and palliative care**Barbara Monroe *United Kingdom*

15.00–15.30

**Plenary 3**

Plenary Hall

Chairs: Rianne De Wit (The Netherlands) – Stein Kaasa (Norway)

**43 Hydration practice: attitudes and evidence**Peter Lawlor *Ireland*

15.30–15.40

**EAPC News 1**

Plenary Hall

Chairs: Rianne De Wit (Netherlands) – Stein Kaasa (Norway)

**44 EPCRC: Improved treatment of pain, depression and fatigue through translation research**Stein Kaasa *Norway*

15.40–16.30

**Poster viewing and Coffee****Poster topics**

Assessment	218 – 274
Complementary therapy	275 – 298
Palliative Care in the Elderly	299 – 315
Non Cancer	316 – 347
Policy	348 – 372
Service Organisation and Place of Care	373 – 473

16.30–18.00

**Follow-up session**

Budapest I. Hall – Building A

**Hydration – Attitudes and Practice**

Chairs: Françoise Porchet (Switzerland) – Peter Lawlor (Ireland)

**45 Hydration attitudes and practice: The nursing perspective**Esther Schmidlin *Switzerland***46 Hydration attitudes and practice: Ethical decision-making**Friedemann Nauck *Germany***47 When Is It Time To Stop – Cultural Perspectives**Eduardo Bruera *United States***48 Stopping hydration a step towards euthanasia**Bregje Onwuteaka-Philipsen, Agnes Van der Heide *The Netherlands*

**16.30–18.00 Follow-up session Budapest II. Hall – Building A****A Change of Perspective – from Risk to Resilience**

Chairs: David Oliviere (United Kingdom) – Barbara Monroe (United Kingdom)

- 49 **Building Resilience into Family Palliative Care: unlocking resilience in the family and its implications for clinical practice**  
David Oliviere *United Kingdom*
- 50 **Palliative care in a multi cultural society**  
Nathan Cherny *Israel*
- 51 **Relation between job stress and satisfaction among palliative care professionals**  
Manuela Ciucurel *Romania*
- 52 **Burden and support needs of family caregivers of patients with malignant brain tumors**  
Maria Wasner *Germany*

**16.30–18.00 Workshop Aachen Hall – Building C****Depression in Palliative Care: The Key Questions and the EPCRC Research Agenda**

Chairs: Irene Higginson (United Kingdom) – Franco De Conno (Italy)

- 53 **“Are you depressed?” The need for diagnostic tools in palliative care**  
Representing the EPCRC research group  
Jon Håvard Loge *Norway*
- 54 **Guidelines for depression in palliative care: current challenges and research agenda**  
Representing the EPCRC research group  
Irene Higginson *United Kingdom*

**16.30–18.00 Parallel session The Hague Hall – Building C****The Needs and Care of Patients with Neurological Diseases**

Chairs: David Oliver (United Kingdom) – Raymond Voltz (Germany)

- 55 **Symptom prevalence amongst people affected by advanced and progressive neurological conditions – a systematic review**  
Tariq Saleem *United Kingdom*
- Challenges in the care of patients with ALS**  
Gian Domenico Borasio *Germany*
- PC Practice in neurology and oncology**  
Ágnes Ruzsa *Hungary*

**16.30–18.00 Workshop Palermo Hall – Building C****Fundraising – The Resource Alliance (Joint EAPC/Help the Hospices)**

Chairs: David Burland (United Kingdom) – Katalin Muszbek (Hungary)

- 57 **Successful fundraising for palliative care**  
David Burland *United Kingdom*

**16.30–18.00 Free paper session Geneva Hall – Building A****Symptoms**

Chairs: Carla Ripamonti (Italy) – Carol Tishelman (Sweden)

- 58 **EEG frequencies: evidence of central origin of cancer related fatigue**  
Mellar Davis *United States*
- 59 **Symptom prevalence in patients with incurable cancer: a systematic review**  
Alexander De Graeff *The Netherlands*
- 60 **Dyspnea in palliative care – a multidimensional experience**  
Ingela Henoch *Sweden*
- 61 **What do patients with inoperable lung cancer report as MOST DISTRESSING during the first year post diagnosis in the Stockholm region of Sweden? An inductive structured assessment approach**  
Carol Tishelman *Sweden*
- 62 **Development of a Care Pathway for the management of constipation on an In-Patient unit**  
Sarah Wells *United Kingdom*
- 63 **Constipation on Opioids: Inter-individual variation calls for individually tailored treatment plans**  
Joanne Droney *United Kingdom*

<b>16.30–18.00</b>	<b>Free paper session</b> <b>Ethical Issues</b>	<b>Barcelona Hall – Building C</b>
	Chairs: Lars Johan Materstvedt (Norway) – Rianne De Wit (The Netherlands)	
64	<b>Attitudes of Flemish Palliative Care Nurses and Physicians towards Euthanasia and Physician Assisted Suicide</b> Joris Gielen <i>Belgium</i>	
65	<b>“It turned out that we were in charge”</b> Gillian Chowns <i>United Kingdom</i>	
66	<b>Diversity in aims of palliative chemotherapy: a care ethical perspective</b> Susanne De Kort <i>The Netherlands</i>	
67	<b>The wish to hasten death among ALS patients in a palliative care program</b> Ralf Jox <i>Germany</i>	
68	<b>Advance directives in palliative care units: a prospective study</b> Sophie Pautex <i>Switzerland</i>	
102	<b>Pastoral care of the elderly: do clergy have an attitude problem?</b> Peter Speck <i>United Kingdom</i>	
<b>16.30–18.00</b>	<b>Free paper session</b> <b>The Diversity of Palliative Care</b>	<b>Bergen Hall – Building C</b>
	Chairs: Katalin Hegedus (Hungary) – Andrew Davies (United Kingdom)	
70	<b>An assessment of the confidence that staff working in palliative care and intellectual disability services have in their ability to provide palliative care to people with intellectual disability</b> Karen Ryan <i>Ireland</i>	
71	<b>Transition towards Palliative Care. An exploration of its meaning for advanced cancer patients in Europe</b> Philip Larkin <i>Ireland</i>	
72	<b>Advanced care planning for Indigenous Australians: the process of engaging, the lessons learnt and the way forward</b> Mark Boughiey <i>Australia</i>	
73	<b>Reporting cancer and dying in the news: a study of Portuguese newspapers and magazines</b> Barbara Gomes <i>United Kingdom</i>	
74	<b>The Battle for Palliative Care during Wartime</b> Amitai Oberman, Mali Szlaifer <i>Israel</i>	
75	<b>Level of unmet need and use of palliative care services in an Australian population</b> Bev McNamara <i>Australia</i>	
<b>16.30–18.00</b>	<b>Workshop</b> <b>Oral History</b>	<b>Paris Hall – Building A</b>
	Chairs: David Clark (United Kingdom) – Michael Wright (United Kingdom)	
76	<b>Oral history: A tool for education, research and development in hospice and palliative care</b> David Clark <i>United Kingdom</i>	
77	<b>An oral history of palliative care in Germany and Austria</b> Sabine Pleschberger <i>Austria</i>	
<b>18.00–18.15</b>	<b>Break</b>	
<b>18.15–20.15</b>	<b>Welcome reception on the Danube</b>	



# Events programme

Friday 8 June 2007

## CONNECTING DIVERSITY

10th Congress of the  
European Association for Palliative Care

08.00–08.45	<b>Meet the expert</b> <b>Opioid – How to Rotate</b> Chairs: Per Sjögren (Denmark) – Franco De Conno (Italy)	<b>Aachen Hall – Building C</b>
78	<b>Opioids – how to rotate</b> Per Sjögren <i>Denmark</i>	
08.00–08.45	<b>Meet the expert</b> <b>Self Management of Symptoms</b> Chairs: Rianne De Wit (The Netherlands) – Carla Ripamonti (Italy)	<b>The Hague Hall – Building C</b>
08.00–08.45	<b>Meet the expert</b> <b>Emergencies in PC</b> Chairs: Friedemann Nauck (Germany) – Philippe Poulain (France)	<b>Palermo Hall – Building C</b>
79	<b>Emergencies in Palliative Care</b> Friedemann Nauck <i>Germany</i>	
08.00–08.45	<b>Meet the expert</b> <b>The Role of Religion in PC</b> Chairs: Michael Wright (United Kingdom) – Piotr Krakowiak (Poland)	<b>Barcelona Hall – Building C</b>
80	<b>The role of religion in palliative care</b> Michael Wright <i>United Kingdom</i>	
81	<b>The role of religion in palliative care</b> Piotr Krakowiak <i>Poland</i>	
08.00–08.45	<b>Meet the expert</b> <b>Paediatric Palliative Care</b> Chair: Millie Solomon (United States)	<b>Bergen Hall – Building C</b>
82	<b>A Mew Model and New Resources for Teaching Pediatric Palliative Care</b> Mildred Solomon <i>United States</i>	
08.00–08.45	<b>Meet the expert</b> <b>Fundraising – Meet the Expert</b> Chairs: David Burland (United Kingdom) – Neelam Makhijani (United Kingdom)	<b>Paris Hall – Building A</b>
57	<b>Successful fundraising for palliative care</b> David Burland <i>United Kingdom</i>	
08.00–08.45	<b>Meet the expert</b> <b>PhD Education – a European Perspective</b> Chairs: David Clark (United Kingdom) – Stein Kaasa (Norway)	<b>Venice Room – Building C</b>
83	<b>PhD education – a European perspective</b> David Clark <i>United Kingdom</i>	
08.45–09.00	<b>Break</b>	
09.00–09.30	<b>Plenary 4</b> Chairs: Chantal Wood (France) – Carlos Centeno (Spain)	<b>Plenary Hall</b>
84	<b>The Courage to be</b> Lars Björklund <i>Sweden</i>	
09.30–10.00	<b>Plenary 5</b> Chairs: Chantal Wood (France) – Carlos Centeno (Spain)	<b>Plenary Hall</b>
85	<b>Paediatric palliative care</b> Finella Craig <i>United Kingdom</i>	
10.00–10.10	<b>EAPC News 2</b> Chairs: Chantal Wood (France) – Carlos Centeno (Spain)	<b>Plenary Hall</b>
	EAPC News 2. European Palliative Care Atlas Carlos Centeno <i>Spain</i>	

**10.10–11.00 Poster viewing and coffee****Poster topics**

Bereavement	474 – 497
Culture and Values	500 – 521
Ethics	522 – 552
Family	553 – 574
Other Symptoms	575 – 636
Paediatric Palliative Care	637 – 653
Pain	654 – 736
Personal Experience	737 – 741
Personnel	742 – 757
Volunteers	758 – 759

**10.15–10.45 The Song Rooms: a recording of a concert from children's hospices worldwide  
Produced by Rosetta Life****11.00–12.30 Archimedes session****Palermo Hall – Building C****Fighting the fire: meeting the challenges of breakthrough cancer pain****This house proposes that: 'a radical approach to breakthrough cancer pain is required in order to optimise patient treatment throughout Europe'**

Chair: Marie Fallon (United Kingdom)

11.15 Introduction

11.20 **THE DEBATE:** This house proposes that a radical approach to BTCP is required in order to optimise patient treatment throughout Europe**Key debating points:**

- Current treatments – how well do they address breakthrough cancer pain?
- What approach should we take – physician- or patient-led prescribing?
- What impact will new treatments & technology have?
- How relevant are clinical guidelines for today's patient?
- Health economics – what are the implications?

