

**Joint meeting of the Heart Disease & Stroke Cross Party Group
and the Palliative Care Cross Party Group
Wednesday 4th December 2013,
Committee Room 5, 1800-2000**

Palliative Care for people living with non-malignant illness

1. Welcome & Apologies

MSP Attendance

Michael McMahon (Convenor)
Dennis Robertson
Margaret McCulloch
Nanette Milne
Siobhan McMahon
Fiona McLeod

MSP Apologies

Alison McInnes
Jayne Baxter
Richard Simpson
Mark McDonald
Dave Thompson
Jackie Baillie

Michael McMahon (MM) welcomed attendees to the meeting. Helen Eadie MSP died on 9th November 2013, and tributes were paid to her both on a personal level and for the work she did to advance the cause of all those affected by stroke and heart conditions throughout Scotland.

2. Matters arising from Heart Disease & Stroke Cross Party Group

2.1 Convenor and Secretariat Update (MM)

Dennis Robertson MSP has agreed to step up from Deputy Convenor to continue taking forward Helen's work as convenor on behalf of the CPG. Deputy convenor Dave Thompson MSP will now be joined by a new deputy convenor Margaret McCulloch MSP, to whom a warm welcome was extended.

MM introduced the interim Secretariat: Laura Hastings (LH) of Chest Heart & Stroke Scotland and David McColgan (DM) of the British Heart Foundation Scotland. LH and DM have agreed to provide interim support to ensure the continuity of the organisational work behind the Cross Party Group.

LH is Head of Advice & Information with Chest Heart & Stroke Scotland. She has worked with Chest Heart & Stroke Scotland for over 10 years, previously as Lead Nurse on their Advice Line. This follows a varied nursing career in cardiology, intensive care and community nursing both in the UK and in America.

DM joined the British Heart Foundation Scotland as Policy & Public Affairs Manager on 25 November. David was previously Policy Officer at the Scottish Council for Voluntary Organisations and prior to that was Policy and Communications Officer at the Scottish Sports Association.

2.2 Minutes from previous meeting of 18 September 2013

The minutes were approved by Jan Buncle and seconded by Marjory Burns.

2.3 Response from the Cabinet Secretary for Health & Wellbeing to the CPG's letter regarding the HEAT target

Please contact the Secretariat (LH) if you would like a copy of the Cabinet Secretary's letter relating to cardiac rehabilitation for heart failure patients: laura.hastings@chss.org.uk

2.3 ACHD (adult congenital heart disease): Progress of Petition and Scottish Congenital Cardiac Network Parliamentary Questions

There is no update on the progress of the Petition at this time. Please contact the Secretariat (LH) if you would like a copy of the Scottish Government's answers to the Parliamentary Questions submitted on behalf of the Scottish Congenital Cardiac Network: laura.hastings@chss.org.uk.

2.4 Sub-group Update

An update on the Stroke Charter sub-group was provided by Kim Hartley, the Royal College of Speech & Language Therapists Scotland Officer. Kim explained that the stroke charter sets out "the care people should be getting after a stroke". A letter seeking endorsement of the charter has been sent to relevant organisations. An event will be held at the Scottish Parliament on Wednesday 11th December 2013 to celebrate the publication of the charter. Following this, the stroke charter website will be launched and a number of promotional events will be held, including the distribution of 10,000 copies of the charter to stroke units and GP practices across Scotland.

Dennis Robertson MSP added that the stroke charter was to be known as The Helen Eadie Charter as a living legacy to Helen's work with the group.

3. Matters arising from Palliative Care Cross Party Group

3.1 Minute of previous meeting of 11 September 2013

The minute of the meeting of 11 September was approved. (Proposed: Stuart Coates; Seconded: Irene McKie)

3.2 Margo Macdonald MSP's Proposed Assisted Suicide (Scotland) Bill

The Bill has now been published. It has been allocated to the Health committee, with the Justice Committee as a Secondary Committee. A timetable for their scrutiny of the bill is still to be published, and the committee will call for written evidence.

