

CROSS PARTY GROUP IN THE SCOTTISH PARLIAMENT ON CHRONIC PAIN

CROSS-PARTY GROUP IN THE SCOTTISH PARLIAMENT ON PALLIATIVE CARE

Note of Joint Meeting held on 13 November 2002 Committee Room 1, Scottish Parliament

Present: Dorothy-Grace Elder, MSP (joint chair); Michael McMahon MSP (joint chair); Dennis Canavan MSP; Kenneth Macintosh MSP; Susan Aitkenhead, RHSC Glasgow; Gordon Anderson, Researcher; John Asbury, Western Infirmary, Glasgow; Janette Barrie, NHS Lanarkshire; John Currie, RHSC Glasgow; David Falconer, Pain Association; Ian Gibson, Macmillan Cancer Relief; Derek Jones, Queen Margaret University College; Gerry Lafferty; Helen McDade, CPG on M.E; Yvonne McEwen, University of Edinburgh; Liz Macleod, Pain Association; Dr Sheila McGettrick, Prince & Princess of Wales Hospice; Bill Macrae, Ninewells Hospital; Denis Martin, Queen Margaret University College; Blair Smith, University of Aberdeen; John Thomson; Pat Wallace and Stephen Grounds, Scottish Partnership for Palliative Care.

Apologies: The following Members sent their apologies for absence: Robin Harper MSP, Frank Clark CBE, Brendan Gill, Dr Martin Leiper, Joan Munro, Susan Munroe, Susan Preston, Dr Jim Rodgers, Stephen Smith, Heather Wallace, Mike Walton, Professor John Welsh, Jenny Whelan and Dr Diana Wilson.

1. Welcome

Dorothy-Grace Elder welcomed those present and requested that agenda item 3 on funding be taken first. This was agreed.

2. Health Spending Review

Dorothy-Grace Elder referred to discussion at the Health & Community Care Committee meeting on 6 November, and informed the meeting that the Health & Community Care Committee's recommendation that money be allocated from the new resources to provide comprehensive chronic pain services throughout Scotland had been turned down. The Scottish Executive had, however, accepted their recommendation for improved neurological services, and the Committee was unhappy at the different approaches to chronic pain and neurology in the Executive response. In particular, the Executive had indicated that ring-fencing of resources was not compatible with the local flexibility and discretion necessary to take account of local circumstances. The issue seemed to be that although the Health Minister had accepted that chronic pain was an issue, it was not regarded as a national priority.

Dorothy-Grace Elder invited suggestions on how to take this issue forward

A general discussion took place. Key points are noted below.

Yvonne McEwan – suggested possible legal action under the Human Rights Act.

Ian Gibson – Possible Trojan horse type issue – the offer of money only if there is a commitment. Macmillan influence the NHS by bringing forward developments.

David Falconer - The big issue is that cancer is always a priority.

Dr Sheila McGettrick - A lot of palliative care comes from voluntary organisations. Statutory funding is only very recent i.e. the Cancer Plan.

Ian Gibson – Part of the Cancer Plan included money to be spent on palliative care and chronic pain is part of that.

Dorothy-Grace Elder - Is this new money?

Ian Gibson - Yes

Pat Wallace – In the 1st round of cancer monies in Scotland, 10% allocated to palliative care.

Ian Gibson - Boards required to conduct a palliative care needs assessment - opportunity when needs assessment completed to challenge Boards if pain is not properly addressed.

Pat Wallace - Some Boards just addressing cancer, others including non-malignant conditions.

Bill Macrae – Compare approach to epilepsy. Epilepsy is funded as a disease, but can say that epilepsy is a symptom and the same would apply to chronic pain. There is a primary neurological disease called chronic pain. See many patients who have neuropathic pain. Many colleagues are using a 1950's model of physiology of pain. Neurological system is far more complicated. SE advisors giving out of date information to Minister.

Dorothy-Grace Elder – Minister relies entirely on advice from Chief Medical Officer. Mary Mulligan has stated in correspondence and at meetings that she does not see pain as a separate issue.

Helen McDade - On issue of ring fencing there has been a sympathetic ear but nothing is ring fenced. This will be the same as M.E. - it is a Health Board issue. There are a lot of common aims (with the CPG on M.E.)- chronic disease should be a priority .

Michael McMahon MSP - There are areas of cross-over.

Kenneth McIntosh MSP - Any model of ring fencing?

Helen McDade - Yes for priority areas. We need to fight to be seen as a priority area. There was ring fencing for HIV a few years ago.

