International Palliative Care Awareness and Training Seminar

Report of a meeting held at the Royal College of Physicians of Edinburgh on 1 October 2009 to describe and stimulate links between Scotland and other countries in palliative care

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The interest and medical resources available in Scotland for supporting international palliative care are considerable. This was apparent at a meeting to exchange information about existing Scottish palliative care links with health organisations in Russia, India, Albania and several African countries. Dr Mhoira Leng, formerly a consultant with NHS Grampian and now Head of Palliative Care at Makerere University and Mulago Hospital, Kampala, Uganda, and Medical Director of the Scottish charity Cairdeas Trust (www.cairdeas.org.uk), chaired the event with Professor Scott Murray, St Columba's Hospice Chair of Primary Palliative Care, Edinburgh University. Dr Leng gave a 'global glimpse' of palliative care and, in particular, the challenges of working in Uganda and India. The purpose of the seminar was to highlight what is already being done and what more is needed to address the huge unmet need for palliative care, teaching and training, policy development and symptom management for end-of-life care globally.

'Palliative care is an urgent humanitarian responsibility,' said Dr Leng, 'and freedom from pain is, officially, designated a human right.' Unfortunately, the reality is very different. For most of the world's population, and in particular for those in sub-Saharan Africa, freedom from pain is a pipe dream. Even though Uganda leads the way in Africa, making oral morphine widely available through nurse prescribing, less than 10% of dying patients there have access to palliative care. In other African countries the numbers are much lower, while in India 80% of all palliative care takes place in only one state, Kerala. The seven richest nations in the world consume 84% of the world's therapeutic morphine but have only 10% of the world's population, while in resource-poor countries access is blocked by bureaucracy, myths about the dangers of morphine or simply by the indifference of the medical profession and the public to the plight of the dying.

Dr Tom Middlemiss, a Palliative Medicine Researcher at the University of Edinburgh, worked in Trivandrum, Kerala, for Pallium India for six months. The Kerala model, which was one of the first worldwide, has won global recognition and is actively promoted by the World Health Organization. Dr Middlemiss's enthusiasm and enjoyment of his time spent in Kerala was obvious, despite being impeded by communication problems which restricted sensitive interaction with patients. Before leaving India he bravely biked, bedecked with palliative care messages, from Kerala to Mumbai (1,500 miles) to raise awareness of the huge unmet needs of the dying in India.

Dr Bruce Cleminson, a GP from Shetland with experience in palliative care, has been involved, for two weeks each year for the past 11 years, in educational facilitation in Samara, Russia, as part of a team of doctors and nurses from the UK and Geneva. The visiting team likes to start their palliative care mentoring at the bedside, and are now involved in the educational support of the Samara GPs, the six hospices in the Samara region and the Samara Cancer Centre. Dr Cleminson summarised things he had learnt through his work in Russia: a visiting team will always have cultural blind spots, so needs to listen to the local team to understand the true situation; there is presently no oral morphine available in Samara, so syringe drivers can make a huge difference, especially in the community; teamwork is essential, as it leads to improved care, both in Samara and the UK. Continuity – repeated trips by the same visiting specialist team – is very important as it allows the development of relationships and trust between the visited hospice team and the visitors.

Dr Martin Leiper, a Consultant in Palliative Medicine at NHS Tayside, and Elizabeth Swain, a retired GP from Kirkintilloch, East Dunbartonshire, described work in Albania and Eastern Europe for Partnership in International Medical Education (PRIME, www.prime-international.org.uk). In Albania, palliative care is not regarded as a medical specialty. 'How,' they asked, 'does one influence government policy to introduce it as a specialty?' Furthermore, oral opiates are not available in Albania. Drs Leiper and Swain also found cultural blocks when trying to tell the truth to a dying patient with strong negative denial from relatives.

Physiotherapist Gillian Craig from Aberdeen and Specialist Palliative Care Nurse Kenny Ferguson from

Elgin taught the management of chronic oedema in Tamil Nadu, India. They found the hand-picked trainers very receptive of the practical skills they taught, which are highly transferable. It is important, however, to recognise that learning styles can be different, with people accustomed to didactic learning. Again, the importance of follow-up was emphasised.

Ruth Wooldridge, co-founder of the Nairobi Hospice, and a member of Help the Hospices International Hospice and Palliative Care Reference Group, introduced the recent Palliative Care Toolkit, of which she is a co-author. This is a simple-to-use handbook covering practical aspects of palliative care and is targeted at nurses and home-based care workers who deliver most of the 'hands on' palliative care in Africa. It also includes the care of children, whom Ms Wooldridge described as 'the neglected patients'. The handbook has been translated into many languages, and can be obtained from TESSA (Open University dissemination to sub-Saharan Africa) or from the Help the Hospices website (www.helpthehospices.org.uk). Funding educational courses to accompany the toolkit has been challenging, but, as 60% of beds in sub-Saharan Africa are blocked by chronically ill and dying patients, there is a huge need to train community workers to care for patients in their own homes.

Three small group seminars covered educational needs and curriculum development; how to get a partnership started; and research opportunities and pitfalls, followed by an open forum about how we in Scotland might support and promote global palliative care.

Several points emerged, including:

- Despite frustrations, everyone enjoyed (and would recommend) working overseas even for short periods.
- High level political support is needed as a catalyst in strategic thinking about the development of services in resource-poor countries.
- In Scotland we should advocate and profile-raise with our government, including the Scottish Parliament Cross-Party Group, with the World Health Organization and with other international agencies.
- We need a Scottish forum for sharing, such as an electronic journal club. While realising that each country has different needs, it is useful to hear about the experiences of others.
- A resource is needed for others thinking of working in, or twinning with, overseas health facilities. A number of organisations supporting global palliative care were listed, and websites identified (see table).
- It would be useful if Scottish-based overseas palliative care work registered with The Health Education Trust (THET) as a formal UK International Health Link in order to network with funders and departments of health.

USEFUL WEBSITES

African Palliative Care Association	www.apca.co.ug
Asia Pacific Hospice Palliative Care Network	www.aphn.org
PRIME (Partnerships in International Medical Education)	www.prime-international.org.uk
Hospice Africa Uganda	www.hospiceafrica.or.ug
Pallium India	www.palliumindia.org
Pain and Palliative Care Society, Calicut	www.painandpalliativecare.org
Christian Medical Fellowship	www.cmf.org.uk
Help the Hospices – International Education & Training	www.helpthehospices.org.uk/international
International Observatory on End of Life Care	www.eolc-observatory.net
'Getting started: guidelines and suggestions for those starting a hospice/palliative care service'	www.hospicecare.com/gs/index.htm
International Association for Hospice and Palliative Care	www.hospicecare.com
The Palliative Care Toolkit and Toolkit Training Manual	www.helpthehospices.org.uk/our-services/international/what-we-do-internationally/education-and-training/palliative-care-toolkit/
The Hospice Africa Uganda 'Blue Book' available in English and French	www.hospiceafrica.or.ug/index.php?mod=article&cat=pubs&article=48

IN SUMMARY

There is great enthusiasm in Scotland for supporting palliative care overseas. This must be offered with cultural sensitivity. Long-term partnerships are encouraged. It is important to focus on training all levels of staff, including caregivers, to ensure improved quality of care is widely available. Partnerships with national bodies and regional co-operation are important. Lobbying with faith groups, medical, government and other organisations will raise awareness of the global lack of pain relief and huge unmet need. The goodwill and resources we have in Scotland need harnessing. Please see the table above for useful international websites and to download clinical and training resources for economically developing countries.