Cross-Party Group in the Scottish Parliament on Palliative Care

Convener	Vice-Conveners	Secretary
Bob Doris MSP	Miles Briggs MSP Colin Smyth MSP	Mark Hazelwood

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

Wednesday 06 September 2017 at 5.45pm
Committee Room 4, James Clerk Maxwell Room, Scottish Parliament

Present:	Bob Doris MSP (Convenor)	Member for Glasgow Maryhill and Springburn
	Colin Smyth MSP	Member for South Scotland
	Gail Allan	HMP Glenochil
	Shaben Begum	Scottish Independent Advocacy Alliance
	John Birrell	Bereavement Consultant
	Rev Margery Collin	Strathcarron Hospice
	Elaine Colville	NES
	Linz Connell	Scottish Independent Advocacy Alliance
	Amy Dalrymple	Alzheimer Scotland
	Pauline Ellison	Scottish Partnership for Palliative Care
	Geraldine Finnan	NHS Borders
	Belinda Hacking	British Psychology Society
	Trisha Hatt	Macmillan Cancer Support
	Mark Hazelwood	Scottish Partnership for Palliative Care
	Annabel Howell	NHS Borders
	Sorcha Hume	Charlie House
	Nigel Ironside	HMP Glenochil
	Helen Keefe	Marie Curie
	Rachel Kemp	Marie Curie
	Fiona Kerr	Queen Elizabeth University Hospital
	Donald Macaskill	Scottish Care
	Eilidh Macdonald	Hospice UK
	Maria McGill	CHAS
	Richard Meade	Marie Curie
	James Neil	Association of Palliative Care Social Workers
	Maureen O'Neill	Faith in Older People
	Euan Paterson	RCGP
	Dr Sally Paul	University of Strathclyde
	Robert Peacock	Scottish Partnership for Palliative Care
	Joanna Prentice	NHS Greater Glasgow and Clyde
	Elizabeth Sanchez-Vivar	NES
	Kirsty Smith	Macmillan Cancer Support
	Jackie Stone	St Columba's Hospice
	Pete White	Positive Prison? Positive Futures ...
	Stewart Wilson	Cruse Bereavement Care Scotland
	Mandy Yule	Ayrshire Hospice
Apologies:	Iain Armstrong	British Heart Foundation Scotland
	Paul Baughan	NHS Forth Valley
	Sandra Campbell	NHS Forth Valley

Apologies: (continued)	Pat Carragher	CHAS
	Josaleen Connolly	NHS Ayrshire & Arran
	Shirley Fife	NHS Lothian
	Carolynne Hunter	
	Dr Murdo Macdonald	Church of Scotland
	Sandra McConnell	Ardgowan Hospice
	Irene McKie	Strathcarron Hospice
	Gordon McLaren	NHS Fife
	John Miller	Duchenne Scotland
	Stuart Mitchell	Sue Ryder
	Dot Partington	St Columba's Hospice
	Rebecca Patterson	SPPC
	Dr Ros Scott	University of Dundee
	Helen Simpson	ACCORD Hospice
	Kenny Steele	Highland Hospice
	Elaine Stevens	IANPC
	Helen Stevens	Scottish Government
	Lorna Stewart	NHS Fife
	Sara Twaddle	Healthcare Improvement Scotland
	Susan Webster	MND Scotland

Action:

1. **Welcome, introductions and apologies**
   Convenor of the group Bob Doris MSP welcomed members to the meeting. Introductions were made and apologies noted on previous page and above. A special welcome was given to presenters Gail Allan (Macmillan Palliative Care Co-ordinator for Prisons), Nigel Ironside (Governor, HMP Glenochil) and Pete White (Chief Executive, Positive Prison? Positive Futures …).

2. **Annual General Meeting 2017** (Separate agenda provided as paper 1) **and Election of Office Bearers** (Convener, Vice-Conveners and Secretary)

   2.1 Minute of AGM 16 September 2016 (paper 2)
   The minute was approved as an accurate record of the meeting.

   2.2 Annual Return and Accounts 2016-2017 (papers 3a & 3b)
   The Annual Return and Accounts 2016-2017 were unanimously approved.