**Principal debaters:**Andrew Davies *United Kingdom*Catherine Urch *United Kingdom*Sebastiano Mercadante *Italy*Frank Elsner *Germany*Geoff Davis *Canada*12.10 **Audience voting**12.15 **Summary****11.00–12.30 Follow-up session****Budapest I. Hall – Building A****'Beyond Words' – Creating Relationships in Unique Ways**

Chairs: Nigel Hartley (United Kingdom) – Lars Björklund (Sweden)

86 **Beyond Words – making relationships in unique ways**Nigel Hartley *United Kingdom*87 **Pet dogs – a genuine support in existential crises**Peter Strang *Sweden*88 **Silence, a language beyond words**Lars Björklund *Sweden***11.00–12.30 Workshop****Budapest II. Hall – Building A****Pain: Clinical Challenges and the EPCRC Research Agenda**

Chairs: Augusto Caraceni (Italy) – Geoffrey Hanks (United Kingdom)

89 **Genetic markers for opioid responses – Representing the EPCRC group**Frank Skorpen *Norway*90 **Pain assessment: How can the clinical tools be improved? Representing the EPCRC Research Group**Marianne Jensen Hjermsstad *Norway*91 **Guidelines for pain: the main challenges from the EPCRC a 6th EU framework research project**Augusto Caraceni *Italy*

**11.00–12.30 Parallel session Aachen Hall – Building C****Paediatric Palliative Care**

Chairs: Chantal Wood (France) – Richard Hain (United Kingdom)

- 
- 92 **Pain in children's cancer – new strategies**  
Boris Zernikow *Germany*
- 
- 93 **The Role of Paediatric Palliative Care in facilitating Resilience in Children infected with HIV in a Resource Poor and Multi-cultural community**  
Joan Marston *South Africa*
- 
- 94 **End-of-life in NICU: differences between deaths occurring naturally and deaths following a medical decision**  
Denis Oriot *France*
- 
- 95 **The palliative care needs of Australian children who die from cancer and their families**  
Leanne Monterosso *Australia*
- 
- 96 **Caring for life: The palliative and supportive care needs of children and families in Western Australia**  
Leanne Monterosso *Australia*

**11.00–12.30 Joint EAPC/ESMO session The Hague Hall – Building C****Palliative Care and Oncology Collaboration in University and Local Hospitals**

Chairs: Lukas Radbruch (Germany) – Nathan Cherny (Israel)

- 
- Common objectives**  
Stein Kaasa *Norway*
- 
- How to do it – clinical cooperation and scientific joint projects**  
Mario Di Cato *Luxembourg*
- 
- How palliative care can improve cancer patients: a need for early collaboration**  
Marilène Filbet *France*
- 
- How to facilitate collaboration between ESMO and EAPC – aspects of care and organisation**  
Håkan Mellstedt *Sweden*

**11.00–12.30 Free paper session Geneva Hall – Building A****Palliative Care in the Elderly**



Chairs: Françoise Porchet (Switzerland) – Elena Vvedenskaya (Russian Federation)

- 
- 97 **Dying in old age: how illness trajectories influence place of death**  
Julie Skilbeck *United Kingdom*
- 
- 98 **Opening the door for older people to explore end of life issues**  
Jane Seymour *United Kingdom*
- 
- 99 **End-of-life care for heart failure in Acute Care for Elders Unit: a retrospective case series**  
Vito Curiale *Italy*
- 
- 100 **Improving End of Life care in care homes in England: An evaluation**  
Collette Clifford *United Kingdom*
- 
- 101 **Analysing End of Life care in care homes: After Death Analysis tool**  
Keri Thomas *United Kingdom*
- 
- 69 **Connectedness: ethics and advanced home care technology in the last phase of life**  
Dick Willems *The Netherlands*

**11.00–12.30 Video presentations London Hall – Building C**

- 
- 103 **The Gifts of Grief**  
Nancee Sobonya *United States*
- 
- 104 **"To care at home: a journey through the experience"**  
Massimo Melo *Italy*



11.00–12.30	<b>Parallel session</b> <b>Teams and Team Working – Conflict, Supervision and Management</b> Chairs: André Rhebergen (The Netherlands) – Pam Firth (United Kingdom)	<b>Barcelona Hall – Building C</b>
105	<b>Team working – fulfilling or frustrating</b> Peter Speck <i>United Kingdom</i>	
106	<b>Sources of stress and reactive behaviours in the PC team</b> Oscar Corli <i>Italy</i>	
107	<b>When the team is limited</b> Daniela Mosoiu <i>Romania</i>	
11.00–12.30	<b>Free paper session</b> <b>Education in Palliative Care</b> Chairs: Steffen Eychmüller (Switzerland) – Betty Ferrell (United States)	<b>Bergen Hall – Building C</b>
108	<b>Resuscitation in palliative care</b> Madeline Bass <i>United Kingdom</i>	
109	<b>The End of Life Nursing Education Consortium (ELNEC) Salzburg Institute for Nurses in Eastern Europe</b> Betty Ferrell <i>United States</i>	
110	<b>The first Nordic Specialist Course in Palliative Medicine 2003–2005. Final evaluation of the course content and the impact of the course on students and on palliative care in their area</b> Tove Vejlgaard <i>Denmark</i>	
111	<b>The Association for Palliative Medicine (APM) Consensus Syllabus for Undergraduate palliative medicine</b> Paul Paes <i>United Kingdom</i>	
112	<b>Evolution of the Subspecialty of Hospice and Palliative Medicine in the United States: The Role of Accreditation and Certification</b> Steven Radwany <i>United States</i>	
113	<b>An Evaluation of an HIV/AIDS Palliative Care Education Strategy in Rural Uganda</b> Julia Downing <i>Uganda</i>	
11.00–12.30	<b>Workshop</b> <b>Bridging the Gap between Oncology and Palliative Care: an Interactive Educational Tool</b> <b>Sponsored by an Educational Grant from Grünenthal GmbH</b> Chairs: Klaus Reckinger (Germany) – Detlef von Zabern (Germany)	<b>Brussels Hall – Building A</b>
	114 <b>Bridging the gap between oncology and palliative care. Presentation of an interactive educational tool</b> Detlef Von Zabern <i>Germany</i>	
	<b>Introduction to the project and current status</b> Detlef Von Zabern <i>Germany</i>	
	<b>Educational background and case presentation</b> Jon Havard Loge <i>Norway</i>	
	<b>Symptom management: dyspnoea</b> Xavier Gomez-Batiste <i>Spain</i>	
	<b>Dignity</b>	
11.00–12.30	<b>Workshop</b> <b>Wound Care Part 1 – Practical Approach to Wound Care</b> <b>Sponsored by an Educational Grant from Mölnlycke</b> Chairs: Frank Ferris (United States) – Rosene Pirrello (United States)	<b>Paris Hall – Building A</b>
	115 <b>Wound Care 1 – Practical Approaches to Palliative Wound Care</b> Frank Ferris <i>United States</i>	

**11.00–12.30 Workshop** **Venice Room – Building C**  
**The Family Focused Grief Therapy**  
 Chairs: David Kissane (United States)

**116 Family Focused Grief Therapy (FFGT) during Palliative Care & Bereavement: a model of family-centered care to optimize adaptation and coping**  
 David Kissane *United States*

**12.30–14.00 Lunch**

**12.45–13.45 Mundipharma Symposium** **Budapest I. Hall – Building A**  
**'EXPECTATIONS'**



Introduction

**EPIC insights – the first European Pain in Cancer Survey of its kind**  
 Franco De Conno *Italy*

**Meeting Patient Expectations**  
 Gerhard Mueller-Schwefe *Germany*

**High Doses of OxyContin**  
 Sebastiano Mercadante *Italy*

**13.00–14.30 Workshop (continued)** **Venice Room – Building C**  
**The Family Focused Grief Therapy**  
 Chair: David Kissane (United States)

**116 Family Focused Grief Therapy (FFGT) during Palliative Care & Bereavement: a model of family-centered care to optimize adaptation and coping**  
 David Kissane *United States*

**14.00–14.25 Plenary 6** **Plenary Hall**  
 Chairs: Pam Firth (United Kingdom) – Lukas Radbruch (Germany)

**117 Implementing quality palliative care – how to prove it**  
 Frank Ferris *United States*

**14.25–14.35 EAPC News 3** **Plenary Hall**  
 Chairs: Pam Firth (United Kingdom) – Lukas Radbruch (Germany)

**Budapest Commitments**  
 Carl Johan Fürst<sup>1</sup>, Lukas Radbruch<sup>2</sup>  
<sup>1</sup>Sweden <sup>2</sup>Germany

**14.35–15.00 Plenary 7** **Plenary Hall**  
 Chairs: Pam Firth (United Kingdom) – Lukas Radbruch (Germany)

**118 Cultural issues in facing death**  
 Katalin Muszbek *Hungary*

**15.00–16.30 Poster viewing and coffee**

**15.10–16.15 Guided poster tour**

**Poster topics**

Bereavement	474 – 497
Culture and Values	500 – 521
Ethics	522 – 552
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Other Symptoms	575 – 636
Paediatric Palliative Care	637 – 653
Pain	654 – 736
Personal Experience	737 – 741
Personnel	742 – 757
Volunteers	758 – 759

15.15–16.15	<b>Cephalon Symposium</b> <b>Breakthrough Cancer Pain (BTcP) – Do we fully understand what our patients need and when they need it?</b>	Budapest I. Hall – Building A
	Chair: Philippe Poulain (France)	
	What do our patients need? – New survey reveals shortcomings and experiences of current BTcP management Andrew N Davies <i>United Kingdom</i>	
	How can we improve on these experiences? – Providing our patients with help when they need it John Zeppetella <i>United Kingdom</i>	
	Future needs – Can we improve on what is available today? Donald R Taylor <i>United States</i>	
	Discussion & questions	
15.00–16.30	<b>Informal meeting</b> <b>The Story so Far – EAPC Paediatric Taskforce</b>	Paris Hall – Building A
	Chair: Richard Hain (United Kingdom)	
	Presentation of the TRENTO guidelines Finella Craig <i>United Kingdom</i>	
	<b>119 Solid facts in Paediatric Palliative Care – A new EAPC Taskforce</b> Franca Benini <i>Italy</i>	
	Discussion: A way forward for Paediatric Palliative Care in Europe Chantal Wood <i>France</i>	
16.30–18.00	<b>Follow-up session</b> <b>The Existential Dimension</b>	Budapest I. Hall – Building A
	Chairs: Peter Strang (Sweden) – Katalin Muszbek (Hungary)	
	<b>120 Meaning</b> Lisa Sand <i>Sweden</i>	
	<b>121 Hope</b> Michael Wright <i>United Kingdom</i>	
	<b>122 The existential dimension of faith</b> Piotr Krakowiak <i>Poland</i>	
	<b>123 Guilt</b> Peter Strang <i>Sweden</i>	
16.30–18.00	<b>Workshop</b> <b>Cachexia in Cancer Patients: Inevitable or Treatable? Research Proposals from the EPCRCP</b>	Budapest II. Hall – Building A
	Chairs: Lukas Radbruch (Germany) – Kenneth Fearon (United Kingdom)	
	Risk factors for Cachexia – is there a genetic profile? Kenneth Fearon <i>United Kingdom</i>	
	<b>124 EPCRC – Session: Cachexia in cancer patients – Classification, what difference does it make?</b> Florian Strasser <i>Switzerland</i>	
	<b>125 Cachexia in cancer patients: Inevitable or treatable? Research proposals from the EPCRC</b> Lukas Radbruch <i>Germany</i>	

