Cross-Party Group in the Scottish Parliament on Palliative Care

Convener	Vice Convener	Secretary
Michael McMahon MSP	Jamie McGrigor MSP	Mark Hazelwood

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

Wednesday 16 June at 5.45 pm
Committee Room 6, Scottish Parliament Headquarters

Present:	Michael McMahon MSP (convener)	Hamilton North & Bellshill
	Andy Kerr MSP	East Kilbride
	Phil Atkinson	Health Policy Scotland
	Andy Carver	British Heart Foundation Scotland
	Dr Derek Doyle	Scottish Partnership for Palliative Care
	Francis Edwards	NHS Grampian
	Dr Belinda Hacking	Palliative Care Clinical Psychology Services, Edinburgh
	Dr Peter Kiehlmann	NHS Grampian
	Maria McGill	Highland Hospice
	Irene McKie	Strathcarron Hospice
	Dr Gordon McLaren	NHS Fife
	Clare Murphy	St Margaret of Scotland Hospice
	Thomas O'Dea	St Margaret of Scotland Hospice
	Ann Scott	
	Elizabeth Thomas	St Margaret of Scotland Hospice
In attendance:	Pauline Britton	Scottish Partnership for Palliative Care
	Mark Hazelwood	Scottish Partnership for Palliative Care
	Jan Killeen	Alzheimer Scotland, Action on Dementia
Apologies:	Jamie McGrigor MSP	Highlands and Islands
	Aileen Anderson	The Ayrshire Hospice
	Irene Barclay	St Columba's Hospice
	Jackie Bell	GMC Scotland
	Ali Blezard	Scottish Kidney Federation
	Derek Blues	NHS Forth Valley
	Dr Duncan Brown	St Columba's Hospice
	Elaine Burt	NHS Greater Glasgow and Clyde
	Dr Pat Carragher	CHAS
	Rev Stuart Coates	Association of Hospice and Palliative Care Chaplains
	Margaret Colquhoun	St Columba's Hospice
	Helen Dryden	NHS Tayside
	Dr Cameron Fergus	NHS Borders
	Linda Kerr	NHS Ayrshire and Arran
	Sam Lavery	St Andrew's Hospice
	Kate Lennon	NHS Greater Glasgow and Clyde
	Jean Leslie	NHS Fife
	Dr Grace Lindsay	NHS Greater Glasgow and Clyde
	Dr. Calum MacKellar	Scottish Council on Human Bioethics
	Elaine MacLean	Care Commission
	Suzy Mercer	Roy Castle Lung Cancer Foundation

Josephine McCulloch	National Network of Palliative Care for People with Learning Difficulties
Susan Morrison	NHS Highland
Professor Scott Murray	University of Glasgow
Dr Euan Paterson	RCGP
Dr Clive Preston	NHS Fife
Anne Robb	NHS Tayside
Ros Scott	CHAS
Carol Somerville	Bethesda Hospice
Elaine Stevens	University of the West of Scotland
Craig Stockton	MND Scotland
Mollie Tevendale	NHS Fife
Janet Trundle	NHS Greater Glasgow and Clyde
Dan Wynn	GMC Scotland

Action

1. Welcome, introductions & apologies:

The Convener, Michael McMahon MSP welcomed everyone to the meeting especially guest speaker Jan Killeen, Director of Policy at Alzheimer Scotland, who would lead that evening's discussion on the Dementia Strategy.

MSPs attending that evening included Andy Kerr, MSP for East Kilbride.

Apologies were noted as above.

2. Annual General Meeting 2010: (paper 1 attached)

The annual general meeting took place including the election of office-bearers for 2010-2011. (Details of this meeting are recorded as a separate minute.)

3. Minute of previous meeting of Tuesday 23 March 2010

The minute of the meeting of Tuesday 23 March 2010 was adopted as a true and accurate record of proceedings.

4. Matters arising from the previous meeting of Tuesday 23 March 2010:

4.1 *Palliative Care (Scotland) Bill* (item 4.1)

The Convener reported that Gil Paterson's *Palliative Care (Scotland) Bill* had been proposed to give people a statutory right to receive needs based palliative care on demand. The proposed Bill had received sufficient support from MSPs to take it forward, and had recently been launched. The Bill had not yet been allocated to a lead Committee for stage 1 of the process and so far no specific timetable was available.