   2.3 Annual Subscription 2016-2017
   The Convener noted that the Cross Party Group currently operated without the need for a subscription and proposed that this continue for the following year. Members present agreed with that proposal.

   2.4 Election of Office Bearers
   Bob Doris passed the Chair to Mark Hazelwood to lead on the election of office bearers.
   Election of Convenor: Mark noted that Bob Doris had indicated a willingness to continue as Convenor. Bob Doris was re-elected as Convenor.

   Election of Vice-Convenors: Bob Doris re-assumed the role of Chair and noted that Colin Smyth MSP was willing to continue as Vice-Convenor of the cross party group. Colin Smyth MSP was elected unanimously as Vice-Convenor.

   The nomination for the other Vice-Convenor was Miles Briggs MSP. Members were pleased to elect Miles to this post if he was willing to accept the nomination. The Convenor would discuss this with Miles.

   ACTION: The convenor to take this forward **BD**

   Election of Secretary/Treasurer**:** Mark Hazelwood was re-elected as Secretary and Treasurer of the Cross Party Group.

3. **Approval of minute of previous meeting of Wednesday 31 May 2017**
   The minute of the previous meeting of Wednesday 31 May 2017 was approved and

adopted as a true and accurate record of the meeting.

4. Matters arising from Wednesday 31 May 2017

4.1 Strategic commissioning relating to the social care sector

Following on from discussions at the two previous Cross Party Group meetings Donald Macaskill asked about the progress of the Commissioning Notes.

Mark Hazelwood agreed to ask Tim Warren from the Scottish Government for an update on this and share it with members of the group.

ACTION: The Partnership to follow up **MH**

5. Presentations/ Discussion: *Palliative and End of Life Care in Scottish Prisons*

The Scottish Parliament Health and Sport Committee had published a report looking at *Healthcare in Prisons* HM Inspectorate of Prisons had also published a report entitled *Who Cares? The lived experience of older prisoners in Scottish prisons* This meeting of the Cross Party Group provided a topical opportunity to explore and discuss palliative and end of life care in Scottish Prisons.

Positive Prison? Positive Futures ... was a community of interest which draws upon the shared lived experiences of people who are or have been subject to punishment. They seek to improve the effectiveness of Scotland's criminal justice system so as to reduce the harms caused by crime and to support the reintegration of those who are or have been subject to punishment.

Pete White (Chief Executive, Positive Prison? Positive Futures ...) explained that when people were in prison, their prison cell was their home. They did not have access to other parts of the prison beyond their own wing and were very much restricted in what they could do – they had lost their liberty and their freedom of movement. During his time in HMP Edinburgh, Pete was able to access each part of the prison in his role of literacy and numeracy peer tutor.

The way in which historic cases of abuse were currently being administered by the courts meant that people who were relatively old were coming to prison a considerable time after their crimes had been committed. Demographically the prison population was changing towards older people.

The majority of people in Scottish prisons came from the top 5% of areas of most deprivation most of whom were less healthy (their life expectancy being 10 – 15 years lower than that of the general public) because they had not traditionally engaged with their local community healthcare services due to their disordered way of life. Because of this, these people were not able to achieve levels of wellbeing that were regarded as being normal. When it came down to people serving long sentences and even relatively short ones at an advanced age, the number of people approaching death in prison was rather high.

Palliative care could be delivered in hospitals, hospices and inside people's own homes but achieving that same level of care within a prison was extremely complicated. Pete suggested that it was well within the reach and capacity of those who provided access to prisoners (Scottish Prison Service) and those who provided care to the prisoners (the NHS) to do something innovative and imaginative and fairly quickly to tackle what that was going to look like. Positive Prison? Positive Futures ... did not campaign against anything but was willing to propose and support this change for the better in prison. The SPS albeit slowly had been moving this forward with NHS colleagues.

