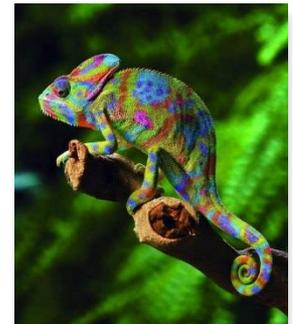


# A chameleon in the team: what social workers have to offer in palliative care

Anne Cullen

Head of Psychosocial and Spiritual Care, Princess Alice Hospice

Chair, Association of Palliative Care Social Workers





# The “Why”

“I became a social worker to support people to live their lives as fully as possible despite limitations. ....The philosophy behind SPCSW [Specialist Palliative Care Social Work] is that people wish to die what they themselves define as a "good death" and that families need support to cope with the loss of their loved ones. Based on the biopsychosocial model of illness, SPCSW uses patients' narratives to identify their sources of pain and to establish their priorities; then support them in achieving their goals” (Diana Murungu, Palliative Care Social Worker)

Diana Murungu (2013) A day in the life of ... a specialist palliative care social worker  
<http://www.theguardian.com/social-care-network/2013/sep/13/specialist-palliative-care-social-worker>

# This presentation

- **The chameleon**
  - Diverse activities
  - Adaptive
  - Mobile
  - Self effacing
- **Social work in the UK**
  - Knowledge, skills and values base
- **Palliative care social work**
  - Model
  - Values and orientation
  - Elements of practice
- **Case examples**
  - Individual cases
  - Service development

# Diverse range of activities

- **A day in the life**
  - One to one support to patient with “spiritual and emotional pain”
  - Sitting with a bereaved daughter who was beyond speech
  - Facilitating a family meeting
  - Teaching professionals about spiritual and cultural issues in EoL care
- **But other palliative care social workers may have been:**
  - Organising a hospital or hospice discharge and ‘package of care’
  - Going out with a police officer to support a victim of abuse
  - Supporting colleagues in Eastern Europe, India or Africa to improve end of life care
  - And there are many more examples...

# Adaptive and mobile

- **Adaptive**

“We’re chameleons really...we use our skills to do whatever the person needs”  
Participant in focus group of experienced palliative care social workers (Cullen, A. 2012)

“I’m a chameleon.... I will become the person I need to become in order to do the job that needs to be done.”

Individual interview with a registered social worker in a national leadership role (current research)

- **In constant motion**

“Social work must be understood in terms of the *flow* of mobile practices...”  
(Ferguson 2008)

“Social work on the ward and going into people’s houses, [is] a ...subtle form of support, advice.....it’s about weaving in and out.... It’s what the need is at the time” Participant in focus group (Cullen, 2012)

Cullen, A..F., “Leaders in our own lives” *British Journal of Social Work* (2013) Vol 43, No 8, pp1527-1544.  
Ferguson, H., “Liquid Social Work: Welfare Interventions as Mobile Practices”, *British Journal of Social Work* (2008) Vol 38 No 3 pp 561-579.



# Self-effacing

- **“A Friend”**

“We don’t see her as a social worker” (Beresford et al 2008)

“.... Service users repeatedly used the word *friend* when they were describing the specialist palliative care social worker ...It was as if they [service users] recognised and appreciated the expertise of the social worker without perceiving him or her as an expert who was remote from them and their lives.” (Beresford et al 2007)

Beresford, P., Adshead, L and Croft, S., (2007). *Palliative Care Social Work and Service Users*. London: Jessica Kingsley.

Beresford, P. Croft, S. Adshead, L. (2008), ‘We Don’t See Her as a Social Worker’: A Service User Case Study of the Importance of the Social Worker’s Relationship and Humanity , *British Journal of Social Work*, Vol 38, No7, pp1388-1407.