<b>16.30–18.00</b>	<b>Follow-up session</b> <b>Developing a Common Language – towards Consensus Based Quality Palliative Care</b> Chairs: Frank Ferris (United States) – Xavier Gomez Batista (Spain)	<b>Aachen Hall – Building C</b>
126	Developing a common language towards consensus based quality palliative care – Why are definitions important? Irene Higginsson <i>United Kingdom</i>	
127	What is “hospice”? Sheila Payne <i>United Kingdom</i>	
	What is “hospice”? Urska Lunder <i>Slovenia</i>	
	What is “hospice”? Xavier Gomez-Baptiste <i>Spain</i>	
128	Developing a Common Language – Towards Consensus-based Quality Palliative Care Frank Ferris <i>United States</i>	
<b>16.30–18.00</b>	<b>Joint EAPC/Help the Hospices National Associations meeting</b> Chairs: David Prall (United Kingdom) – Marilène Filbet (France)	<b>The Hague Hall – Building C</b>
129	EAPC national association task force David Prall <i>United Kingdom</i>	
<b>16.30–18.00</b>	<b>Parallel session</b> <b>Family and Bereavement</b> Chairs: Pam Firth (United Kingdom) – Unnur Valdimarsdottir (Iceland)	<b>Palermo Hall – Building C</b>
	Evidence base and bereavement Unnur Valdimarsdottir <i>Iceland</i>	
130	Grieving is a Family Affair Pam Firth <i>United Kingdom</i>	
131	The cultural determinants of grief Eszter Biro <i>Hungary</i>	
<b>16.30–18.00</b>	<b>Free paper session</b> <b>Communicating in Palliative Care</b> Chairs: Luigi Grassi (Italy) – David Oliviere (United Kingdom)	<b>Geneva Hall – Building A</b>
132	Decision-making in end-of-life care: a pilot study on the attitudes, knowledge and medical acts of 602 Belgian GPs Marc Cosyns <i>Belgium</i>	
133	The care givers point of view in the approach of sexual concerns in palliative cancer patients Mario Barmaki <i>France</i>	
134	Handling Bad News for People with Learning Disabilities Facing Death Jacqueline Saunders <i>United Kingdom</i>	
135	Family-Oriented Communication in Palliative Care Iris Cohen Fineberg <i>United Kingdom</i>	
136	Patient-Family Communication About End-of-Life Topics: Development & Pilot Testing of a New Measure (PFICQ) Jennifer Abbey <i>United States</i>	
137	Body images and communication in psychotherapy and pastoral care Helle Jensen <i>Denmark</i>	
<b>16.30–18.00</b>	<b>Video presentations</b>	<b>London Hall – Building C</b>
103	The Gifts of Grief Nancee Sobonya <i>United States</i>	
138	Art therapy in palliative care Wadih Rhondali <i>France</i>	

**16.30–18.00 Free paper session** **Barcelona Hall – Building C****Research – Patient and Staff Perspective**

Chairs: Raymond Voltz (Germany) – Carol Tishelman (Sweden)

- 139 **“Doing good care” – a grounded theory of palliative home nursing care**  
Anna Sandgren *Sweden*
- 140 **A Cross-sectional, Consecutive Patient Survey of the Views of Cancer Patients and their Relatives towards Randomized Controlled Trials in Palliative Care**  
Clare White *United Kingdom*
- 141 **What Are Patients Research Priorities for Palliative Care?**  
Paul Perkins *United Kingdom*
- 142 **Self reported mobility in palliative patients: Does wording of items matter?**  
Jorunn Helbostad *Norway*
- 143 **Assessment of the patients' spiritual needs: the influence of investigators' attitudes on patient drop-out rates**  
Gian Domenico Borasio *Germany*
- 144 **Combining Patient & Professional Perspectives Using “Speed Dating”**  
Jane Maher *United Kingdom*

**16.30–18.00 Free paper session** **Bergen Hall – Building C****Paediatric Palliative Care**

Chairs: Richard Hain (United Kingdom) – Chantal Wood (France)

- 145 **The Coordination Centre for Paediatric Palliative Medicine in Munich – a model for the future?**  
Monika Fuehrer *Germany*
- 146 **SisBroJekt – A German project for healthy siblings of chronically ill children**  
Wilma Henkel *Germany*
- 147 **An Ethical Framework for Pediatric End-of-Life Decision Making**  
Mildred Solomon *United States*
- 148 **The lived experience of parenting a child with a life limiting condition: A focus on the mental health realm**  
Alison Rodriguez *United Kingdom*
- 149 **Paediatric hospice care: parental feelings, thoughts and remarks**  
Matthias Schell *France*
- 150 **Pediatric Advanced Care Team: one of the models of delivery of pediatric palliative care in the USA**  
Tamara Vesel *United States*

**16.30 – 18.00 Workshop** **Brussels Hall – Building A****Bridging the Gap between Oncology and Palliative Care: an Interactive Educational Tool****Sponsored by an Educational Grant from Grünenthal GmbH**

Chairs: Frank Elsner (Germany) – Detlef von Zabern (Germany)

- 114 **Bridging the gap between oncology and palliative care. Presentation of an interactive educational tool**  
Frank Elsner *Germany*
- Introduction to the project and current status**  
Detlef Von Zabern *Germany*
- Educational background and case presentation**  
Frank Elsner *Germany*
- Prognosis**  
Daniela Mosoiu *Romania*
- Symptom management: cancer related fatigue**  
Marie Fallon *United Kingdom*

**16.30–18.00 Workshop** **Venice Room – Building C****Absolute Attention – Using Music at the End of Life – an Informative and Practical Workshop**

Chair: Nigel Hartley (United Kingdom)

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<b>18.00–18.15</b>	<b>Break</b>	
<b>18.15–19.30</b>	<b>EAPC General Assembly</b>	<b>Budapest II. Hall Building A</b>

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# Events programme


Saturday 9 June 2007

## CONNECTING DIVERSITY

10th Congress of the  
European Association for Palliative Care

08.00–08.45	<b>Meet the expert</b> <b>Quality of Life – a Valuable Concept in PC</b> Chairs: Irene Higginson (United Kingdom) – Raymond Voltz (Germany)	<b>The Hague Hall – Building C</b>
	151 <b>Quality of life – a valuable concept?</b> Raymond Voltz <i>Germany</i>	
08.00–08.45	<b>Meet the expert</b> <b>Nutrition</b> Chairs: Florian Strasser (Switzerland) – Ylva Orrevall (Sweden)	<b>Palermo Hall – Building C</b>
	152 <b>Nutrition – Meet the expert – morning session</b> Florian Strasser <sup>1</sup> , Ylva Orrevall <sup>2</sup> <sup>1</sup> Switzerland <sup>2</sup> Sweden	
08.00–08.45	<b>Meet the expert</b> <b>Constipation – European Guidelines</b> Chairs: Philip Larkin (Ireland) – Nigel Sykes (United Kingdom)	<b>Geneva Hall – Building A</b>
	153 <b>Constipation – European guidelines</b> Philip Larkin <i>Ireland</i>	
08.00–08.45	<b>Meet the expert</b> <b>Education – Adult Learning</b> Chairs: Ruthmarijke Smeding (The Netherlands) – John Ellershaw (United Kingdom)	<b>London Hall – Building C</b>
	154 <b>Adult Education</b> Ruthmarijke Smeding <i>Germany</i>	
08.00–08.45	<b>Meet the expert</b> <b>Communication</b> Chairs: Luigi Grassi (Italy) – Urska Lunder (Slovenia)	<b>Barcelona Hall – Building C</b>
08.00–08.45	<b>Meet the expert</b> <b>The Dead Body – Cultural Competence</b> Chairs: Françoise Porchet (Switzerland) – Nathan Cherny (Israel)	<b>Bergen Hall – Building C</b>
08.00–08.45	<b>Meet the expert</b> <b>User Involvement</b> Chairs: David Oliviere (United Kingdom) – Sheila Payne (United Kingdom)	<b>Brussels Hall – Building A</b>
	155 <b>Meet the Expert Session: user Involvement and Palliative Care</b> David Oliviere <i>United Kingdom</i>	
08.00–08.45	<b>Meet the expert</b> <b>Fundraising – Meet the Expert</b> Chairs: David Burland (United Kingdom) – Neelam Makhijani (United Kingdom)	<b>Paris Hall – Building A</b>
	57 <b>Successful fundraising for palliative care</b> David Burland <i>United Kingdom</i>	
08.00–08.45	<b>Meet the expert</b> <b>Volunteers</b> Chairs: Anne Merriman (Uganda) – Barbara Monroe (United Kingdom)	<b>Venice Room – Building C</b>
	156 <b>Meet the Expert – Volunteers</b> Anne Merriman <i>Uganda</i>	
08.45–09.00	<b>Break</b>	
09.00–09.25	<b>Plenary 8</b> Chairs: David Clark (United Kingdom) – Katalin Muszbek (Hungary)	<b>Plenary Hall</b>
	157 <b>Evaluation of palliative education: why bother?</b> Jose Pereira <i>Switzerland</i>	



09.25–09.35	<b>EAPC News 4</b> Chairs: David Clark (United Kingdom) – Katalin Muszbek (Hungary)	Plenary Hall
	Results of the elections of the EAPC Board of Directors 2007 Marilène Filbet <i>France</i>	
09.35–10.00	<b>Plenary 9</b> Chairs: David Clark (United Kingdom) – Katalin Muszbek (Hungary)	Plenary Hall
	158 The pathological states of consciousness. " <i>Spiritus animalis residet in substantia cerebri</i> " (Varolius 1543–1575) Augusto Caraceni <i>Italy</i>	
10.00–11.30	<b>Poster viewing and Coffee</b>	
10.15–11.15	<b>Molteni Symposium</b> "Start" Therapy: New Strategies to Improve Clinical Success in Cancer Pain Control Chairs: Geoffrey Hanks (United Kingdom) – Franco De Conno (Italy)	Budapest I. Hall – Building A
	 Initiating treatment with oral morphine: terminology and guidelines Geoffrey Hanks <i>United Kingdom</i>	
	Epidemiology of cancer pain with an overview of opioid treatment options Stefan Wirz <i>Germany</i>	
	"Start" therapy: Evidence to support a fixed dose regimen and factors predictive of analgesic response Franco De Conno <i>Italy</i>	
	Therapeutic strategies for breakthrough pain: Initial and maintenance therapy Philippe Poulain <i>France</i>	
	Discussion	
10.15–11.15	<b>Guided poster tour</b>	
	Poster topics	
	Basic Research, Epidemiology	760 – 797
	Communication	798 – 819
	Education	821 – 893
	Methodology	894 – 913
	Other	914 – 988
11.30–13.00	<b>Follow-up session</b> <b>Delirium – a Challenge to Contact and Communication</b> Chairs: Eduardo Bruera (United States) – Augusto Caraceni (Italy)	Budapest I. Hall – Building A
	159 Managing the Patient with Pain and Delirium Eduardo Bruera <i>United States</i>	
	160 Delirium in the patient and its impact on the family and staff Pam Firth <i>United Kingdom</i>	
	161 Delirium – a challenge to contact and communication. Nursing challenges Marianne Hjermsstad <i>Norway</i>	
11.30–13.00	<b>Parallel session</b> <b>Palliative Sedation – an Update</b> Chairs: Philippe Poulain (France) – Lars Johan Materstvedt (Norway)	Budapest II. Hall – Building A
	162 Definition and principles of palliative sedation therapy Alexander De Graeff <i>The Netherlands</i>	
	163 Palliative sedation: Pharmacology – evidence and practice Staffan Lundström <i>Sweden</i>	
	164 Ethical Considerations Lars Materstvedt <i>Norway</i>	