The way forward was not just a question of ensuring those in prison had a sufficient diet or regime or more places to move around in, but something far more imaginative that could be achieved within the prison population itself. Many of the people serving sentences inside Scottish prisons were capable of becoming part of the process of supporting people who were moving towards the end of their lives eg by becoming a peer carer, peer supporter or someone who was able to listen. This benefitted both the

person who gave that care and support as well as the person that provided that care and support. People could do something good even though they were in prison for having done something bad. There was an idea of peer support for general healthcare in prisons but Pete suggested that something more imaginative would be peer support in looking after people who would not be going back to their family homes in the community and who would die in prison.

It was important to see ways forward rather than dwelling on things that had not gone well in the past.

Nigel Ironside, Governor, HMP Glenochil: Nigel informed members that the prison population trend had been fairly static over the past 4 to 5 years. He shared some statistics including the numbers of people in custody in Scotland and their sentence type. In Scotland there were 15 prisons – two of which were privately owned and operated under contract to the SPS, the other 13 were run by the SPS. HMP Glenochil was a long-term prison (668 spaces) that housed the majority of the sex-offender population in Scotland and also those mainstream prisoners from the Falkirk and Fife postcode regions who had been convicted of drugs, violence and acquisitive crimes.

Internationally 50 years of age was the age recognised as an elderly prisoner in custody – their physiology was usually 10-15 years older than those 50 and over living in the community. This was due to a number of reasons eg coming from areas of deprivation, problems with substance misuse, the cumulative effect of being in custody for a very long period of time etc. As of the previous week, there were around 1,020 elderly prisoners split across all of the prisons in Scotland. 50% of those were from HMPs Barlinnie, Edinburgh and Glenochil whilst the other 50% were spread across the other 12 Scottish prisons.

Research into elderly prisoners and the problem of social care showed that prisons configuration was a significant issue. Over the past 10 – 15 years there had been an extensive refurbishment programme and new design concepts within the Scottish prisons infrastructure on the principal of a long-term projection aimed at maximising space and increasing capacity. Most prisons were still not fit for purpose with regards to meeting the needs of elderly prisoners.

There was a fairly large increase in the number of first-time prisoners over the age of 50/ 60/ 70 being given custodial sentences for historical sexual offences some of whom already had long-term conditions, multiple complex needs or co-morbidity issues. The oldest prisoner currently in custody was 85 years old. There was also the pending cohort of those who came in with long-term sentences and would be in custody for the next 1, 2 or 3 decades to be cared for by the State.

There were significant challenges in accessing social care provision within prison.

Peer caring and peer support were a critical part of the delivery of palliative and end of life care in prisons. Maintaining both physical and mental meaningful activities for elderly prisoners was crucial as many of them had lost contact with family and community because of the nature of their offences.

Research findings showed that for the elderly cohort of prisoners a number of issues were crucial: social interaction/ networking; dependence on staff; self-determination, independence; healthcare; dignity; self-isolation created mental health issues; peer support and peer carers (not always welcome!) and overarching all of these was the fear of death/ dying in prison.

Gail Allan, Macmillan Palliative Care Co-ordinator for Prisons: Macmillan Cancer Support has funded Gail's post for two years to support the implementation of palliative and end of life care standards in Scottish prisons. The post was hosted between HMP Glenochil and the Lead Cancer Office in Falkirk Community Hospital.

The Strategic Framework for Action on Palliative and End of Life Care was about the delivery of palliative care no matter what the settings were.

Gail highlighted an article published earlier that week about someone in custody currently being cared for in an Edinburgh hospice and used it to show the outcry and negativity that tended to come to the surface when prisoners accessed external services. However because the current prison demographic was increasing in age it was likely that the need for prisons to transfer to local community hospitals, hospices or larger hospitals for nursing care would also increase.

