

**Cross-Party Group in the Scottish Parliament  
on Palliative Care**

**Convener**  
Michael McMahon MSP

**Vice Convener**  
Dennis Canavan MSP

**Secretary**  
Patricia Wallace

**Approved minute of the meeting of the Cross-Party Group  
on Palliative Care in the Scottish Parliament**

**Wednesday 7 March 2007 at 5.45pm  
Committee Room 5, Scottish Parliament Headquarters**

<b>Present:</b>	Michael McMahon MSP (convener) Dennis Canavan MSP	Hamilton North & Bellshill  Falkirk West
	Phil Atkinson Dr Duncan Brown Dr Pat Carragher Fiona Cathcart Rev Stuart Coates Jenny Doig Dr Rosalie Dunn Rhona Else Shirley Fife Dr Elizabeth Ireland Marian Keogh Kirsty Leavey Dorothy McElroy Maria McGill Irene McKie Dr Euan Paterson Ros Scott Robert Shorter Craig Stockton	Scottish Health Magazine St Columba's Hospice Children's Hospice Association Scotland St Columba's Hospice Strathcarron Hospice NHS Lothian NHS Lanarkshire St Columba's Hospice NHS Lothian NHS Forth Valley Children's Hospice Association Scotland Association of Palliative Care Social Workers Ardgowan Hospice Highland Hospice Strathcarron Hospice RCGP Scotland Children's Hospice Association Scotland NHS Lanarkshire Scottish Motor Neurone Disease Association
<b>In attendance:</b>	Pauline Britton Rebecca Patterson Pat Wallace	Scottish Partnership for Palliative Care Scottish Partnership for Palliative Care Scottish Partnership for Palliative Care
<b>Apologies:</b>	Roseanna Cunningham MSP Carolyn Leckie MSP Nanette Milne MSP	Perth Central Scotland North East Scotland
	Joan Adam Aileen Anderson Rhona Baillie Dr Rosaleen Beattie Dr T F Benton Margaret Dunbar Jean English Professor Marie Fallon Ann Gourlay Dr David Jeffrey Linda Kerr Dr Peter Kiehlmann	St Columba's Hospice The Ayrshire Hospice Prince & Princess of Wales Hospice NHS Orkney St Columba's Hospice St Columba's Hospice St Margaret of Scotland Hospice NHS Lothian NHS Tayside NHS Borders NHS Ayrshire & Arran NHS Grampian

Dr Calum MacKellar  
Marie McGill  
Claire Murphy  
Anne Robb  
Dr Catriona Ross  
Hazel Taylor  
Anne Thomson  
Professor John Welsh

Scottish Council on Human Bioethics  
Scottish Huntington's Association  
St Margaret of Scotland Hospice  
NHS Tayside  
St Andrew's Hospice  
WOSMCN for Palliative Care  
Scottish Huntington's Association  
NHS Greater Glasgow

## 1. Welcome and apologies

Michael McMahon MSP, Convener of the Cross Party Group in the Scottish Parliament for Palliative Care, welcomed attendees to what was to be the final meeting of the group for the current parliamentary session.

## 5 Presentation and Discussion

With the group's agreement, item 5 was taken before the other items on the agenda.

### 5.1 Children's Hospice Association Scotland (CHAS)

Dr Pat Carragher, Depute Chief Executive (Medical), CHAS

Michael McMahon welcomed Dr Pat Carragher, Depute Chief Executive (Medical) of the Children's Hospices Association Scotland (CHAS), to give a presentation on the work of CHAS and current issues in palliative care for children and young people (presentation attached as appendix 1).

Dr Carragher explained that the purpose of CHAS is to provide a high level of specialist palliative care, encompassing support and friendship to the whole family of a child with a life limiting condition. This support spans the child or young person's life, their death and beyond. The care provided addresses the social, emotional, physical, spiritual and recreational needs of the child and his siblings and parents, maximising the use of the multi-skilled team. This means being there to help each family in whatever way they decide is right for them.

The emphasis is on caring for the entire family, and as well as symptom control expertise, CHAS aims to provide a caring approach and self awareness, good communication skills and a flexible and open-minded approach.

The need for children's palliative care began to be recognised in the 1980s, and there are now 39 children's hospices in the UK with plans to open more in the future. Children's Hospices provide specialist palliative respite, 24 hour advice and support, support for home care crises, end of life care and bereavement support.

CHAS provides a Scotland-wide service through its two hospices, Rachel House in Kinross and Robin House in Balloch. Robin House

## Action

opened in August 2005, and is opening in phases, according to demand. Both hospices are purpose built, and aim to 'encourage and enable both the child and the family to face the situation with which they are faced, in their own unique way'.

The Medical Teams at these hospices:

- have personal knowledge of the child and facility
- liaise closely with hospital/community paediatrician, GP/PHCP, and Specialist Nurses
- have a simple, holistic approach
- aim to do simple things well
- insist on a multi-disciplinary team approach, both within and outwith the hospice, with the involvement of the child and a family-centred approach.

CHAS continues to face a number of challenges as it works to improve its service and accommodate wider developments. Part of this is working in partnership with other organisations, increasing training and education provision, and increasing home care. More and more youngsters are surviving to the age of 18, and a growing issue is the provision of appropriate care during the transition from childhood to adulthood.