**11.30–13.00 Follow-up session** **Aachen Hall – Building C**  
**From Basic Education to Specialist Training – EAPC Task Forces on Education**  
 Chairs: David Clark (United Kingdom) – Jose Pereira (Switzerland)

**165 From basic education to specialist training – EAPC Taskforces on Nurse Education**

Philip Larkin *Ireland*

**EAPC medical curriculum**

Marilène Filbet *France*

**166 Palliative care education and accreditation**

David Clark *United Kingdom*

**11.30–13.00 Joint EAPC/IPOS session** **The Hague Hall – Building C**  
**Communication**

Chairs: Katalin Muszbek (Hungary) – Luigi Grassi (Italy)

**167 Suggestions in the communication with cancer patients**

Éva Bányai *Hungary*

**168 Integrated Psycho–Oncology focusing the needs in palliative care: experiences and empirical data**

Elisabeth Andritsch *Austria*

**169 Communication skills – a core competence in Palliative care**

Luzia Travado *Portugal*

**11.30–13.00 Free paper session** **Geneva Hall – Building A**  
**The Diversity of Palliative Care 2**

Chairs: Jane Seymour (United Kingdom) – Furio Zucco (Italy)

**170 A love affair as palliativum?**

Hans-Christof Müller-Busch *Germany*

**171 An Alternative Perspective on Palliative Care: How Homeopaths approach Chronic Illness**

Petra Plunger *Austria*

**172 Complementary therapies in cancer: exploring the contributions of therapy & therapist to patient care**

Charlotte Wilson *United Kingdom*

**173 A large multicenter prospective randomised trial on the treatment of death rattle in palliative care**


Johan Menten *Belgium*

**174 Measuring Attitudes to Change and Relation Competence in a Palliative Medicine Unit**

Beate André *Norway*

**175 Double-blind randomized comparison between double-dose of immediate morphine versus single-dose morphine at bedtime to cancer patients**

Maria Piribauer *Norway*

<b>11.30–13.00</b>	<b>Free paper session</b> <b>The Organisation of Palliative Care Services</b> Chairs: Tine De Vlieger (Belgium) – Daniela Mosoiu (Romania)	<b>London Hall – Building C</b>
176	Hospital death rates in six European countries: a population-based cross national study of clinical, sociodemographic and health care system factors Joachim Cohen <i>Belgium</i>	
177	Description of a new integrated palliative care model Gunnhild Jakobsen <i>Norway</i>	
178	Inequity in the provision of and access to palliative care services for cancer patients in Italy. Results from the Italian survey of the dying of cancer (ISDOC) Monica Beccaro <i>Italy</i>	
179	A comparison of the quality of care provided to cancer patients in the last three months of life in hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire Julia Addington-Hall <i>United Kingdom</i>	
180	Specialist palliative care services (pcs) at home in Spain: structure, outputs, and outcomes Jose Espinosa <i>Spain</i>	
181	Cultural Pain and its impact on patient and family care: Connecting diversity in culture, policy and practice David Oliviere <i>United Kingdom</i>	
<b>11.30–13.00</b>	<b>Parallel session</b> <b>AIDS – Challenges for Palliative Care (Epidemiology Resources and Organisation of Care etc)</b> Chairs: Faith Mwangi–Powell (Uganda) – Mary Callaway (United States)	<b>Barcelona Hall – Building C</b>
182	AIDS – challenges for palliative care in Uganda Anne Merriman <i>Uganda</i>	
	AIDS – challenges for palliative care in Russia Elena Vvedenskaya <i>Russian Federation</i>	
183	HIV infection and AIDS – challenges for palliative care in Romania Ovidiu Popa Velea <i>Romania</i>	
184	AIDS and Palliative Care in France: new challenges Jean-Michel Livrozet <i>France</i>	
<b>11.30–13.00</b>	<b>Video presentations</b>	<b>Brussels Hall – Building A</b>
185	The Song Rooms Lucinda Jarrett Jarrett <i>United Kingdom</i>	
138	Art therapy in palliative care Wadih Rhondali <i>France</i>	
104	“To care at home: a journey through the experience” Massimo Melo <i>Italy</i>	
<b>11.30–13.00</b>	<b>Workshop</b> <b>Wound Care Part 2 – Demonstration and Practice</b> <b>Sponsored by an Educational Grant from Mölnlycke</b> Chairs: Frank Ferris (United States) – Rosene Pirrello (United States)	<b>Paris Hall – Building A</b>
	186 Wound Care Part 2 – Wound Pain and Other Symptoms Associated with Wound Care Frank Ferris <i>United States</i>	

**13.00–14.00 Lunch and Poster viewing****Poster topics**

Basic Research, Epidemiology	760 – 797
Communication	798 – 819
Education	821 – 893
Methodology	894 – 913
Other	914 – 988

**14.00–15.00 Parallel session****Budapest II. Hall – Building A****Sleep and Fatigue – Two Tiring Symptoms**

Chairs: Carol Tishelman (Sweden) – Ágnes Ruzsa (Hungary)

187 **Fatigue in palliative care – a position paper from an EAPC workgroup**  
Frank Elsner *Germany*

**Sleep disturbances – research in paediatric palliative care**  
Boris Zernikow *Germany*

188 **Distress or just a symptom?**  
Carol Tishelman *Sweden*

**14.00–15.00 Parallel session****Aachen Hall – Building C****The Liverpool Care Pathway – Development, Implementation, Evaluation and International Experience**

Chairs: John Ellershaw (United Kingdom) – Massimiliano Panella (Italy)

189 **An integrated care pathway – overview**  
Massimiliano Panella *Italy*

190 **Promoting excellence in care of the dying: The Liverpool Care of the Dying Pathway (LCP)**  
John Ellershaw *United States*

191 **Experiences with the Liverpool care pathway for the dying in the Netherlands**  
Lia Van Zuylen *The Netherlands*

192 **Liverpool care pathway for the dying phase: implementation process in Slovenia**  
Urška Lunder *Slovenia*

**14.00–15.00 Workshop****The Hague Hall – Building C****The Budapest Commitment – the Final List of Priorities**

Chairs: Lukas Radbruch (Germany) – Liliana de Lima (United States)

**14.00–15.00 Parallel session****Palermo Hall – Building C****Facets of PC Delivery – ‘My Own Palliative Service’ (Reimbursement, Some Statistics: eg Length of Stay and Case mix, Quality Control)**

Chairs: Furio Zucco (Italy) – Csaba Simkó (Hungary)

193 **Palliative care in Georgia**  
Rema Ghvamichava *Georgia*

194 **My own Palliative Care Service – Italy**  
Furio Zucco *Italy*

195 **The regional palliative care program of Extremadura**  
Javier Rocafort *Spain*

196 **My own palliative care service – Hungary**  
Csaba Simkó *Hungary*

**14.00–15.00 Follow-up session****Geneva Hall – Building A****New Perspectives on Palliative Care Education**

Chairs: Jose Pereira (Switzerland) – Steffen Eychmüller (Switzerland)

197 **Competencies in Palliative Care**  
Jose Pereira *Switzerland*

198 **Assessment in Palliative Care education: Reviewing the instruments and their properties**  
Mone Palacios, Ron Spice *Canada*

199 **“Multiprofessional teaching and learning: taking the lead in a novel approach”**  
Steffen Eychmueller *Switzerland*

14.00–15.00	<b>Workshop</b> <b>Review and Critique of a Scientific Paper</b> Chairs: Geoffrey Hanks (United Kingdom) – Marie Fallon (United Kingdom)	London Hall – Building C
14.00–15.00	<b>Free paper session</b> <b>Symptoms in Palliative Care 2</b> Chairs: Tine De Vlieger (Belgium) – Nathan Cherny (Israel)	Barcelona Hall – Building C
200	<b>Twist in the evaluation of the terminal patient</b> Pilar Lazaro Malo <i>Spain</i>	
201	<b>The Use of Drugs at the End of Life</b> Ruth Flockton <i>United Kingdom</i>	
202	<b>Physicians preference of thromboprophylaxis in palliative care patients</b> Herbert Watzke <i>Austria</i>	
203	<b>Helping people with advanced cancer and their care givers manage conflict over food</b> Jane Hopkinson <i>United Kingdom</i>	
14.00–15.00	<b>Free paper session</b> <b>Policy</b> Chairs: Xavier Gomez Batista (Spain) – André Rhebergen (The Netherlands)	Bergen Hall – Building C
204	<b>Categorising palliative care development: a global perspective</b> Michael Wright <i>United Kingdom</i>	
205	<b>Opioid prescribing – changing Romanian legislation</b> Alison Landon <i>Romania</i>	
206	<b>Creativity in Promoting Palliative Care Awareness</b> Mali Szaifer <i>Israel</i>	
207	<b>Providers' Assessments of Barriers to Optimal Cancer Pain Management in 5 Latin America Countries: Argentina, Brazil, Cuba, Mexico, and Peru</b> Isabel Torres Vigil <i>United States</i>	
14.00–15.00	<b>Free paper session</b> <b>Palliative Care – Non Cancer</b> Chairs: David Oliver (United Kingdom) – Katherine Frogatt (United Kingdom)	Brussels Hall – Building A
208	<b>Renal patients have symptoms too – a cross-sectional survey of symptoms in stage 5 Chronic Kidney Disease managed without dialysis</b> Fliss Murtagh <i>United Kingdom</i>	
209	<b>Multiple Sclerosis and Palliative Care: Unmet needs of severely affected patients in Germany</b> Maren Galushko <i>Germany</i>	
210	<b>Addressing the diversity of symptoms in every day life in end-stage COPD patients</b> Jolanda Habraken <i>The Netherlands</i>	
211	<b>Patients with advanced heart failure attending a specialist heart failure unit – do specialist palliative care services have a role?</b> Norma O'Leary <i>Ireland</i>	
14.00–15.00	<b>Free paper session</b> <b>The Diversity of Palliative Care 3</b> Chairs: Florian Strasser (Switzerland) – Françoise Porchet (Switzerland)	Paris Hall – Building A
212	<b>A Family Perspective on the Emotional Burden of End-of-Life Decision Making in an Intensive Care Unit</b> Teresa Albanese <i>United States</i>	
213	<b>Are psycho-social factors underestimated in managing nausea?</b> Peter Martin <i>Australia</i>	
214	<b>Burnout syndrome, coping strategies and risk behaviors in doctors from Romanian palliative services</b> Ovidiu Popa-Velea <i>Romania</i>	
215	<b>Physician strategies in communication about prognosis. An observational study</b> Lotte Rogg <i>Norway</i>	

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<b>15.00–15.15</b>	<b>Break</b>	
<b>15.15–15.45</b>	<b>Plenary 10</b> Chairs: Franco De Conno (Italy) – Tine De Vlieger (Belgium)	<b>Plenary Hall</b>
	<b>216 Into the unknown: advance care planning for the end of life</b> Jane Seymour <i>United Kingdom</i>	
<b>15.45–16.15</b>	<b>Plenary 11 – Floriani Lecture</b> Chairs: Franco De Conno (Italy) – Tine De Vlieger (Belgium)	<b>Plenary Hall</b>
	<b>217 Are we prepared to unmask the face of death?</b> Jacek Luczak <i>Poland</i>	
<b>16.15–16.45</b>	<b>Closing ceremony</b>	<b>Plenary Hall</b>