4.2 Launch of GMC's *Treatment and care towards the end of life: good practice in decision making* (item 4.2)

The Convener reported that Jackie Bell, Scottish Project Officer at GMC Scotland had requested that the following message be announced:

'We are delighted to invite you to a joint parliamentary briefing event on the GMC's new guidance: Treatment and care towards the end of life and NHS Scotland's new integrated adult policy: Do not attempt cardiopulmonary resuscitation (DNACPR) which were both launched on 20 May 2010.

The meeting will be hosted by Michael McMahon MSP, Convenor of the Cross Party Group on Palliative Care.

Over the past two years the GMC has worked with a wide range of individuals and organisations to develop the guidance.

We would like to take this opportunity to thank you for any contributions you have made. We have learned an enormous amount and we hope that this is reflected in the new publication.

We are in the initial process of promoting the guidance and developing learning materials in the form of case studies. We very much hope you will be willing to help us with this work too.

End of Life Care/DNACPR Briefing event: Thursday 24th June 2:30 pm – 4.00 pm at the Scottish Parliament.'

The Convener informed members that if anyone wanted to attend they should send details to Pauline Britton at their earliest convenience.

4.3 International perspectives on palliative care from economically developing countries (item 5.1)

The Convener updated the group that so far his efforts to meet with interested MSPs had been unsuccessful, although some 1:1 discussions had taken place. This matter was ongoing and he would continue to try to schedule a meeting of interested members at some point after the summer recess.

ACTION: The Convener to take forward **MMcM**

4.4 The Annie Lennox SING campaign (item 5.2)

The Convener reminded the group that this campaign was intended to be a voice for women and children with HIV/AIDS. The money raised by SING aimed to help prevent the spread of HIV in South Africa, and also supported those currently living with HIV. The campaign also aimed to raise awareness and understanding.

The Convener reported that Patricia Ferguson MSP had informed the Partnership that

'The Cross Party Group on International Development had looked at doing something with Annie following her appearance at the Festival of Politics last year. It became clear, however, that the Parliament wanted to build its links with her and has begun to do so. Given this situation I don't think there is anything further that we will do until we see how the relationship with the Parliament works out'

4.5 End of Life Assistance (Scotland) Bill (item 6)

Mark Hazelwood reported that the formal consultation on the draft submission of evidence to the End of Life Assistance (Scotland) Bill Committee had closed on Friday 7 May 2010. Responses from 30% of member representatives had been received of which 93% were supportive of the submission. This meant that the Partnership was able to present their written evidence to the Committee (the closing date of which was 12 May 2010) a copy of which was available on the Partnership's website at:

http://www.palliativecarescotland.org.uk/news/end-of-life-assistance-scotland-bill

Mark offered a vote of thanks to everyone who had contributed to the consultation.

In response to their call for evidence, the End of Life Assistance (Scotland) Bill Committee had received a very large number of written submissions which would be published online at the end of June 2010.

The Committee would start to take oral evidence on the Bill in September 2010, after the Parliament's summer recess.

The Parliament had set an end date of Wednesday 24 November 2010 for the completion of stage 1 of the Bill (which included the Committee's report to the Parliament, and the Parliament's debate and decision on the general principles of the Bill). At this point the Bill would either fall or move on to Stage 2 for further consideration by the Committee.

The End of Life Assistance (Scotland) Bill Committee had now appointed a legal advisor, Alison Britton, a senior lecturer in law from Glasgow Caledonian University, to assist in its work. It was noted that a challenge had been made by Care Not Killing to the process of appointment and also the perceived impartiality of the advisor.

The previous week the Convener discussed the Bill and the advisor's appointment to the Committee with Baroness Illora Finlay, who advised him that Lord Joffe's Assisted Dying for the Terminally Ill Bill had been scrutinised by a Select Committee (under the chairmanship of Lord Mackay) which had at that time appointed two specialist advisors (one with knowledge of palliative care) to assist in its work.

The Convener reported that he was considering following this precedent and might write to the Committee with his concerns, requesting the appointment of a second advisor (with palliative care experience) to the Committee.

ACTION: The convener to take forward **MMcM**

UPDATE: All the evidence submitted to the End of Life Assistance Committee has now been published on the Parliament's website at: http://www.scottish.parliament.uk/s3/committees/endLifeAsstBill/evidence/ela-submissions-alph.htm

4.6 Scottish Partnership for Palliative Care's Annual conference (item 7.2)

Mark Hazelwood reported that the Partnership's Annual Conference *'Palliative care is everybody's business'* and AGM would take place on Thursday 28 October 2010 at the Heriot-Watt Conference Centre, Heriot-Watt University, Edinburgh.

The theme of the conference would reflect issues addressed by SLWG(7) - facilitating a wider discussion of death, dying, loss and bereavement across society.