General discussion followed and Dr Carragher expanded on a number of points in response to questions from the group:

- Identifying appropriate transitional care must involve asking children and families what they need, and asking health professionals how they can meet these needs. CHAS is currently in discussions with Highland Hospice to see how they can assist in meeting some of these needs, and CHAS is keen to involve more adult hospices in similar discussions. CHAS has identified the issue of transitional care as a research priority.
- Considering that most GPs come into contact with very few children with palliative care needs, it is understandable that GPs may lack confidence in working with these families. However, GPs can adapt their skills, and by seeking appropriate support can play an essential role for children and their families.
- The Big Lottery Fund provided three years of funding to run the 'Rachel House at Home' pilot, and a small number of staff were employed to provide general support to children with palliative care needs and their families in the Highlands and Islands. Informal feedback on this service is positive, and CHAS hope to continue to run and improve this service.
- CHAS employs 180 staff, has 800 volunteers, and is currently working with over 200 families, with many more being supported in bereavement. Rachel House provides six respite beds, and two emergency beds, and Robin House currently has six beds though this service is likely to expand in the future. The complex and flexible nature of the support provided by CHAS makes it impossible

- to calculate the 'cost of a bed per night' in any meaningful way.
- Children are supported in their educational needs. Many attend mainstream schools, and on occasion teachers come into the hospice to teach.

## 2. Minutes of meeting of Wednesday 6 December 2006

The minute of the previous meeting held on Wednesday 6 December 2006 was adopted as a true record. (Proposed: Rev Stuart Coates; Seconded: Maria McGill.)

## 3. Matters arising

### 3.1 Prescription charges (item 3.1)

Michael McMahon updated the group that there has been no further progress on this since the December meeting. The 'NHS Prescription Charges and Exemption Arrangements' consultation closed on 30 April 2006. Comments have been collated by the Scottish Executive and are with the Minister for a decision. It is hoped that a report on the consultation will be published in the near future though no exact date has been provided.

**ACTION: This is an ongoing issue and will remain on the agenda**

**PB / PW**

### 3.2 Lymphoedema update (item 3.2)

Michael McMahon updated the group. As was reported at the last meeting, the British Lymphoedema Society has produced a practice statement which was launched at their conference in October 2006. NHS Quality Improvement Scotland (NHS QIS) intend considering whether this could be endorsed as best practice in Scotland. This matter will be discussed when the Partnership holds its biannual meeting with NHS QIS on 04 April, and an update will be provided at the next Cross Party Group meeting.

**ACTION: This is an ongoing issue and will remain on the agenda**

**PB / PW**

### 3.3 House of Lords: Palliative Care Bill (item 3.3.1)

Michael McMahon updated the group that a Palliative Care Bill has been introduced to the House of Lords by Baroness Finlay of Llandaff, who is herself a consultant in palliative medicine. It would make mandatory the provision of appropriate palliative care to everyone with a terminal illness in England and Wales. The second reading of the Bill took place on 23 February 2007, when it was agreed that the Bill should be sent to Committee. There is an expectation that the Bill will eventually go through the House of Commons. The government opposed the bill on the basis of enshrining in law a duty for the NHS to provide a service to the level determined by the patient rather than by the NHS.

Reverend Stuart Coates expressed concerns that during a previous debate in the House of Lords, several members of the House raised questions as to the necessity of providing specialist palliative care services. Michael McMahon said he would address this point under agenda item 4 – Public Petition PE1031.

### **3.4 House of Commons: Provision of Palliative Care Bill**

Michael McMahon updated the group that Jim Dobbin's Provision of Palliative Care Bill was due to have its second reading on 23 February however this has now been rescheduled to 15 June 2007.

### **3.5 Modernising Medical Careers (MMC) (item 4.1)**

Michael McMahon updated the group that the Partnership sent a letter to the Chief Medical Officer on 12 February, highlighting concerns expressed by the Scottish Hospices Forum, Specialist Palliative Care Group and Cross Party Group about the implications of MMC for palliative medicine in Scotland, and offering the Partnership's support in resolving these issues. No reply has been received to date.

Pat Wallace updated the group that the Department of Health has announced that it will undertake a review of MMC.

## **4. Public Petition PE1031**

Michael McMahon informed the group that he is also Convenor of the Public Petitions Committee, which recently received a petition from Professor Donald M Macdonald calling for Members of the Scottish Parliament to oppose the introduction of any legislation which would permit assisted suicide.

The Committee has contacted the Partnership to seek comments on the issues raised within the petition, and on the issues raised during the Public Petition Committee's discussion of the petition. The Partnership will carry out a consultation exercise before responding to the Committee in time for its next meeting in September 2007.

The Committee has sought various other views on this petition, and has received a response from Andy Kerr MSP stating that if a workable Bill to change the law were introduced privately, the Scottish Executive is likely to remain neutral and allow a free vote as is customary on 'matters of conscience'. The Minister's response went on to make clear the Scottish Executive's support for the development of specialist palliative in Scotland, and Michael McMahon felt that this may help to ease some of the concerns expressed by Rev Coates under item 3.3.

## **6. Any other business**

### **6.1 Thanks to Dennis Canavan**

This was Dennis Canavan's final meeting as vice-convenor of the group. Michael McMahon expressed his sincere thanks to Dennis for the tremendous amount of support he has shown to the Cross Party Group, and for his even more long-term interest and dedication to the hospice movement and specialist palliative care. The group echoed these sentiments and expressed their strong appreciation for all of Dennis' work and support over the years. The Convenor signed a letter to Dennis expressing these sentiments.

**7. Date of next meeting**

Pending sufficient support for the reconvening of the group following the election in May, the next meeting of the group will take place on Wednesday 6 June, beginning at 5.45 pm, and will include the group's annual general meeting (AGM).