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# Posters programme

Thursday 7 June 2007

## CONNECTING DIVERSITY

10th Congress of the  
European Association for Palliative Care

## Assessment

- 218 **Sensitivity and specificity of a two-question screening tool for depression in a specialist palliative care unit.**  
Ann Payne, Brien Creedon, Sandra Barry, Carol Stone, Kathleen O' Sullivan, Catherine Sweeney, Tony O' Brien *Ireland*
- 219 **Illness-related hopelessness in advanced cancer: influence of anxiety, depression, and preparatory grief.**  
Kyriaki Mystakidou, Eleni Tsilika, Efi Parpa, Paraskevi Athanasouli, Maria Pathiaki, Antonis Galanos, Anna Pagoropoulou, Lambros Vlahos *Greece*
- 220 **Screening for increased preparatory grief in advanced cancer patients.**  
Eleni Tsilika, Kyriaki Mystakidou, Efi Parpa, Maria Pathiaki, Elisavet Patiraki, Lambros Vlahos *Greece*
- 221 **The Distress Thermometer (DT) a tool to monitor changes in psychological distress over time in patients with supportive and palliative care needs.**  
Joe Low, Sue Gessler, Emma Daniells, Rachael Williams, Veronica Brough, Adrian Tookman, Louise Jones *United Kingdom*
- 222 **Is Macedonia ready for palliative care?**  
Ann Sturley<sup>1</sup>, Blasko Kasapinov<sup>2</sup>, Frank Ferris<sup>1,1</sup> *United States*  
<sup>2</sup>*Macedonia*
- 223 **The first experience of palliative care for cancer patients in Georgia (Cancer Prevention Center Palliative Care Clinic, Georgia)**  
Rema Ghvamichava, Mikheil Shavdia, Ioseb Abesadze, Giorgi Metivishvili *Georgia*
- 224 **Heart-Rate variability in palliative patients - a pilot study**  
Gernot Ernst *Norway*
- 225 **The Schedule for Meaning in Life Evaluation (SMILE): Validation of a new instrument for meaning-in-life research**  
Mechtild Kramer, Gian Borasio, Sibylle L'hoste, Martin Fegg *Germany*
- 226 **Longitudinal Study of Distress: The Interactions between Distress Domains and Their Impact on the Global Distress Experience of Advanced Cancer Patients from Time of Referral to Palliative Care Services to Death**  
Katharine Thompson, Scott Murray, Gordon Murray, Marie Fallon *United Kingdom*
- 227 **Results of a Study to Assess Quality of Life and Cost of Home-Based Palliative Care Delivery in New Delhi, India**  
Harmala Gupta<sup>1</sup>, Stephan Tanneberger<sup>2</sup> *India* <sup>2</sup>*Italy*
- 228 **Quality of life in patients with prostate cancer: (A) comparison between a disease-targeted questionnaire and an individualised assessment method**  
Patrick Stone, Robert Murphy *United Kingdom*
- 229 **Quality of life in patients with prostate cancer: (B) development and application of a hybrid assessment method**  
Patrick Stone, Robert Murphy *United Kingdom*
- 230 **Development of a palliative medicine comprehensive computer based symptom assessment questionnaire**  
Jordanka Kirkova, Mitchell Russell, Declan Walsh *United States*
- 231 **'Fear of the Unknown' A Retrospective Analysis of Management of Unknown Primary Carcinoma in a District General Hospital**  
Jennifer Doherty, Ernie Marshall, Clare Littlewood, Muhammad Abbas *United Kingdom*
- 232 **Detecting symptoms of depression and anxiety in patients with severe pulmonary disease: a pilot study**  
Magnus Lindskog, Lars Wahlström, Göran Isacson, Sverre Sörenson *Sweden*
- 233 **Symptom variability in advanced cancer during repeated measurements**  
Wael Lasheen<sup>1</sup>, Declan Walsh<sup>1,2</sup>, Katherine Hauser<sup>1</sup>, Matt Karafa<sup>1</sup> <sup>1</sup>*United States* <sup>2</sup>*United Kingdom*
- 234 **Impact of acute complications on quality of life in palliative lung cancer patients**  
Verena Gartner, Katharina Kierner, Michael Weber, Herbert Watzke *Austria*
- 235 **Implementation of the mittz in a palliative care network in the Netherlands**  
Ireen Proot, Paula Hoync van Papendrecht, Annemie Courtens *The Netherlands*
- 236 **'Brief Solution-Focused Practice'. A tailor-made psychological approach for palliative care**  
Dominic Bray, Karen Groves *United Kingdom*
- 237 **Assessment of quality of life in palliative care**  
Ana Pinto, Pedro Ferreira *Portugal*
- 238 **Is continuity of care for the terminally ill possible when offered by Palliative Support Teams (PST) in general hospitals (GH)?**  
Ruddy Verbinnen, Fred Louckx *Belgium*
- 239 **Evaluating the effectiveness of hospital-based palliative care team: the first 3-year audit using a numeric rating scale in Japan**  
Tetsusuke Yoshimoto, Yuki Ishino, Atsuo Hisada, Atsunaga Kato, Kazuhito Matsubara, Masao Matsuda *Japan*
- 240 **Screening for psychological distress in palliative care using Touch screen questionnaires**  
Parvez Thekkumpurath, Chitra Venkateswaran, Manoj Kumar, Mike Bennett *United Kingdom*
- 242 **The effect of the Liverpool care pathway for the dying: a multi centre study**  
Laetitia Veerbeek, Lia Van Zuylen, Siebe Swart, Paul Van der Maas, Elsbeth De Vogel-Voogt, Carin Van der Rijt, Agnes Van der Heide *The Netherlands*
- 243 **Prevention of Pathological Fractures: Do Healthcare Professionals Recognise the Warning Signs?**  
Helen Emms, Nicholas Emms, Caroline Osborne, Andrea Whitfield *United Kingdom*
- 244 **Subjective well-being, meaning in life and personal values in health care professionals working in palliative care vs. maternity wards**  
Sibylle L'hoste, Gernot Hauke, Gian Domenico Borasio, Martin Fegg *Germany*
- 245 **The enigma of documenting nursing care according to the hospice philosophy**  
Helena Hallgren, Birgit Rasmussen *Sweden*
- 246 **Effectiveness of symptom control in advanced cancer patients for palliative care teams in Catalonia, Spain**  
Rosa Roca, Jose Espinosa, Albert Tuca, Josep Porta-Sales, Xavier Gómez-Batiste *Spain*
- 247 **Measurement of meaning in life: a systematic review of meaning-in-life scales (1956-2006)**  
Tobias Skuban, Claudia Bausewein, Gian Domenico Borasio, Martin Fegg *Germany*
- 248 **Symptom Control In An Acute Palliative Care Unit: Preliminary Results**  
Josep Porta-Sales, Jose Espinosa, Gala Serrano, Silvia Paz, Cristina Garzón, Albert Tuca, Xavier Gómez-Batiste *Spain*



- 249 **Predictors of patient ratings of depression on admission to a tertiary-level inpatient palliative care unit: What is the role of pain and symptom burden?**  
Cheryl Nekolaichuk<sup>1</sup>, Peter Lawlor<sup>2</sup>, Alan Kelly<sup>2</sup>, Robin Fainsinger<sup>1</sup>, Eduardo Bruera<sup>3</sup>, Sharon Watanabe<sup>1</sup>, Hue Quan<sup>1</sup>  
<sup>1</sup>Canada <sup>2</sup>Ireland <sup>3</sup>United States
- 250 **Cost effectiveness of oral opioids in pain management**  
Mamuka Tatishvili, Rema Ghvamichava, Mikheil Shavdia, Ioseb Abesadze *Georgia*
- 251 **Cross cultural adaptation of the Spanish version of the Edmonton symptom assessment (ESAS)**  
Ana Carvajal, Carlos Centeno, Julia Urdirroz, Marina Martinez, Antonio Noguera, Maria Angustias Portela *Spain*
- 252 **Production of a computer-based database for use in clinical palliative care**  
Toshihiko Nakatani, Ruiko Hatto, Nobue Uchida, Takuji Inagaki, Shihoh Okazaki, Yuji Morita, Yoji Saito *Japan*
- 253 **Evaluation of the palliative care activity with using palliative care database**  
Ruiko Hatto, Toshihiko Nakatani, Keiko Ota, Chie Itakura, Koji Naora, Yoji Saito *Japan*
- 254 **Measuring quality indicators in all Extremaduran palliative care teams**  
Javier Rocafort, Marco Antonio López, Laura Blanco, Silvia Librada, Beatrice Pop *Spain*
- 255 **Attitudes of Nurses - a key to outcome measures in palliative cancer care?**  
Carina Lundh Hagelin, Yvonne Wengström, Carl Johan Fürst *Sweden*
- 256 **Occurrence and nurse documentation of oral problems in palliative care**  
Lillian Fransson, Lena-Marie Petersson, Carl Johan Fürst *Sweden*
- 257 **Effectiveness of parenteral antibiotics in terminally ill hospice patients: a retrospective study**  
Elinor Brabin, Leslie Allsopp *United Kingdom*
- 258 **Body composition changes in advanced cancer associated with Angiotensin-Converting Enzyme gene polymorphism (ACEGP): preliminary results**  
Antonio Viganò, Barbara Trutschnigg, Rachel Bond, Seema Brar, Nancy Hamel, Jean-Francois Theberge, William Foulkes, Jose Morais *Canada*
- 259 **What does the experience of people with intellectual disabilities tell us about the concept of "total pain"?**  
Linda McEnhill *United Kingdom*
- 260 **Assessing sleep disorders in hospitalized patients: attention to details**  
Jorge Eisenchlas, Joanna McEwan, Maximiliano Zuleta, Cecilia Jacobsen, Marisa Pérez, Lorena Alvarenga, Gustavo De Simone *Argentina*
- 261 **Feasibility study of the palliative outcome scale (POS) in hospitalized patients**  
Jorge Eisenchlas, Ernesto Vignaroli, Marisa Perez, Mariela Bertolino, Lorena Alvarenga, Celina Berenguer, Lorena Aranda, Silvina Dulitzky, Melina Armada, Gustavo De Simone *Argentina*
- 262 **Collecting research data by computers in palliative care - results from a pilot study**  
Frode Laugen, Line Oldervoll, Vanja Stroemsnes, Marianne Jensen Hjermsstad, Jon Haavard Loge, Stein Kaasa *Norway*
- 263 **Watch out for the mouth – taking care of the oral cavity in palliative care**  
Federica Bresciani, Isabella Caracristi, Michela Paolazzi, Claudia Bortolotti, Monica Gabrielli *Italy*
- 264 **Web based After Death Analysis (ADA) tool for supporting End of Life care in primary care**  
Thomas Thomas, Helen Meehan, Karen Shaw, Collette Clifford, Mike Parry, Frances Badger *United Kingdom*
- 265 **Our plan for the patient - applying the N.A.N.D.A. recommendations in Trento**  
Monica Gabrielli, Federica Bresciani, Monica Claus, Helmut Menestrina *Italy*
- 266 **Heart rate variability for prediction of life span in hospice cancer patients**  
DoHoon Kim, Youn Seon Choi, Jeong A Kim, Su hyun Kim, Dae Gyeon Kim *South Korea*
- 267 **Diagnostic Value of Kidney, Ureter, and Bladder (KUB) Radiographs in Palliative Management of Gastrointestinal (GI) Symptoms. Preliminary Findings**  
Ruth Lagman, Armida Parala, Mellar Davis, Declan Walsh, Susan LeGrand, Lesley Bicanovsky *United States*
- 268 **Prospective study of workload in palliative care unit**  
Marilene Filbet, Marina Portier, Stephane Gobatto, Aurelie Laurent, Mario Barmaki, Wadih Rhondali, Isabelle Brabant *France*
- 269 **Improving the Holistic Assessment of Palliative Care Patients Needs – a Help the Hospices Initiative**  
Dai Roberts, Nick Pahl *United Kingdom*
- 270 **Suffering and Relational Centred Medicine in Palliative Care**  
António Barbosa *Portugal*
- 271 **Palliative care needs assesment in Roma community**  
Daniela Mosoiu, Liliana Ilie *Romania*
- 272 **SICP Suggestions of Recommendations on Palliative Sedation/Sedation at the end of life**  
Raffaella Speranza *Italy*
- 273 **The Borg CR 10 Scale - an alternative to NRS in symptom assessment?**  
Marcus Wiklund, Carl Johan Fürst *Sweden*
- 274 **Liverpool Care Pathway - integration into the electronic patient record**  
Irene Larsson-Daderman, Mary-Jane Windus, Uta Marinko, Carl Johan Fürst *Sweden*
- Complementary therapy**
- 275 **Complementary Therapies at St Joseph's Hospice**  
Maura Cochrane *United Kingdom*
- 276 **Psychosocial Intervention in C.P.: Art and Meditation as a road to the Spiritual Dimension of the Being**  
Gustavo Rodio, Dorita Gonzalez, Gabriela Boso, Ana Laura Ottonello, Varya Kuis, Stella Salgueiro *Argentina*
- 277 **A PNIE point of view (psychoneuroimmunoendocrinological). Complementary therapeutics for symptom control**  
Gustavo Rodio, Dorita Gonzalez, Gabriela Bosso, Ana Laura Ottonello, Varya Kuis, Stella Salgueiro *Argentina*
- 279 **Evidence of art-therapy efficacy in patients with terminal cancer**  
Nadia Collette, Antonio Pascual *Spain*
- 280 **The role of a physiotherapist at the Hungarian Hospice Foundation**  
Nóra Ferdinandy *Hungary*
- 281 **Alternative Therapy in Cancer In seeking of the Miracle Cure or the Power and the Ethics of the advertisement**  
Nikolay Yordanov, Rumen Stefanov *Bulgaria*