NHS Scotland took over prison health care in 2011, prior to that healthcare was provided by the Scottish Prison Service (SPS). Each NHS Board was responsible for the delivery of healthcare for those prisons situated within its own locality. With regards to prison healthcare – there were no hospital facilities in prisons; no 24-hour nursing care; the core prison healthcare team was made up from a primary care team, an addictions team and a mental health team; prison healthcare ran between 7am to 9pm weekdays, 7am to 6pm at weekends; there were no overnight services with only 7 or 8 custodial staff on duty. According to the newspaper headlines earlier that week, prisoners should be locked up and not allowed out for care. However people should be made aware just how challenging must it be for staff looking after prisoners with major healthcare issues.

The essence of the Macmillan Project was based on the Scottish Governments Strategic Framework for Action on Palliative and End of Life Care and included supporting SPS and NHS staff to identify those prisoners requiring supportive, palliative and end of life care (eg diagnosing dementia was extremely challenging because every day had the same times for the same routine); looking at the health of the prison population; holding supportive and palliative care meetings; developing a palliative care register; working in a multidisciplinary way etc.

There was a need to join up the work being carried out externally to that being carried out within the prisons eg ACPs, the domains of the SFA, use of the SPICT tool etc.

Despite the recent media headlines, everyone had the right to healthcare and palliative care.

At this point Trisha Hatt (Senior Service Development Manager (Scotland), Macmillan Cancer Support) formally thanked everyone involved in the project for all their sterling work and the Scottish Partnership for Palliative Care for the opportunity to present that night.

Main points from the ensuing discussion included:

- The Macmillan project would be evaluated.
- There was a peer to peer support project in Maine (supported by Aberdeen University) where prisoners were trained to provide care.
- SPS was looking towards formalising peer to peer training. Offering care and support contributed towards self-respect and self-reliance.
- There was multi-faith chaplaincy in prisons – spirituality and chaplaincy was an integral part of palliative care.
- There was a tendency for long-term prisoners to take more interest in religion than short-term prisoners.
- The Listeners service within prisons in Scotland was an alternative to the services provided by the Samaritans in the wider community. The Samaritans trained prisoners to be listeners for people who were feeling suicidal or in despair. They had made a huge difference across Scottish prisons in reducing prisoner suicide. Perhaps a similar model could be used to help train people in palliative care and support inside prisons? There could be a layering of these roles to suit different strengths and needs.
- The training Pete received re helping people with their reading and writing took just a few weeks – having that role in prison transformed his life.
- The responsibilities of the SPS was custody, order, care and opportunity now it was ‘unlocking potential, transforming lives’
- There was an assumption that prisoners would prefer to be treated externally but

this was not the case – their home was their prison cell but healthcare was not provided there 24/7 – the infrastructure was not currently in place to deliver hospice services in prison. Prisoners preferred to remain in prison to be treated because they tended to be judged by the public (and the media) when accessing external services.

