RCN Pain and Palliative Care Forum

Innovations
Your forum representatives

- Felicia Cox  Chair
- Lucy Carlisle  Newsletter Co-Editor
- Fiona Duncan  Interim Deputy Chair, Website Editor
- Olwen Minford  Fringe event co-ordinator
- Helen Taylor  Newsletter Co-Editor
- Mary Young  Website Editor
Your Chair

• Lead Nurse Specialist, Head of Pain Services
  Royal Brompton & Harefield NHS Foundation Trust

• Former Chair RCN London Pain Interest Group

• Former Editor *Journal of Perioperative Practice & Perioperative Pain Management*

• Current Editor the *British Journal of Pain*

• Co-opted Council member British Pain Society

• Widely published
My interests

Clinical

• Acute pain
• Procedural pain
• Persistent pain after thoracic surgery
• Analgesedation
• Delirium
• [Constipation]

• Research
• Acute pain after thoracic surgery
• Persistent post-surgical pain
• Nerve injury during surgery
What’s new in acute pain?

Clinical
• New opioid medicine (Tapentadol)
• Regional analgesia in the battlefield
• PCEA in early labour considered gold standard
• Neonates

• Research
  • Pharmacogenetics & polymorphisms
  • Adverse effects of opioids
Figure 1 World Health Organisation (WHO) analgesic ladder

**STEP 1** Non-opioid. With/without adjuvant analgesic.

**STEP 2** Opioid for mild to moderate pain. Plus non-opioid. With/without adjuvant analgesic.

**STEP 3** Opioid for moderate to severe pain. Plus non-opioid. With/without adjuvant analgesic.

- **Moderate to severe pain**
- **Mild to moderate pain**
- **Mild pain**

Pain persisting, move up one step. Reduce dose or move down one step. Signs of toxicity or severe side effects.
What’s new in acute pain in neonates?

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**Fig. 1.** A stepwise approach for the management of acute pain in neonates.
Evidence to practice

Fiona Duncan
Nurse Specialist Acute Pain
Research Fellow
Gap between what we should do and actually do
End-to End military pain management
http://rstb.royalsocietypublishing.org/content/366/1562/268.full
Pain education
Website under construction
Please respond to our survey
Resources

The RADAR approach – a free resource about recognizing pain
http://www.painradar.co.uk/improving-acute-pain-management.aspx

Australian and New Zealand College of Anaesthetists: Melbourne.

The British Pain Society
http://www.britishpainsociety.org
An Age Old Problem
A review of the care received by elderly patients undergoing surgery
Managing chronic pain in the primary care setting.

Helen Taylor
RGN SPQ BA Hons MSc
Chief Medical Officer report 2008

- Chronic pain and its consequences are not as well controlled as they could be.
- Early intervention may stop pain becoming persistent.
- The limited number of specialist pain clinics around the country are inundated with referrals, and only 14% of people with pain have seen a pain specialist.
- Systems and infrastructure are not adequate to meet need or demand.
- Better coordination of services and services designed around the patient’s needs are essential.
Independent providers of community based pain clinics to the NHS was one solution.

- Available on National Choose & Book and currently trading with more than 10 CCGs
- A self-management, rehabilitative model, using minimal injection therapies
- Trading only with the NHS, CQC registered.

www.pmsltd.co.uk
The Department of Health

Finally recognised chronic pain as a disease in its own right on February 2012 when Rt Hon Paul Burstow MP, Minister of State for Care Services announced ;-)

- "The Department recognises chronic pain as a long-term condition, either in its own right or as a component of other long-term conditions. Everyone who suffers persistent pain should have a timely assessment in order to determine the cause of the pain—if a cause can be determined—and to advise on options for treatment, including self-help. Patients with refractory chronic pain will benefit from the care planning approach, but decisions should be taken on an individual basis depending on the severity of symptoms and any co-morbidities"
Royal College of GPs

Chronic pain now a clinical priority

Stakeholder group have developed a work plan for a three-year program:
◆ To raise profile and awareness of this priority area
◆ To help RCGP improve quality of patient care

Engaging with:
◆ Policy-makers and opinion-formers: UK and devolved countries
◆ General Practitioners and other professionals
◆ Patients
◆ Other key stakeholders
Aims

- Improve Evidence Base for Pain
- To improve education
- Provide clear policy direction & clinical guidance on pain management
- Raise the profile of Pain in all 4 UK Countries
British Pain Society