- 282 **The Combined use of Complementary Therapies and Bio-medically Oriented Health Care in Palliative Stages of Cancer: A Narrative Analysis**  
*Johanna Hök, Caroline Wachtler, Torkel Falkenberg, Carol Tishelman Sweden*
- 283 **The use of Phallus Impudicus as a complementary remedy in palliative care in cancer**  
*Sergejs Kuznecovs, Klara Jegina, Ivans Kuznecovs Latvia*
- 284 **Attitudes to Acupuncture among Patients and Physiotherapists in Oncology care**  
*Anna Enblom, Johanna Selmonsson, Malin Asterud, Sussanne Borjesson Sweden*
- 285 **An exploration of massage and communication, including recommendations for teaching strategies to enable colleagues to use touch in safe and therapeutic ways**  
*Lisa Smith United Kingdom*
- 286 **Use of blood transfusion in palliative care patients. Health ? Related Quality Of Life**  
*Feliks Blaszczyk, Anna Oronska Poland*
- 287 **Cancer as an Anticipated Form of Loss**  
*Katalin Muszbek, Eszter Biró, Tamás Halmay Hungary*
- 288 **Sexual Dysfunction and Cancer: a Behavioral Intervention Study**  
*Karin Stinesen Sweden*
- 289 **How art therapy in palliative care unit can help patient and family?**  
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## Faith Mwangi-Powell

Dr Faith Mwangi-Powell is currently the Executive Director of the African Palliative Care Association (APCA), a post she has held since joining in January 2005.

Dr Mwangi-Powell is a member of the board of directors for the International Association for Hospice and Palliative Care (IAHPC) and the Foundation for Hospices in Sub-Saharan Africa (FHSSA) and a member of the advocacy committee for the Worldwide Palliative Care Alliance (WPCA). Prior to the APCA, Faith worked for two and a half years with the Diana, Princess of Wales Memorial Fund, London, UK as an International Advocacy Officer for Palliative Care.

# Connecting diversities to scale up palliative care in Africa

Globally, approximately 56 million people die each year. Moreover, 42 million currently live with HIV/AIDS, and there are 15.3 million new cancer cases per annum. An estimated 60% of such people would benefit from palliative care. However, scaling up palliative care services to meet this need has numerous challenges that have worldwide applicability, including: limited workforce capacity; lack of policy integration; unavailability of effective pain relieving medication; lack of research evidence; low public awareness; uncommitted governments; the lack of funding; entrenched attitudes within the medical profession; cultural taboos surrounding death and the disclosure of diagnosis; and the absence of a consensus that regards palliative care a basic human right.

In Africa, these challenges are compounded by the high disease burden and poverty. It is against this backdrop that this presentation will provide an overview of palliative care development across Africa.

Following a description of the existing levels of palliative care need, it will explore the different service models that have been developed to address that need. It will be contended that connecting the diversities in service provision, whereby achievements and successes are replicated and weaknesses identified, is essential to optimise service delivery across the continent to those in need.

One of the ways in which these connections can be forged is through differing partnership models: both at the micro (ie peer-to-peer) and the macro (ie provider-to-provider, organisation-to-organisation, both nationally and internationally) level. Drawing upon the experiences of the African Palliative Care Association, this presentation will review such collaborative partnerships, highlighting their value in collectively beginning to address the need for palliative care development, and outlining some of the challenges entailed in ensuring they function successfully ■



## Barbara Monroe

Barbara has been a social worker for over 30 years. She joined St Christopher's Hospice in 1987 and became Chief Executive in 2000. She is also Chair of the national Childhood Bereavement Network. She has written extensively about the psychosocial aspect.

# Resilience and palliative care

Resilience is receiving increasing research attention as we seek to explain the variety and complexities of human response to difficult circumstances and the recent understanding that many more individuals than initially thought can continue to thrive despite adverse experiences and compounding risk factors. Resilience is not just about re-forming but about the possibility of growth. It offers a unifying concept to sustain the most significant understandings of four decades of palliative care and incorporate more effective investment in community and public health approaches. This integration is vital if we are to reconcile the tension between the rhetoric of choice and equity in end-of-life care and the demands of rising healthcare expectations in aging populations with increasingly limited professional and financial resources. These Western world challenges are compounded by the huge needs of resource-poor countries.

Resilience is inextricably linked to risk in an interactive process occurring over time and influenced by individual and family variables, social context and social structure. Resilience demands a more sophisticated assessment, recognising that many of these variables are cross-cutting and can be positive or negative in impact. It is important for the future development of end-of-life care that health and social care issues remain integrated. A return to the privileging of a narrow medical definition of palliative care is presaged, 'The central aspect of palliative care is symptom control delivered humanely with adequate information... undue emphasis on attending to families is demanding of resources which might be better

devoted to a wider population of patients' (Randall and Downie 2006). Fortunately some of the economic realities of modern healthcare are drivers in a more positive direction. A recent systematic review of factors influencing death at home in terminally ill patients with cancer emphasises the need to explore family support and empowerment and the role of prevention and public education (Gomes and Higginson, *BMJ* 2006). Palliative care has often been slow to respond to the challenges of disadvantage and exclusion. If it is to do so it must not lose the founding ethos of hospices which sought to empower and to promote strengths and resources.

Analysis of a series of ten study days on resilience in palliative care held at St Christopher's in 2005 revealed key themes: secure attachments, meaning and sense, hope, coherence, creativity, good memories, public education and community support, cultural awareness, internal locus of control, wellbeing, self-esteem, one supportive person and learned optimism. Insights from the field of bereavement underline the importance of balancing vulnerability and health promotion. Evidence supports the beneficial power of narrative in meaning making and the integration of difficult experiences. Studies on 'hope' emphasise the value of reminiscence therapy, humour and the nurturing of independence. Creative therapies can also increase the resources of individuals for use at time of threat. Resilience work supports the concept of brief, focused, cost-effective interventions designed to avoid pathologising and to boost confidence, coping and action. Examples include cognitive behavioural therapy and Kissane's

family-focused grief therapy. A clearer understanding of the neurobiological basis of behaviour and its links to resilience is developing.

Palliative care must work in partnership with the communities in which people live to change attitudes and empower them to respond supportively. Canada and Australia have developed government and workplace initiatives to support carers and the terminally ill. Palliative care already uses professional education to extend its messages beyond its immediate sector. School-linked programmes and attempts at wider public education are emerging. Social marketing and information strategies will become more important as we try to find the right balance between expert professional interventions and general loss education. Public receptiveness to internet

based resources points to some of the possibilities. Studies of user involvement and group work in palliative care demonstrate the positive therapeutic impact of engagement and increased social connectedness. The future will hold new forms of mutual help groups and volunteering.

The concept of resilience makes it clear that individual factors such as a sense of agency and seeing the world as understandable must be linked to positive family, community and cultural resources, values and connections. Efforts to improve individual welfare cannot alone meet the aspirations of society in relation to high quality, cost-effective and equitable care for all dying people. The West has much to learn from the community-funded and volunteer-supported programmes in resource-poor countries ■



## Dr Peter Lawlor

Dr Lawlor worked with the Edmonton Regional Palliative Care Program prior to returning to Dublin in 2004 as a consultant at Our Lady's Hospice and St James's Hospital. He holds an adjunct Associate Professor appointment in Palliative Care Medicine at the University of Alberta.

# Hydration practice: attitudes and evidence

Hydration in end-of-life care is often viewed as signifying the essence of compassionate care. Much of the literature on artificial hydration (AH) relates to rhetorical arguments and studies of limited scientific rigour. Much of the controversy has arisen from diametrically opposed viewpoints: the hydrate "all" approach of the relatively more aggressive biomedical model of care, versus the more conservative hydrate "none" approach of the more traditional hospice model of care.

The opposing views are reflected by the great variation in the practice of AH. Variation occurs in the proportion of patients who receive AH in different cultural settings and care locations. Variation has also been noted in the volumes of fluid administered and in the route used for hydration administration. It has been suggested that patients will often defer to their physicians in the decision-making process, and ultimately do what the physician suggests.

Hypovolaemia and dehydration are fluid deficit states. In hypovolaemia, the fluid deficit is in the intravascular volume, which can be iso-, hypo-, or hypertonic depending on the proportion of water and solute that is lost. In dehydration, there is a loss of total body water, which invariably comes from the intracellular compartment. Dehydration is associated with hypernatraemia, whereas hypovolaemia can be associated with iso-, hypo-, or hypernatraemia. Fluid

deficits can arise due to decreased intake, increased loss, or both. It should be remembered that fluid loss can occur with "third spacing" of fluid, as occurs in ascites. Physiological changes occur with aging, including a reduced proportion of total body mass due to water, a possible reduction in thirst response to dehydration, and a decrease in renal response to intravascular volume changes. Many of the classical symptoms and signs of fluid deficit are unreliable in the elderly and in cancer patients.

The identification of clinical outcome measures and biochemical indices that truly reflect hydration status has been a major research challenge. Only six studies met the inclusion criteria of a systematic review, in which no conclusion could be drawn regarding benefit. The studies that have examined dry mouth or thirst suggest that it occurs in 61–87% of patients receiving end-of-life care. However, confounding variables such as anticholinergic or psychotropic medication use, stomatitis, and mouth breathing can create difficulty in interpreting study findings. The biochemical indices of hydration have largely proved inconsistent in their reflection of hydration status. One study found that atrial natriuretic peptide levels may prove useful in determining hydration status.