# UK social work

- **Knowledge**
  - Social sciences – sociology and psychology
  - Law – legislation, policy, powers and responsibilities
  - Social work practice theory
- **Skills**
  - Communication skills
  - Relational/therapeutic/systemic skills
  - Empirical and analytic skills
  - Risk management and exercising authority
  - Sourcing and managing resources
- **Values**
  - Autonomy and self determination
  - Identify and challenge discrimination
  - Human rights and social justice

Draws on: The College of Social Work Professional capabilities framework for social workers in England  
<http://www.tcsw.org.uk>



# Telling the story

- **Communication**
  - Personalised, adaptive
- **Containment**
  - Holding painful thoughts and feelings
  - Listening space – finding meaning
- **Telling the story**
  - Oral: e.g. Storytelling workshops
  - Written: e.g. “Stories from the Day Hospice”
- **Storing messages and memories**
  - Cards
  - Memory boxes

<https://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Newsandupdates/MacVoice/Spring2014/LifeStories.asp>

Giles, C; (2013) Stories from the Day Hospice. London: Wellcome Collection

# The right to record

- **Using legal tools to record preferences and decisions**
  - Advance Care Plans
  - Advanced Decisions to Refuse Treatment
  - Lasting Power of Attorney
  - Wills
- **Examples – sharing expertise**
  - “Advance Care Planning with a group of people with early stage dementia”
  - “Deciding Right” in Cumbria

Madsen, E., Delaney, C. Whithead, C. and Horne, C. (2015) “Advance Care Planning with a group of people with early stage dementia” Poster presented at European Association for Palliative Care in Copenhagen

<http://conversationsforlife.co.uk/conversation-game>

Becky Chaddock, Carol Bradley, Melvyn Laycock (2014) *Implementing Deciding Right in Cumbria*. Eden Valley Hospice, Hospice at Home West Cumbria and St Mary’s Hospice Cumbria.



# Practical interventions

- **Resources**
  - Housing, financial and legal problems
  - Entitlements to benefits, grants, allowances
  - “Packages of care” at home or in residential care
- **Advocacy**
  - Disadvantaged groups
  - People with learning disabilities, mental health conditions, histories of drug and alcohol dependence
- **Protection**
  - Children and young people
  - Vulnerable adults

# Adam: “total pain”

- **Situation**
  - Man in Late 30s, partner and young children
  - Late stage metastatic cancer
  - Admitted to inpatient unit for intractable pain
- **Interventions**
  - Identifying “total pain”- the importance of family
  - Ranking problems
  - “Mobilising personal and family resources
  - Providing specialist information and advice
  - Negotiating with MPT
  - Organising package of care
- **The chameleon factor - what it looked like:**
  - A couple of conversations and a few phone calls



# Bella: Telling the children

- **Situation**
  - Woman in early 40s with partner Richard and 3 children under 10
  - Recently diagnosed with terminal ovarian cancer
- **Interventions**
  - Containing painful emotion and providing a safe “listening space” to process information
  - Providing specialist advice and resources
  - “Normalising” “giving them back their role as parents”
- **The chameleon factor - what it looked like**
  - Chatting over a cup of tea at the kitchen table

# Clifford: right to die in pain

- **Situation**
  - Man in his 60s, late stage metastatic cancer from laryngeal primary
  - Unable to speak due to total laryngectomy
  - Living alone, refusing physical care (touch) and any help in home
- **Interventions**
  - Finding a way to communicate
  - Understanding the history
  - Assessing mental capacity
  - Negotiating exceptional care arrangements
  - Being a “fellow traveller” (Holloway and Moss 2010): “When all the practical things ran out...I could just sit with him.”
  - Containing colleagues’ distress
- **The chameleon factor - what it looked like:**
  - Moving fast and sitting quietly

Holloway, M. and Moss, B. (2010) *Spirituality and Social Work*. Basingstoke: Palgrave Macmillan

# Multi-professional team

- **The “wider dimensions” of patients’ lives**
  - History
  - Family
  - Identities
  - Priorities
- **Containment for colleagues**
  - Individuals
  - Groups
  - Organisation
- **Improving Services**
  - Evaluation and research
  - Negotiating and/or campaigning for change in practice, policy and legislation
  - Training and education

# Improving services

- **Auditing discharges to nursing homes**
  - Empirical evidence to inform policy change in an organisation
- **“Special Rules” – national campaign**

“people who are dying need money now, not in 6 months time”  
Letter by David Oliviere to MP for North London Hospice, Margaret Thatcher.
- **People with learning disabilities**
  - Palliative Care for People with Learning Disabilities Network
- **Action research – children and young people**
  - “No you don’t know how we feel”
- **Compassionate communities**
  - Diana Murungu: St Mary’s Hospice in Birmingham: meeting 56 communities “on their own ground”; “Sharing Care” conferences, being a “cultural broker”

References on next slide



# Improving services

## References

Reith, M and Lucas, C. (2008) Questioning the Evidence for Service Assumptions: Audit of Transfers from a Hospice to Nursing Home Care. *Journal of Social Work* 8(3): 233-45.