- Resources were not available for any redevelopment/ refurbishment/ refit – prisons had been designed for security not for the needs of older prisoners. It was possible that existing nursing/ care home facilities no longer in use could be acquired at a significantly lower cost and used to provide healthcare services for end of life prisoners – security was not the issue in those circumstances.
- There was a national wages policy in place for prisoners so they would not qualify for carers benefit/ allowance.
- In reality, elderly sex offenders with long-term healthcare problems were being looked after by peer carers who were also sex offenders therefore the idea of having a reasonable expectation that there would be some type of care job for them in the community when they left prison was just not there. Realistically what was achievable by individuals in custody was a significant value set in terms of their own offending behaviour going forward. Realistically getting some work on the outside in a similar field was unlikely, not impossible but unlikely. Often these people would be under license or some kind of post release supervision.
- Individuals could be trained to work in a prison and in turn become trainers themselves.
- In Dumfries prison there were a lot of bookshelves against the walls on the ground floor which was an unusual setup, the reason being was that some people were unable to climb stairs to access the library so they brought the library to them – that sort of approach could be expanded upon.
- There was now collaboration between the SG's Justice Directorate and Healthcare Directorate on a range of issues including reducing health inequalities in prison. It was vitally important that the issues raised tonight at the meeting needed to be included on their agenda – the opportunity for goodwill was there to get something sorted out.
- The SPS had an ambition and aspiration to ensure that everyone who came into prison had a plan for what they were going to do – not just for the prisoner but for all the services they would engage with – including those that would require/ required palliative care.
- There was an increased number of sexual offenders in custody due to the 'Savile Effect' with life and long-term sentences – those sentences were now becoming even longer. Young men in their 20s coming into prison would now not be released until they were in their 40s, 50s or even 60s.
- 85% of High Court business dealt with sexual offending. Allegations of sexual offending and pursuit of sexual offenders would continue to increase dramatically.
- In Glenochil there were 20 prisoners currently on the palliative care register and 5 on Personal Emergency Evacuation Plans (PEEPs) – these numbers were growing all the time
- There needs to be consideration of how to support families visiting individual cells to spend time (sometimes overnight) with a dying loved one because that is what would happen in the community.
- There was the issue of having morphine drivers on the premises for such patients
- Work was taking place in Shotts Prison around recognising dementia and identifying dementia amongst prisoners – the susceptibility to dementia in prisoners was very high due to a number of issues including prisoners' socioeconomic background, health issues etc.
- The Dementia Dogs Project at HMP Castle Huntly – prisoners were helping to train these dementia dogs. This project was very much at a research and trial stage.
- The Health and Sport Committee looked at this issue recently and had taken evidence from a number of sources. When healthcare provision was transferred from SPS to NHS social care provision remained with the SPS – the committee

had discussed this in relation to integration and agreed it should be kept under review. There was a lot of current good practice eg in Glenochil and Forth Valley however that was not universal throughout Scottish Prisons as standards varied considerably.

- Working in partnership with the NHS, SPS and Healthcare Improvement Scotland, Macmillan was developing an integrated approach which included supporting prisons to identify palliative prisoners; having regular multidisciplinary meetings/ holistic conversations about these prisoners; developing a governance structure to record and evidence a good standard of care including a palliative care register; working in a multidisciplinary way etc.
- The Health and Sport Committee had made a number of recommendations in its report – part of its work plan was to check at a future date if any progress had been made around these recommendations.
- Forums were being set up in a number of prisons looking at bereavement care however what was still lacking was the care around death for prisoners who died within prison. The funeral of prisoners who did not have a family lay with the local authority in which the prison had been built – which might not be anywhere near their own home or community. There was an opportunity for Community Justice Scotland to become involved in this matter.
- Having 24-hour nursing care and social care was core to looking after people in their custodial home.
- Within social care dimension of home care delivery there was a massive legislative gap following publication of the Public Bodies Act – that needed to be addressed. Implementing the new National Health and Care Standards which were explicitly based on human rights principals in Scottish Prisons was crucial. In terms of human rights to die in a manner that was dignified, person-centred, in a place of your choice with as much control as possible. That was the crux of good palliative and end of life care in the community and that should be available to those living in a custodial home. The National Health and Care Standards were about the delivery and resourcing of that care and support. Prison Governors had to bid for social care packages which meant exclusion for some who were unable to afford that. This was something that the Health and Sport Committee should look at going forward.
- Moving on beyond the 2 years of Macmillan commitment one impact that could be measured would be for someone in a prison cell to have a good death and for staff (and families) to be supported through bereavement. Breaking down the red tape barriers at Glenochil was difficult but with the help and support of working with other organisations such as the SPS, Marie Curie, district nurses the local GPs was an example of true integrated care and approach to support that person in prison.

In light of the recently published Health and Sport Committee's report looking at Healthcare in Prisons members agreed that a courtesy copy of the minute of the meeting should be forwarded to Neil Findlay MSP as Convener of that Committee.

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

6. Any other competent business

On this occasion no further business was discussed.

7. Date of next meeting

Wednesday 06 December 2017 in **Committee Room 4** (James Clerk Maxwell Room) at **5.45 pm**. The topic for this meeting will be **Palliative Care in Scottish Hospitals**, and Dr Deans Buchanan (Consultant in Palliative Medicine, NHS Tayside) will be among those presenting.

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