Professor David Clark, Director of Dumfries Campus, University of Glasgow, had agreed to deliver the keynote opening address based on a historical and cultural perspective on where palliative care was now and where it could go next.

Building on evaluations of previous conferences, delegates had requested a more participatory format, therefore the following three parallel sessions had been planned into the programme:

1. What if.....? What would we do if the End of Life (Scotland) Bill was passed? (Nora Kearney, Professor of nursing and cancer care, University of Dundee)
2. Raising awareness of death, dying, loss & bereavement (Hilary Fisher, Director of the Dying Matters Coalition, National Council for Palliative Care)
3. Exploring the challenges of belief, time, space, culture and self in delivering empathetic compassionate care (Dr Stephen Smith, Lead Nurse, Leadership in Compassionate Care Programme, Napier University)

Discussions were ongoing regarding a speaker for the closing plenary.

The programme and registration form were available on the Partnership's website.

5. Discussion: The Dementia Strategy

Please note that this is not a verbatim record but a summary of key points raised.

The Convener reported that the Scottish Government's Dementia Strategy was launched on 1 June 2010 and represented a major milestone in the history of dementia care in Scotland.

Alzheimer Scotland believed that it was a significant step forward in tackling many of the difficulties experienced by people with dementia and their families. The Strategy was for an initial 3 years, to be followed by a 2nd three-year stage to take into account the progress and learning from the first stage.

The Convener invited Jan Killeen to speak about the Strategy, after which there would be an opportunity for further discussion.

Jan reported that she had been in a position of campaigning for improved services for people with dementia and their carers over the past 25 years. Firstly from Age Concern Scotland, then as Director of Scottish Action on Dementia over a 10 year period, and since then as Director of Policy within Alzheimer Scotland - Action on Dementia where she had been since the charity was formed in 1994.

The Dementia Strategy represented an important landmark in the history of dementia care in Scotland. Earlier milestones included the Miller Report (1970) which recognised the need for specialist psychogeriatric care within the NHS and the Timbury Report (1979) which recognised the need for small specialist continuing care units for people with dementia within the NHS (at that time people were often only diagnosed at a late stage when the behavioural and psychological symptoms were more extreme).

In 1984 Scottish Action on Dementia (SAD) had been established in response to an outcry about the poor quality of care, lack of appropriate services in the community to help carers struggling at home, lack of specialist continuing care, archaic laws to protect and promote the rights of adults with incapacity, and the high costs of care to carers (all recognised and exposed by the Equalities Commission).

In the second half of the 1980s the Conservative Government had introduced several initiatives which had supported the development of specialist services for people with dementia, for example Community Care Grants for voluntary organisations and Mental Illness Specific Grants. In 1988 the SHARPEN Report (Scottish Health Authorities Priorities for the Eighties and Nineties) had been published and had recommended top priority for the development of community based services for older people with dementia. This had been endorsed by Malcolm Rifkind, the then Secretary of State for Scotland, in the NHS Scotland policy priorities document. It was in that year that SAD's proposal for the Dementia Services Development Centre had been taken forward with Stirling University having had received initial funding from the then Scottish Executive. The Centre was now in its 21st year.

The next key landmark was the 1991 Community Care Planning Circular which for the first time had identified dementia as a discrete group for community care planning purposes (dementia care had always been the poor relation) being pushed between mental health and older peoples services within local authorities.

Jan went on to explain that the need for comprehensive, integrated health and social care services for people with dementia and their carers had long been recognised but had not been delivered upon.

The Scottish Government had made dementia a priority in 2007 and had included a focus on the provision of information for cares and people with dementia; the piloting of three post diagnostic support services and the introduction of HEAT targets for the diagnosis of dementia. The Dementia Strategy, first announced at the end of May 2009 and launched on 1 June 2010, had built on this - the word ***tackle*** in the Strategy being the most important one. The Strategy was for an initial 3 years, to be followed by a 2nd three-year stage to take into account the progress and learning from the first stage.

Alzheimer Scotland had welcomed the Strategy as recognising the need for improvements to the quality of care across all health and social care services, with the Charter of Rights for People with Dementia and their families and carers being central to the transformation of services. The Cross Party Group in the Scottish Parliament on Alzheimer's, in conjunction with Alzheimer's Scotland and the Scottish Human Rights Commission, had developed the Charter which was launched on 8 October 2009 by Irene Oldfather MSP, Convener of the Cross Party Group. (A copy of the Charter is attached as appendix 1).