Primary & Community Care SIG

- Raise awareness of pain management in primary care
- Help support development of primary care pain management
- Organise meetings, seminars and workshops

www.britishpainsociety.org
The Chronic Pain Policy Coalition is a forum established in 2006 to unite patients, professionals and parliamentarians in a mission to develop an improved strategy for the prevention, treatment and management of chronic pain and its associated conditions.

www.policyconnect.org.uk/cppc
Online education

www.paincommunitycentre.org

This site has been developed by Cardiff University with contributions from key opinion leaders across the UK. It is aimed at all those who want to enhance their knowledge and expertise in the management of pain. The aim is to foster and support a community who want to improve the lives of those suffering pain and welcome advice, help and support in developing the community further.
Innovations in Specialist Palliative Care

Acute Hospital Setting

Mary Young
Specialist Palliative Care

- The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.

(WHO 2002)
Key Documents

- NHS Cancer Plan 2000, and subsequent White Papers
- National Service Frameworks (DH) – Coronary Heart Disease 2000; Older People 2001; Renal Disease 2002; Longterm Conditions 2005.
- DH ‘End of Life Care Strategy’ 2007
- National Audit Office ‘Improving services & support for people with dementia’ 2010
- The Route to Success 2010
Websites and Resources

- National Council for Palliative Care
  www.ncpc.org.uk
- Help the Hospices
  www.helpthehospices.org.uk
- Macmillan Cancer Support
  www.macmillan.org.uk
- British Heart Foundation
  www.bhf.org.uk/
- Age UK
  www.ageuk.org.uk
- National End of Life Care programme
  www.endoflifecareforadults.nhs.uk
- Dementia UK
  www.dementia.org
Implications for Practice

- Education of specialist staff – primary and secondary care
- Communication/liaison between sectors
- End of life care planning – GSF, Advance Directives, Preferred Priorities of Care, Palliative Registers.
Specialist Palliative Care
The facts

Lucy Carlisle
Macmillan Community Nurse
Specialist Palliative Care

- Philosophy and Principles - aims
- Who provides Palliative care?
- Referring to the Macmillan Community Team
- Other agencies
- Benefits
- Temporary Discharging patients – what that means?
- Contact details
Philosophy and Principles

- Dame Cicely Saunders: Nurse, Doctor, Social Worker, Writer
- St. Christopher’s Hospice, first modern hospice in Britain for people with cancer
- Palliative care - care of patient and their families who have any life-threatening illness
- Physical, emotional, psychological and social needs of the person
- Focus on Quality of Life at End of Life
Palliative care aims

- Affirms life and regards dying as a normal process
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of care
- Supports family and friends before and after death
Who provides palliative care?

- Those who provide day-to-day care to patients and carers in their homes and in hospitals
- Able to assess care needs within their competence in palliative care
- Know when to seek advice from or refer to Specialist Palliative care services
- Attendance at Gold Standard Framework Meetings with Primary Care Team at GP practices
continued

- Macmillan Community Team – Specialist Palliative Care team - MDT
- Specialist in-patient facilities i.e. hospices
- Intensive co-ordinated home support for patients with complex needs
- Advice and support to all the people involved in a patient’s care
- Bereavement support
- Education and training in palliative care
Referring to the MCT

- Patients with complex symptom needs
- Complex psychological needs
- Family difficulties
- Advance care planning
- Serious financial concerns
Other Agencies

- GP’s
- District nurses
- Hospice/Hospice@Home
- Hospital Macmillan Team/Oncologists/Other
- Social services – care agencies
- Out of Area hospitals/hospices
- Nursing Homes – Care Home Support Team
- Respite services
- Lymphoedema nurse/ chiropodist/domiciliary dentist
Benefits

- If expected to live for only 3-6 months patient will qualify for Disability Living Allowance if <65

  or

- Attendance Allowance >65 or over, both under special rules and with a DS1500 from GP

- Although there is an approximate time limit, death is unpredictable so it doesn’t stop if the patient exceeds this time

- Have had some patients over two years!!

- For complex issues – referral to Benefit Advisor
References

End of Life Strategy (2008) Department of Health


The National Council for Palliative Care – www.ncpc.org.uk

World Health Organization – www.who.int/cancer/palliative/definition/en

Gold Standards Framework (Thomas) – www.goldstandardsframework.com
RCN CONGRESS 2012

The Application of the Arts in End of Life Care education

Olwen Minford
What do we mean by the Arts?