Mark Hazelwood updated the group that the Scottish Partnership for Palliative Care intends to submit written evidence to the committee, as it is important that the issue is debated in the context of good understanding about palliative care. At this stage the intention is to adopt a similar approach to that adopted in respect of the last bill on this subject - the SPPC is not able to adopt a position on the principle of whether or not physician assisted suicide and voluntary euthanasia should be legalised. This is because the topic raises issues of a moral, personal and ethical nature upon which many of the SPPC member organisations (for example member NHS Boards) are institutionally unable to hold a position.

The content of the SPPC submission will focus on the need for MSPs should give careful regard to:

- Any possible damage to the practice and provision of palliative care.
- The protection of vulnerable people.

Those wishing to discuss further any aspect of this should get in touch with Mark: mark@palliativecarescotland.org.uk

(The Bill and associated explanatory notes and policy memorandum are available here: <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/69604.aspx>)

3.3 Liverpool Care Pathway: update

Some members of the public present at the September meeting wished to know how their experiences could be used to inform decisions being made relating to future use of the LCP in Scotland. Michael McMahon had undertaken to make inquiries about opportunities for public engagement on this issue, and had written to the Cabinet Secretary asking him this question, and is currently awaiting a reply.

Mark Hazelwood updated the group that the Scottish Government is currently considering advice relating to the future provision of end of life care in Scotland, provided by the by Scottish Government's National Advisory Group (NAG) to Living and Dying Well. The Scottish Government has not yet published a response, but Mark expects that the SG will announce a phasing out of the LCP, and that a process will be introduced to build on improvements in end of life care, and that this process will include public and patient involvement.

4. Presentations

4.1 Better end of life care for patients with heart failure: Caring Together

A presentation was given by Dr Iain Armstrong, who has been project and programme manager of Caring Together for five years. Caring Together is a partnership programme between Marie Curie Cancer Care, the British Heart Foundation Scotland and NHS Greater Glasgow and Clyde improving the palliative care of patients with advanced heart failure. The programme aims to improve equity and access to palliative and supportive care for patients with advanced heart failure and their carers. (Slides attached.)

4.2 Supportive & Palliative Care for people with advanced illnesses

A presentation was given by Dr Kirsty Boyd, Consultant in Palliative Medicine, NHS Lothian and Honorary Clinical Senior Lecturer, University of Edinburgh Primary Palliative Care Research Group. (Slides attached.)

4.3 The Scottish Non-malignant Palliative Care Forum

Helen Coles, Chair of the Scottish Non-malignant Palliative Care Forum gave an overview of the purpose and structure of the Forum, which has the key objective of using the knowledge and experience of their membership of healthcare professionals to address the challenges experienced in delivering palliative care to patients with advanced, non-malignant illnesses (slides attached). Hilary Gardener, Community Palliative Nurse Specialist, Marie Curie Cancer Care then presented a case study of a patient with advanced heart and lung illness and a past history of stroke.

5. Discussion

Group discussion ensued and the following issues were raised:

- the importance of continuing to raise the profile of palliative care for non-malignant conditions within Scottish Government and wider society.
- the difficulties and reluctance professionals can experience with broaching the subject of 'palliative care' with patients and families. Suggestions of how this might be addressed included: use of the term 'supportive' rather than 'palliative'; palliative care specialists engaging and helping without calling their care 'palliative'; and improving the palliative care skills of generalists.
- The importance of shared care and of specialists being called on to support generalists as needed.
- The influence that wider society's reluctance to talk about death, dying and bereavement has on the ability of individuals to talk about their own decline and death, and the role of the alliance *Good Life, Good Death, Good Grief* in addressing this.
- The possibility of trialling the Caring Together model in other areas.
- The importance of palliative care planning as a part of the hospital discharge process alongside care package planning, though this currently doesn't always happen.
- The importance of Heart Failure Specialist Nurses in co-ordinating care.