The Government had taken a partnership approach to the development and implementation of the Strategy, with the expectation that this would be mirrored at local level. This was reflected in the multiple forewords to the document from CoSLA, Alzheimer Scotland, and the Scottish Dementia Working Group.

In the Strategy's Executive Summary there was a commitment from the Scottish Government to the following eight key service delivery areas:

- developing and implementing standards of care for dementia, drawing on the Charter of Rights for People with Dementia and their families and carers
- improving staff skills and knowledge in both health and social care settings - *Remember I'm Still Me* was a joint report produced by the Care Commission and the Mental Welfare Commission highlighting a range of concerns, most notably the excessive use of drugs used to control behaviour and the lack of regular medication reviews.
- providing integrated support for local change, through implementation of the dementia care pathway standards and through better information about the impact of services and the outcomes they achieved
- continuing to increase the number of people who had a diagnosis enabling them to have better access to information and support
- ensuring that people receiving care in all settings had access to treatment and support that was appropriate, with a particular focus on reducing the inappropriate use of psychoactive medication
- continuing to support dementia research in Scotland
- following diagnosis, providing excellent support and information to people with dementia and their carers
- in general hospital settings, improving the response to dementia, including alternatives to admission and better planning for discharge.

The Scottish Government was giving priority to making improvements in the last two key service delivery areas in particular which were viewed as achieving immediate benefits for people as well as improving the efficiency and quality of the care system, releasing resources to improve services.

The work to deliver the Strategy would be overseen by a Dementia Strategy Implementation and Monitoring Group, involving key stakeholders responsible for taking forward the changes, as well as people with dementia and their carers. The key tasks of the monitoring group would be to establish a monitoring framework to track improvements over time in respect of dementia services, prepare an Annual Report on progress which would be published in June 2011 and June 2012 and commission a revision of the Dementia Strategy which would take account of progress and learning to be in place from June 2013.

Jan then went on to explain that within the Strategy, training had been recognised as a significant issue (action II) and work to improve staff skills and knowledge in both health and social care settings would be taken forward in two stages. Firstly a common understanding of what the baseline knowledge and skills was in respect of dementia should be for each particular role would be established, the work of which would be taken forward by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) working together under the guidance of a project board chaired by the Chief Executive of Alzheimer Scotland. The second stage would be to develop a plan to ensure that staff had the appropriate knowledge and skills which would include embedding new competencies into existing frameworks and continuous professional development structures as well as developing new training opportunities and requirements.

A key area for reform was the way in which people with dementia had been treated in relation to what was commonly labelled *'Challenging Behaviour'*. Included in the Strategy (action VI) was a series of activities to ensure better outcomes for individuals. It included support and training for staff in person-centred care, the use of psycho-social therapies where the person had distressing symptoms of dementia and the use of psycho-active drugs only as a last resort in relation to severe psychological symptoms (ie adherence to the ICP dementia care standards). There could possibly be a review of SIGN guidelines on the management of dementia. Work would be taken forward to establish a base line and set targets for a reduction in the prescribing of psychoactive drugs, as well as work to improve compliance with the legal framework in Part 5 of the Adults with Incapacity Act, to ensure that where a person with dementia was given medical treatment his or her capacity to its consent would be properly assessed.

The Strategy had stated that a Government objective was to produce *'transformational change across health and social care system that goes beyond changes to elements or parts of the system* (action III). An integrated change project would be piloted in one area of Scotland which would involve an NHS Board and its local authority exploring the impact of a whole system redesign based on the dementia pathway. Once the pilot site had been identified, the project would begin with direct support from the Mental Health Collaborative and the Joint Improvement Team.

Jan reported that the Strategy had recognised that current information available for monitoring, planning and developing dementia services was often poor (action IV). It therefore aimed to deliver information systems fit for purpose that enabled collection and reporting on data across the whole system, allowing people managing, delivering and scrutinising services to access better information about service delivery and outcomes. The development of a Dementia Balanced Scorecard would be taken forward by the Mental Health Benchmarking Project and would be completed by May 2011 with the scorecard being operational by July 2011.

Another area to be taken forward was the continuing work around diagnosis (action V) increasing the identification of the numbers of people with dementia who have had a diagnosis as this improved access to services and support for people with dementia and carers.