To date there is only one published randomised controlled trial that examined hydration benefits in advanced cancer patients. It demonstrated a



significant improvement in the sedation and myoclonus scores in the hydration treatment group. The authors of this study reported patient accrual difficulties due to the frequent co-occurrence of dehydration signs and cognitive deficit, thereby creating difficulties with obtaining consent at study entry.

Studies of delirium, a multifaceted syndrome that is often potentially reversible, have demonstrated some conflicting results. In one study dehydration was identified as a covariate significantly associated with delirium reversibility. A Japanese study demonstrated that dehydration occurs in association with delirium but not necessary with reversibility. Most opioids and their metabolites are renally eliminated. Demonstration of opioid toxicity in association with elevated levels of opioid metabolites has been inconsistent, except in the case of renal impairment. Given that a fluid deficit state may progress inexorably to the state of prerenal renal impairment, it seems logical at least to consider AH in

patients on opioids who are fluid deficient, or at risk of fluid deficit, in order to prevent prerenal renal impairment.

In the decision-making process on AH we need to consider: the true hydration status of the patient, the complications and symptom burden occurring with the fluid deficit state versus AH; the patient's prognosis and decision-making capacity; knowledge, attitudes, beliefs and wishes, of patients, their families or proxies, and the multidisciplinary team regarding AH; concomitant use of sedatives and withholding or withdrawal of AH; the assessment of delirium reversibility. Ultimately, the best ethical and evidence based practice will involve an individualised approach to AH. A timed trial may be considered. Education and support is essential for relatives, who should receive clear and consistent communication from the multidisciplinary team ■



## Lars Björklund

I was ordained as a priest in the Church of Sweden in 1979 and I have been employed as a chaplain at Sigtunastiftelsen since the autumn of 2001. Previous employment: 22 years at Akademiska Sjukhuset (the university hospital) in Uppsala, Sweden, with ten years based in the children's ward.

# The courage to be

Several years ago, when I thought of writing a book about meeting people in pain and crisis and close to death, I considered naming the book *The Art of Doing Nothing*. Early on, I had the experience that in the really difficult meetings, there was nothing to be done. All attempts to make it better or maybe bring out a positive feeling were in vain. The sorrow and the pain were too great. I still felt that it was important to be there. Not for the purpose of doing something but perhaps to lessen the loneliness a bit, in the midst of all pain.

In circumstances where it is constantly important to accomplish something, and where that which is accomplished is given the greatest meaning, a person quickly becomes lonely if there is nothing to be done. Or she might also be put through unnecessary things. What is being done, is done only for the act of doing, and this involves the risk that the person who longs only for closeness is abandoned. Another risk is that what can still be done appears worthless and is seen as nothing at all. I am thinking of such things as turning the pillow for someone who is too tired to do it themselves, to stretch out the sheet and make sure there is clean and fresh water in the glass at the bedside table next to someone who is dying. If this is all that is possible to do for another human being, then this is all you can do. To do all you can for someone is a great act, and should not be called "nothing".

Sometimes we need to do absolutely nothing, and have faith that our presence is enough. But even if we can let go of the thought to accomplish something, there can still be an unspoken wish that things will get better for

the one we meet, or at least that there will be a change. I dare say there are moments when our wish can be conceived as a demand and can cause us to let down the one we meet. In certain vulnerable situations the same risk arises if we give something. In the emptiness that is born if we do nothing, want nothing and give nothing, a meeting can still take place. A meeting without expectations and demands, where a fellow human being is made visible and confirmed.

My mission is that of love, and no matter how I turn the word love inside out, I always come to the conclusion that love means to demand nothing at all. If I give love, and by the act of giving accept another person, I have fulfilled my mission. Without expectations love grows. But if I expect something in return or expect something to get better, the love can die if the answer or the improvement fail to occur. A love that expects an answer can in certain situations be conceived as a threat. But love demands no success. It is there without expectations of results and without expectations of gratitude. Redone in the difficult meeting it turns into a form of method. When I meet a person who needs help I can stay without doing anything. I can be there without giving anything else than my presence and I can leave without the expectation of gratitude. Several meetings have looked exactly like this. I could do nothing, give nothing, and I could not see any measurable result. What makes me believe that it is still important to stay are stories from people who a long, long time after a crisis realise that the one who offered the most help was the one who was there with neither demands nor expectations. Patiently and lovingly ■



### Finella Craig

Finella Craig has been a Consultant in Paediatric Palliative Care at Great Ormond Street Hospital for Children since 2002. Her palliative care training included two years with a community and hospital-based adult palliative care service as well as with the paediatric palliative care team at Great Ormond Street Hospital. She has particular interests in palliative care for children with non-malignant conditions.

## Paediatric palliative care

Plenary abstracts

Living with a life-threatening or life-limiting condition can be challenging, particularly for adolescents and young adults as they face the physical, cognitive and emotional changes of the transition to independent adulthood. Some may have been progressing through normal adolescent development prior acute illness. For those with progressive disorders, adolescence may be accompanied by deteriorating physical health and/or mental ability. Others may be coping with lifelong chronic conditions, which may not fit easily alongside adolescent development and activities.

This presentation will explore the impact of life-limiting illness on adolescent development and how, as professionals, we can support children with life-limiting illness through adolescence to adulthood. The presentation will address issues of physical independence, independence in decision-making, financial independence, peer group identification, changing relationships with parents, sexuality and spirituality. We will discuss how, with the right support, a young person's sense of individuality, autonomy, value and continuity can develop and be reinforced ■



## Frank D Ferris MD

Frank D Ferris, MD is the Medical Director of Palliative Care Standards and Outcome Measures and responsible for the international programmes at San Diego Hospice & Palliative Care. He is a Clinical Professor, Voluntary, in both the Department of Family & Preventative Medicine, and the Department of Medicine, at the University of California, San Diego School of Medicine, San Diego, California.

# Implementing quality palliative care – how to prove it

Quality palliative care is of interest to everyone who is receiving or providing care. The quality of the care that is provided depends on everyone's understanding of the underlying model that is guiding patient/family care; the organisation's mission and vision; and the consistency of the language, practice and treatment guidelines, outcome assessment and performance improvement strategies that everyone is using from day to day.

Implementation of quality palliative care within an organisation starts with careful strategic planning followed

by the systematic development of guidelines, outcome measures, standards and a performance improvement process through an inclusive consensus-building process. By modifying existing widely-accepted models, organisations can expedite their implementation of quality palliative care. Through careful attention to evolving this process over time, everyone will be the benefactors of a high-quality palliative care experience.

This plenary presentation will focus on the process and the potential outcomes/benefits for key stakeholders ■



## Katalin Muszbek MD

Katalin Muszbek MD, psychiatrist, psychoanalyst, Director and founder of the Hungarian Hospice Foundation, Vice-president of the board of the Eastern and Central European Palliative Task Force and member of the International Psycho-oncology Society.

# Cultural issues in facing death

Plenary abstracts

Individual and social attitudes relating to reaction for loss have been undergoing significant changes during the last decade. The aftermath of loss depends on various conditions. The presentation separates the role of traditions and psychological aspects of the individual while it also touches the role of palliative care.

1. Social attitudes: attending to a dying person in traditional cultures relies on both the family and the society while in the developed world individual autonomy is dominant. Formerly it was the community, the rituals and the traditions that helped facing death. In traditional communities mourning was not only accepted, but it was an expected form of behaviour associated with numerous rituals.

By today the majority of these traditions have ceased and the attitude system of the society regarding death and bereavement have also undergone changes.

Effective bereavement today means rapid mourning process, few personal reactions and an early back-to-normal lifestyle.

2. The individual psychological reactions depend on personality structure. Coping and defensive mechanisms in facing death and loss processing both vary with the individual. It is important to analyse aggression and remorse handling linked to loss as well as the role and the consequences of suppression.
3. Healers – enchanters, shamans and doctors are omnipotent people helping us to cope with illnesses and symptoms. Cultural differences in this area are substantial but the omnipotent saver is a determinative personality in all different cultures. In today's modern societies this mission is completed through palliative care. The need for it is universal, regardless of frontiers and nations ■



## Professor Jose Pereira

Jose is the Leenaards Foundation Professor of Palliative Care at the University of Lausanne and the University of Geneva. He is also Director of the Palliative Care Service at the Centre Hospitalier Universitaire Vaudois in Lausanne and has a cross appointment at the Universities of Calgary and Alberta in Canada. He has a special interest in palliative care education.

# Evaluation of palliative education: why bother?

Envisage a palliative intervention that costs a small health region with 600,000 inhabitants 250,000 euros annually. Clinicians and administrators would be justified in asking for evidence in support of it. If that evidence was lacking, a study with an appropriate design and with validated outcome measures would likely be initiated. Suppose the intervention was an education programme. Would the questions regarding evidence and cost-effectiveness still apply and what would constitute sufficient evidence?

From a broad perspective, educators such as Miller and Kirkpatrick have described a hierarchy of levels of evaluation. At the bottom of the pyramid are studies that look only at participation, in the middle participants' reactions and learning gains in terms of changes in knowledge and attitudes, and at the top the direct impact on the delivery of healthcare and patient care. The latter, the "holy grail" of education interventions, is elusive but not impossible.

With some notable exceptions, the palliative education literature has focused on descriptive reports and participant satisfaction. Wider utilisation of standardised validated instruments to evaluate changes in attitudes, knowledge and skills is encouraged. Several instruments, particularly in the domain of attitudes, are available. However, the assumption that changes in learners' personal attitudes to death translate to improvements in clinical

care warrants further study. Standardised instruments (usually MCQs) evaluating knowledge are uncommon and often lack validity, reliability and item analysis data. The use of objective structured clinical examinations and other forms of evaluation is receiving increased attention. The need for economic analyses is also stressed.

Many of the concepts and principles of biomedical research are also applicable in medical education research. The fundamental steps of hypothesis generation, uniform outcomes measures, and sound statistical analysis also apply in medical education. Education research has been classified into three broad categories; a) observational/descriptive; b) co-relational; and c) experimental. Within these are quantitative, qualitative, and mixed methods. All are important in education research. Not all medical education research is quantifiable, and qualitative research remains a key contributor to understanding education and its impact. Co-relational research attempts to establish relationships between observed differences among or between groups of participants. Experimental research is inherently difficult to conduct in medical education. Proper randomisation and double blinding are challenging. The large numbers of participants required for randomisation are often not available, particularly with small classes. It is difficult to achieve standardisation in educational interventions as there is no fixed dose and the intervention is vulnerable

to many confounding factors (eg dynamism of the instructor). Lastly, it is often difficult to separate the specific effects of different educational activities within one programme. Nevertheless, randomised studies are possible, do exist, including in palliative care, are generally promoted in medical education, and when appropriate and possible, should be considered. Collaboration with education experts is essential.

There is almost universal recognition in medical education circles of the need for improved evidence to support education interventions, hence the emergence of 'best evidence medical education' (BEME). However, what constitutes best evidence remains highly debated. Some argue for quantitative, randomised-type methods, while others argue that such designs are not appropriate for medical education. Attempts to develop an evidence-level classification for medical education (similar to that used in biomedical research) has yielded mixed results.

Comparisons between interventions are also difficult when different methods and evaluation instruments have been used. The complementary use of statistical significance and effect size (which does not rely on sample size) is advocated. Effect sizes of  $> 0.5$  are optimal and levels of  $>0.8$  highly desirable.

However, education research covers a much broader field than what is discussed above and palliative care is well positioned to participate in that activity. An example is interprofessional education, a current topic in healthcare. Despite its importance, it remains poorly understood from an education perspective. What are the best methods of implementing it? The introduction of spirituality in health curricula is another area.