<http://www.pcpld.org>

Chowns, Gillian (2008) "No you don't know how we feel". *Groupwork* Vol. 18(1), 2008, pp.14-37G.

Paul, Sally (2013) Public Health Approaches to Palliative Care: The Role of the Hospice Social Worker Working with Children Experiencing Bereavement *Br J Soc Work* (2013) 43 (2): 249-263 first published online February 13, 2013 doi:10.1093/bjsw/bct017

Barry V. and Patel, M. (2013 ) *An Overview of Compassionate Communities in England* Murray Hall Community Trust and National Council for Palliative Care Dying Matters



# Education

- **UK**
  - Frances Sheldon established first masters programme in palliative care in Europe; on first board of directors of EAPC
  - David Oliviere established international education programme at St Christopher's Hospice, London
- **Europe:**
  - Pam Firth: commissioned to teach and work with alongside local colleagues to develop and establish palliative care within the health and social care services in Rumania and Serbia
- **Africa:**
  - Gillian Chowns: association with Africa over 30 years e.g. teaching in Kenya and researching effectiveness of palliative care education and support for children of terminally ill people in east and southern Africa

Web links and references for further information on next slide

# Education

## Links and selected list of publications by British palliative care social workers

<http://www.eapcnet.eu/Corporate/AbouttheEAPC/Homages/FrancesSheldon.aspx>

<https://eapcnet.wordpress.com/2013/11/06/david-oliviere-helping-social-work-thrive-in-palliative-care>

<https://eapcnet.wordpress.com/2012/12/16/a-social-work-first-in-the-republic-of-serbia>

<http://www.palliativecareworks.org/partners.htm>

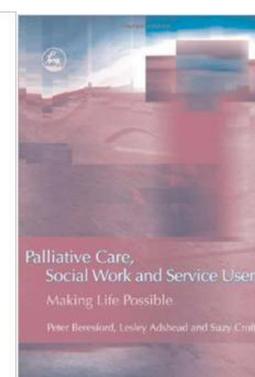
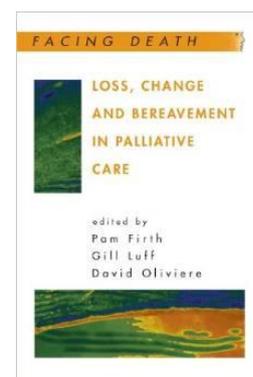
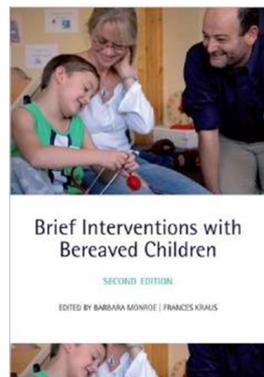
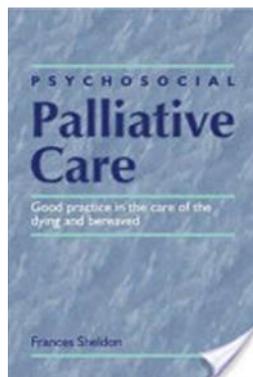
Sheldon, F. (1997) *Psychosocial Palliative Care*. Cheltenham: Nelson Thomas.

Oliviere, d. and Monroe, B. (Eds) (2013) *Patient Participation in Palliative Care: A Voice for the Voiceless*. Oxford: OUP.

Monroe, B. and Kraus, F. (Eds) (2010) *Brief Interventions with Bereaved Children*. Oxford: OUP.

Firth, P. Luff, G and Oliviere, D. (2005) *Loss and Change and Bereavement*. Basingstoke: OUP

Reith, M. and Payne, M. (2009) *Social Work in End of Life Care*. Bristol: The Policy Press





# The range

- **Modalities**
  - Therapeutic containment
  - Detailed practical casework
  - Service development
- **Settings**
  - Family homes
  - Day services
  - Nursing homes and inpatient units
  - Primary health and community bases
  - Education settings
- **Levels:**
  - Individuals and families
  - Organisations and communities
  - Local, national, international



# Summary

- **Palliative care social workers:**
  - Operate from a holistic perspective
  - Combine psychotherapeutic, empirical and practical skills
  - Focus on enabling people to identify their own priority needs and to achieve what matters most to them
  - Are active in practice, education, research and service development
  - Are mobile and adaptive
  - And are at their best when they are least conspicuous