6. AOCB

The Scottish Partnership for Palliative Care in conjunction with Marie Curie Cancer Care will hold a Round Table seminar on 5th February 2014 'Are we living and dying well yet?' to mark the 5th anniversary of Living and Dying Well. A panel of experts will reflect on the achievements and look ahead to the challenges of the action plan. Invitations will be sent out shortly. Outcome will be fed back to interested parties.

7. Future meeting dates of the Heart Disease & Stroke Cross Party Group:

- **Wednesday 12th March 2014, Committee Room 5 - Rural issues in the treatment of stroke and heart failure**
- Wednesday 11th June 2014
- Tuesday 23rd September 2014
- Wednesday 3rd December 2014

8. Future meeting dates of Palliative Care Cross Party Group:

- **Wednesday 26 March 2014 (Committee Room 5) 5.45 pm**
- Wednesday 11 June 2014 (venue tbc) 5.45 pm
- Wednesday 10 September 2014 (Committee Room 1) 5.45 pm (Date to be reviewed due to pre-referendum recess)
- Wednesday 10 December 2014 (Committee Room 4) 5.45 pm

Non-MSP Attendance

Title	Forename	Surname	Organisation
Mrs	Wendy	Armitage	CHSS
Dr	Iain	Armstrong	Caring Together / Marie Curie
Ms	Jackie	Bell	GMC in Scotland
Dr	Kirsty	Boyd	NHS Lothian
Mrs	Jan	Buncle	Chest Heart & Stroke Scotland
Ms	Marjory	Burns	British Heart Foundation
Ms	Sandra	Campbell	NHS Forth Valley
Mr	David	Clark	Chest Heart & Stroke Scotland
Rev	Stuart	Coates	
Ms	Helen	Coles	Scottish Non-malignant Palliative Care Forum
Ms	Margaret	Colquhoun	St. Columba's Hospice
Ms	Rebecca	Duff	MS Society Scotland
Ms	Shirley	Fife	NHS Lothian
Dr	Fiona	Findlay	NHS Tayside
Ms	Hilary	Gardener	Marie Curie
Ms	Maura	Gillespie	British Heart Foundation
Ms	Kim	Hartley	Royal College of Speech & Language Therapists
Mrs	Laura	Hastings	Chest Heart & Stroke Scotland
Mr	Mark	Hazelwood	Scottish Partnership for Palliative Care
Ms	Frances	Johnston	
Ms	Hannah	Lowish	Medvivo
Dr	Gordon	Maclaren	NHS Fife
Ms	Elaine	Maclean	Care Inspectorate
Ms	Sharon	McCaffrey	Prince and Princess of Wales Hospice
Mr	David	McColgan	British Heart Foundation
Ms	Sandra	McConnell	Ardgowan Hospice
Ms	Linda	McEnhill	Prince and Princess of Wales Hospice
Ms	Maria	McGill	CHAS
Ms	Irene	McKie	Strathcarron Hospice
Ms	Jacqueline	McShane	Medvivo
Mr	Richard	Meade	Marie Curie Cancer Care
Ms	Yvonne	Millerick	Caring Together / Heart Failure Palliative Care
Mr	David	Mills	PSP Association
Mrs	Susan	Milne	NHS Forth Valley
Ms	Libby	Milton	Prince and Princess of Wales Hospice
Ms	Gill	Mitan	Bravehearts Patient's Group
Ms	Elspeth	Molony	The Stroke Association
Mr	Bruce	Nichol	Marie Curie Cancer Care
Ms	Morag	Osborne	NHS GGC
Ms	Rebecca	Patterson	Scottish Partnership for Palliative Care
Mr	Ian	Reid	Bravehearts Patient's Group
Mr	Geoff	Sage	St Andrew's Hospice
Ms	Lorna	Stevenson	CHSS
Prof	Allan	Struthers	University of Dundee/Ninewells Hospital
Ms	Jemima	Traill	British Heart Foundation Scotland
Ms	Lily	Tsvetanova	
Ms	Susan	Webster	MND Scotland
Ms	Mandy	Yule	Ayrshire Hospice