Jan informed members that a few key issues had been omitted from the Strategy:

- there was no reference to palliative care or the Scottish Government's national palliative care action plan *Living and Dying Well* – Jan reported that work to help inform development of the Strategy had been taken forward through 5 workstreams focussing on specific areas, and recommendations around palliative care had been made through two of the workstreams as well as submitted in the consultation process
- there was no reference directly to commissioning issues and personalisation
- lack of funding - most people with dementia had wished to continue to live at

home for as long as possible and currently carers had provided about £1 billion in care costs, without their continued commitment the cost to the public purse would be immensely more.

The BIG lottery fund was donating in the region of £3m a year over the next 10 years, which might give priority to the development of post-diagnostic support services.

Jan concluded by saying that although the Strategy provided for the development of a strong improvement programme and highlighted the role of community in supporting people with dementia to continue their normal lives as long as possible, it did not address the need to increase services to meet the growing demands from Scotland's ageing population. This issue would hopefully be addressed within the Scottish Government's *'Reshaping Care for Older People'* agenda which was currently out for consultation. That document, along with the Dementia Strategy and the forthcoming Carers Strategy should be considered together.

The Dementia Strategy (attached as appendix 2) and consultation reports can be viewed on the Scottish Government's website at:

www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/Strategy

The Charter of Rights for People with Dementia can be viewed on the Alzheimer Scotland website at: www.alzscot.org

A discussion ensued, the main points arising from which included:

- NES would ascertain the current dementia training available for GPs and develop this as required to include early diagnosis, planning ahead, power of attorney etc
- England already provided dementia training for GPs which included awareness, early diagnosis etc
- RCGP had been invited to participate in the Dementia Strategy workstreams but no one had attended
- there was a need to ensure that palliative care was addressed within the action programmes on standards and competencies
- throughout Scotland, re-skilling generalists could to a certain extent be taken forward in collaboration with the work of *L&DW*
- working collaboratively was paramount in progressing the Strategy
- the Mental Health Collaborative had carried out a lot of work in this area and had secured protected training time within a number of health boards
- two main issues coming out of the consultation and engagement processes for people with dementia were a lack of support following diagnosis and the poor quality of care received in general hospitals
- research evidence supported the view that outcomes for people with dementia were considerably worse than for older patients in general
- increased specialist support and improved staff training were required for care homes
- people in care homes had sometimes experienced impersonal care with medication being overused to address behaviours that staff and carers found challenging
- the Alzheimer Scotland Beyond Barriers Project supported both staff and relatives in care homes to meet the palliative care needs of people in the later stages of dementia
- the trajectory for dementia was a particularly difficult one and showed that those experiencing dementia and frailty would dwindle away slowly, becoming increasingly incapacitated over years or even decades
- NHS Fife had produced a local dementia strategy, and a dementia pilot project in Fife had been funded by the Scottish Government to look at ways of

supporting people with dementia (and co-morbidities) in the community to prevent unnecessary hospital admission
- GPs were looking after an ageing population resulting in an increase of people with dementia - GP training on diagnosing dementia was therefore essential
- the Strategy incorporated a broad understanding of the needs of patients
- it was important to use evidence-based approaches, such as those used in the three post-diagnostic support pilots funded by the Scottish Government
- psychological input had a profound impact on the support work carried out with families and carers
- the Scottish Government and its partners in local government and the voluntary and private sectors would develop and implement standards of care for dementia (drawing on the Charter of Rights) to cover all stages of the dementia journey in all care settings
- it was imperative to have palliative care input into the development of these standards
- it was not yet known who would lead the work on the development of the standards
- there was considerable evidence that the generic National Care Standards of 2002 had not delivered for people with dementia
- the palliative care approach had not been reflected in the Strategy - this needed to be addressed urgently
- a huge amount of progress had been made but there was still a lot to take forward.

The Convener thanked guest speaker Jan Killeen for leading the debate, and everyone else for their valuable contributions to the debate.

6. Any other competent business:

6.1 International Palliative Care Conference – Professor Scott Murray

The Convener reported that Professor Scott Murray and Dr Mhoira Leng were planning a one-day conference on International Palliative Care for the day after the Partnership's Annual Conference (Friday 29 October 2010). It would be held at Edinburgh University, Teviot Place, and the theme would be around mentorship to support clinicians in the field. Further details would be circulated to members when available.

7. Date of next meeting:

Mark Hazelwood reported that the next meeting would be held on **Wednesday 8 September 2010** at 5.45 pm in Committee Room 5 and would be dedicated to the Proposed Palliative Care (Scotland) Bill. Gil Paterson MSP had agreed to attend. Attendance at the meeting would be limited to two members per organisation and would be on a first come first served basis as numbers were restricted due to the size of the room available.

There being no further business the meeting closed at 7.15 pm.