In conclusion, education evaluation and research does matter and is an important area of work in palliative care ■



## Augusto Caraceni

Augusto Caraceni trained in neurology and palliative care in Italy and the USA. His main clinical and research expertise is in cancer pain, opioids, neuropathic pain, pain measurement, delirium and palliative medicine in general. In these fields he has published about 140 different publications, both in journals and books.

# The pathological states of consciousness. *"Spiritus animalis residet in substantia cerebri"* (Varolius 1543–1575)

Consciousness has been explained as a function of a number of brain structures, starting with several studies between the second half of the 19th and the first half of the 20th centuries that were able to associate lesions and diseases in humans and animals with altered states of consciousness, abnormalities of the sleep-wakefulness cycle and the neural activity of the cortex, the hypothalamus and the brainstem reticular formation and nuclei.

The "level and the content of consciousness" are relatively simplistic neurological definitions that can be used to uncover the whole complexity of human subjective experience from emotion to personal identity. The philosophical and ethical implications of the meaning of higher brain functions at the end of life are important in the discourse about general medical decision-making as well as in end-of-life decisions about limitation of treatments, but they are not within the scope of this talk. The clinical evaluation of these functions is fully in the domain of palliative care, as at least 40% of patients experience episodes of delirium and many more go through stupor or coma before they die. Therefore, the appropriate assessment and diagnosis of pathological states of consciousness require that palliative care professionals are experienced in the basic mechanisms of the underlying higher brain

functions and with the use of routine instruments to assess clinically relevant findings.

Delirium is certainly one of the most common neurological syndromes seen in palliative care. Delirium, according to the DSM IV definition, can be viewed as an altered state of consciousness and attention and it is described by clinical findings ranging from a disordered sleep wakefulness cycle to hallucination or hypersomnia. The pathophysiology of delirium or of deliria is poorly understood as we know that very many causes, from metabolic changes to drug toxicities, can cause it. A common final pathway theory privileges the idea that all aetiological factors impact on the same neurological system. A more empirical theory could consider that a group of relatively similar symptoms and signs can be caused by lesions and factors that can be individually identified but not always present altogether. Hallucinations can be present as an isolated phenomenon and then evolve into frank delirium, level of consciousness can be reduced in hypoactive deliria or exaggerated in delirium tremens.

While clinically it is still practical to use the DSM IV definition and the distinction between hypoactive and hyperactive deliria, it is unlikely that we can just talk of a single clinical condition. The differential diagnosis of the



clinical syndrome requires an extra effort as again it can impact on management: non-convulsive status epilepticus, stupor-coma from structural brain lesions and drug toxicities can present with very similar clinical findings. Most recent research data show that we often do not have a better explanation to offer than the old "seed and soil" theory, understanding that advanced illness and compromised brain functions due to age or disease predispose to excessive brain reactions to most offending agents, from fevers to drugs. From a neuropharmacological point of view it is already clear that several systems are implied: acetylcholine, serotonin, dopamine, noradrenaline, histamine, hypocretine, GABA, are some of the most well known neurotransmitters who have individual and integrated roles in the modulation of consciousness and in sleep-wakefulness cycle regulation.

Therapeutic implications in palliative care include the ability to manage anxiety, insomnia, delirium, drug side-effects, and sedation at least. The wide use of sedation

as a therapeutic option in palliative care, often, but not only, at the end of life, has not been paralleled by a growth of knowledge and research among palliative care professionals about the pharmacology of sedation itself, leading to a lack of evidence-based protocols and guidelines specific to the palliative care conditions. The use of opioids, neuroleptics, benzodiazepines, antihistamines, sedatives such as propofol, noradrenergic or serotonergic agents is reported or anecdotal in palliative medicine and their indications and contribution to sedation poorly reflected in clinical practice.

To advocate more research in this area is a ritual statement, while I suggest that it represents indeed a unique opportunity to cross-fertilise the fields of anesthesiology, neurology, psychiatry and palliative medicine, to say the least, in producing an original set of data for a better understanding of the clinical, aetiopathological and therapeutic aspects of the altered states of consciousness ■



## Jane Seymour

Jane Seymour is the Sue Ryder Care Professor of Palliative and End of Life Studies at the School of Nursing, University of Nottingham, UK. She is a nurse and social scientist, with research interests in palliative care beyond cancer, end-of-life decision-making and public and professional education in relation to advance care planning.

# Into the unknown: advance care planning for the end of life

Advance care planning is a process of discussion between an individual and their care providers which takes place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity or the ability to communicate wishes to others. The goals of advance care planning have been identified as: ensuring that clinical care at the end of life is in keeping with patient preferences; improving the end-of-life care decision-making process by facilitating shared decision-making; improving wellbeing by reducing the frequency of under- or overtreatment. Outcomes of advance care planning may include the recording of: general values, wishes and preferences for care; nomination of proxies; and advance refusals of life-prolonging treatments; these are often known as 'living wills'. The legal status and frequency of use of such records varies across the developed world.

### The evidence base

The apparent potential for advance care planning to provide a means of improving palliative care outcomes has led to a sharp increase in international debate and in the development of a variety of interventions. However, the evidence base for the application and use of advance care planning is conflicting. It has been associated with increasing individuals' autonomy in terms of their sense of control and a greater congruence between treatment and expressed preferences. In some contexts it appears to facilitate

understanding between patients, clinicians and families by enabling open discussion of concerns. There have been untested suggestions that advance care planning may enable care in the place of choice and that this may therefore reduce the costs of end-of-life care. Published data from North America suggest, however, that this may not be the case.

### Social and cultural challenges

Challenges to advance care planning come from evidence that individuals' views and decisions may change over time as illness leads to changes in perceptions of quality of life. Concerns have been voiced that advance care planning is a means of healthcare rationing or may endorse euthanasia: this has been particularly visible in the public debate that has taken place in the UK in relation to new legislation for mental incapacity and attempts to legalise assisted dying. Additional deeply rooted cultural challenges are presented by a widespread reluctance to anticipate death, and by some evidence that patients prefer their families or clinicians to make end-of-life decisions on their behalf. How views, knowledge, and preferences in relation to advance care planning differ across different generations and cultural groups is unclear, but it is likely that 'one size' does not fit all.

### Developing practice

In terms of developing clinical practice, little is known about what constitutes best practice in advance care

planning, and there is a lack of awareness among those health and social care professionals most likely to come into contact with people with palliative care needs. Moreover, providing service users and members of the public with accurate information about the risks and benefits of advance care planning is necessary but challenging.

## Conclusions

Development of policy and practice in advance care planning may be one means, among the many required, to address the consequences of the rising incidence of chronic illness as the primary route to death. Any attempts to improve end-of-life care planning must particularly take account of the challenges facing older people, who now make up the majority of those who die. Rising incidence of co-morbidity, disability and extreme general frailty in older age not only make prognostication complex but mean

that many older people receive inappropriate end-of-life care, which is out of step with their needs, wishes and preferences. It therefore seems urgent to develop a better knowledge and understanding of whether and in what ways the processes of advance care planning might assist in providing better care to dying people and equally, what are the risks that may be associated with raising the issues and with the use of any resulting record. But we need to take great care as well that we do not treat people who are facing death as just another group of 'consumers' who can easily make choices about what happens to them. Such a discourse threatens to move us too far away from the traditional model and philosophy of palliative care and risks neglecting any consideration of how best to provide care thoughtfully, compassionately and empathically to vulnerable people who cannot or do not wish to enter the world of 'choice' and 'control' so admired and sought after today ■



## Professor Jacek Luczak MD PhD FRCP

Consultant in palliative medicine in Hospice Pallium, founder of palliative medicine at the University of Medical Sciences in Poznan, Chair and Department Chairman of the Eastern and Central Europe Palliative Care Task Force (ECEPT). Member of the Board of Directors of the International Association for Hospice and Palliative Care (IAHPC).

# Are we prepared to unmask the face of death?

There is evidence that doctors and nurses are usually not sufficiently prepared to assess and alleviate the suffering of dying patients and their families, don't know how to communicate with dying patients and their loved ones or how to prepare the patient to die. Physicians have difficulty in addressing the clinical and emotional needs of dying patients and are uncomfortable in caring for them. Furthermore, doctors who routinely work with the dying, experience emotional anxiety as a result of been closely involved with suffering patients near death and use many coping mechanisms: medicalisation, euphemism, denial, distancing and even objectifying the patient's attitude to minimise personal distress (Schulman-Green). Many doctors avoid telling the truth and share the opinion of the patient's family that disclosure will evoke depression and anxiety, as well as destroy hope and increase the suffering of the psychologically weak patient. This situation is common in Eastern Europe, including in Poland, despite continuous progress in palliative and hospice care (PHC).

The reason that doctors in Poland, particularly those of an older generation – even prestigious clinicians – are not trained in palliative medicine is that this medical specialty was only established in 1998. PHC was instigated into all the medical and nursing university students' curricula in the time from 1991 until 2000. In a study carried out in Krakow on 870 cancer patients cared for in a home hospice setting between 1994 and

1997, it was reported that only 48% of patients referred to the hospice on admission were aware of their diagnosis and 61% of families hadn't discussed this diagnosis with the patient (Gradalski *et al*). Collusion results in avoiding discussing the psychosocial and spiritual needs of patients, including a visit from the chaplain. Patients' wishes or autonomy if not respected can lead to inappropriate futile treatment and bad symptom control (SUPPORT Study). The primary caregivers and the doctors' attitude and fear of death and dying and their unawareness of PHC can result in delayed referrals. This resulted in ineffective treatment and care of suffering patients. Opiophobia is a strong barrier for early installation of strong opioids (especially morphine, an essential analgesic recommended by the IAHPC and WHO for moderate to strong pain). The unmasked face of dying/death/EoLC has many meanings and takes into consideration the various dimensions (somatic, psychic, social, spiritual) of a person, in addition to suffering and attitude/feelings of those involved. A study of 250 Polish hospice caregivers showed that many defined masked death/dying as when patients and families are not prepared for dying (88%). This study also highlighted that many patients hadn't been given a diagnosis or prognosis and had no awareness of death.

The suffering of dying patients is frequently masked (Ventafriidda: 70% are semi or fully unconsciousness in the last 24 hours). Osler found symptoms of pain and distress only in 20% of 500 dying patients.

Unfortunately, these data only correspond to the last 24 hours of life and hence do not assess the suffering and anguish of the patient and their loved ones leading up to this. It is obvious that in the last weeks and days of life, the majority of dying patients experienced suffering which increased and is often unrelieved, including pain, anxiety and so on, especially existential–spiritual distress. Furthermore, we need to appreciate the often hidden needs or masking of the suffering patient and their loved ones and improve our EoLC. Preparing patients and their loved ones for death and dying is a very challenging task for the PHC team who may have particular problems with patients cared for previously by colluding families and professionals who are uncomfortable with dying patients. Other problems include assessment of spiritual–existential needs and

finding ways to alleviate spiritual pain. Additionally, finding the best ethical solution to appropriate management at the end of life. The opening of true dialogue can be difficult, even for patients who benefit from good PHC, which can mask the effects of an incurable disease (Rec (2003) 24: the term palliative derives from the Latin word *pallium*, meaning ‘mask’ or ‘cloak’), bringing about a false hope of recovering from a terminal disease.

It is necessary not only that we improve the programme of widespread training in palliative care and EoLC for all medical professionals, but also to provide the palliative caregivers with continuous expert skills training and support programmes to improve their coping skills alongside ongoing public education on this crucial health issue ■