The arts means virtually any sort of creative activity. This includes:

- music
- poetry and creative writing.
- visual arts - drawing and painting, carving, sculpture, murals
- performance – drama, dance and movement, role play
- photography and video making.
Why use the arts in EoLC education?

◆ The arts are not outpourings of emotion—they are disciplined forms of enquiry through which to organise feelings and ideas about experience.

◆ The art image can defy the limits of language, capture the multilayered aspect of the emotional experience and play a vital role in the communication of pain and pleasure.
Images of death- impact of 1980’s HIV/AIDS tombstone advertising campaign
Death as Taboo.
Inadequacy of words-art images can identify, concretise, clarify and organise emotional experience.
Death Denying Society

- Fear and death anxiety
- “I don’t wanna talk about it”.

Nursing times reader survey 2010-1 in 4 nurses do not feel competent to broach subject of death with a patient.

- Knowledge and skills gap. (EoLC strategy 2008)
Euphemisms

- 200 in English language-practice of using euphemisms to do with belief that to speak the word death was to invite death

- Examples “kick the bucket”
Dismantling the taboo—“the elephant in the room”

As many poets and writers have talked about death as birth
Death as lonely & isolating or sorrowful, happy
- Walt Whitman “Come lovely and soothing death”
- Ben Franklyn “Nothing is certain but death and taxes”
- Francis bacon “Men fear death as children fear to go in the dark”
- Bible “the valley of the shadow of death”
  “the angel of death”
  “the last enemy”
- Henry Holland “Death is nothing at all”
Dismantling the taboo in practice

- Exercise using post card images choosing one to symbolise current feelings and facilitate reflection about death (cultural, religious, spiritual, historical experiences and perceptions)
- Used with GPs, District nurses, Care home and hospital staff in north central and east London
Example of post card image

A male carer with afro carribean background chose this card to symbolise his thoughts and feelings about death. He pondered deeply about the importance of his cultural roots and how he would wish to return to his own country if he were dying.
The Arts and identifying Dying

- Surprise Question ? Multidisciplinary team

- Staff in Mile End Hospital in conjunction with EoLC facilitator identified symbol to be used on Patient Status At a Glance Board for patients with palliative care needs and act as a prompt for anticipatory planning.
Palliative care symbol
Triggers:

- Consider whether a referral to Macmillan team is necessary
- Undertake ACP (Advance Care Planning) discussions
- Record preferred place of care and DNACPR discussions
- Ensure that discussions with pt and family are ongoing
- Place on LCP appropriately
The Arts and Advance Care Planning (ACP) A Conversation for Planning
Choices?

- Do you want to have a say?
- Have you made a will?
- Where do you want to be cared for and to die?
- Burial or cremation?
- Any other wishes for end of life?
Crazy coffins-Festival for Living
Consequences of not doing Advance Care Planning

- Video clip
- Use of drama and role play in communicating the emotional experience and providing therapeutic vehicle for bringing about change.
If I had my life to live over

- If I had a life to live over. I’d try to make
- more mistakes next time. I would relax, I would
- limber up, I would be crazier than I’ve been on
- this trip. I know very few things I’d take
- seriously any more.
- I would take more chances, I would take more
- trips, I would scale more mountains, I would swim
- more rivers, and I would watch more sunsets. I
- would eat more ice cream and fewer beans.
- I would have more actual troubles and fewer
- Imaginary ones. You see....
- I was one of these people who lived
prophylactically and sensibly and sanely, hour
after hour and day after day.
Oh, I’ve had my moments and if I had to do it all
over again, I’d have many more of them.
- In fact, I’d try not to have anything else, just
- moments, one after another, instead of living so
- many years ahead of my day.
I’ve been one of those people who never went
anywhere without a thermometer, a hot water
bottle, a gargle, a raincoat and a parachute.
- If I had it to do all over again,
  I’d travel lighter, much lighter than I have.
  I would start barefoot earlier in the spring, and
- I’d stay that way later in the Fall.
- And I would ride more merry-go-rounds, and
- catch more gold rings, and greet more people,
and pick more flowers, and dance more often. If
- I had it to do all over again.
But you see,
I don’t.

from: The Journal of Humanistic Psychology – by an 82 year old man, dying and accepting death
Together

We Can Do It!