Kenneth MacIntosh MSP - Priority areas are set by government

Ian Gibson - There are no output programmes for the cancer plan - under ring-fencing one has to demonstrate that money spent is making a difference. Clinical networks are the new buzzword. We should be trying to influence the work plans of the clinical standards boards, which are a lever to influence. It is up to the health professionals to take it forward.

Pat Wallace - Endorse point about Managed Clinical Networks which are very much the thing of the future. Could be future way of channelling funding rather than through Health Boards and structures. MCNs also set up to address chronic conditions.

Bill Macrae – Re ring-fencing and decisions made by the Health Boards. When we ask for money the response is ' what are you wanting to cut?'. No new money. Since 1992 there has been cuts in budgets every year. Cynical view of Labour government-cuts in budget yet politicians go on television proclaiming extra money- How cynical can you get? This is letting down the whole parliament.

Kenneth MacIntosh - Budgets are year on year. Who takes decisions - political or medical people?

Bill Macrae - Cancer, heart disease, primary care and mental health are all priorities - the rest have cuts.

Sheila McGettrick - Patients with cancer don't have to wait for pain treatment in Glasgow as they are a priority. It is outrageous for a 52 week waiting list otherwise

John Thomson - Personal experience of a 14-15 month wait in Glasgow to be referred to Astley Ainslie Hospital. Until then received no advice with my condition getting worse- mentally I just didn't know what to do.

Dorothy-Grace Elder - Think people convinced that the Executive would meet their needs. Have drafted a letter to send to the First Minister as well as to the Health Minister.

Dorothy-Grace Elder read out draft letter she proposed to send to First Minister and Health Minister re Health & Community Care Committee rejection of funding –and asked if people present were happy to sign the letter. The letter was passed around for signature.

Dorothy-Grace Elder - Mary Mulligan advised yesterday that she was unable to attend today. The HCC chair, Margaret Smith, asked for the health professionals to draw up specific requests and rough costings.

Bill Macrae - Do I cancel a clinic to do this? Very cynical about this.

Sheila McGettrick - We have to do this in palliative care and provide the evidence in support of funding.

Gordon Anderson - Problem is the cross party group are 'too nice' and it is time to get into a 'bare knuckle fight in order to campaign. There are 130 k hits on the web and an estimated 550 k sufferers - all of these have a carer, partner, family, friend or relative. All of whom have a vote next year in which a significant proportion will not use. However, if a even a small portion of these people start to organise and lobby the effects could be significant. The hospital service review has thrown up a single issue candidate although that is not being necessarily advocated. Time to up the ante, lobbying local MSPs ,write to newspapers as chronic pain has not been viewed as a 'sexy issue' for the media, need to copy methods of cancer charities/campaigns who regularly have good media coverage.

Denis Martin - suggest use SCVO website and publicise issues through that. Website links voluntary websites and tracks MSPs statements.

Michael McMahon MSP – You have spoken to politicians but what about speaking directly to the Advisors?

John Currie - The worst thing is to ask for ring fenced money. The so-called "czars" deal with issues of co-ordinating national service provision. Who co-ordinates chronic pain services at government level and sees that it is provided where people need it?

Ian Gibson - There will be medical advisors within the Health department with this remit.

Helen McDade - Civil servants have appalling work conditions with huge pressures and have to provide advice on various issues.

Michael McMahon - Are there any other issues for the Palliative Care CPG to raise with Chronic pain CPG?

Pat Wallace - Suggest identify who has the portfolio among civil servants and make a friend of them, seek advice on how to proceed, educate and inform.

Blair Smith - Problem may well be that there is no such person.

Pat Wallace - Find the person who is nearest to this issue.

Sheila McGettrick - Need to raise profile within the Scottish Executive and the public. Is there any scope for fundraising?

Bill Macrae - Spoke of a charity which campaigned hard and which folded.

John Asbury - What is the minister sensitive to?

Dorothy-Grace Elder - Publicity

Kenneth Macintosh - There is no simple key to this, try them all. It is wrong to assume that the minister is unsympathetic but it is difficult to change funding streams overnight -need to keep pushing. Decisions tend to be taken over a period of time. Suggest individual letters to MSPs are helpful as they make them aware and they almost certainly result in a letter being generated from MSP to the minister. There is a barrier of awareness, need to put across case. There is a lack at professional level of a link between chronic pain and the NHS decision makers - a professional gap. Invite someone from the Scottish Executive to explain what they are doing.

Dorothy-Grace Elder - Time is critical, as the new Gordon Brown money will kick in around May 2003.

Dorothy-Grace Elder requested that Kenneth Macintosh, Michael McMahon and herself meet CMO Dr Mac Armstrong rather than invite him to another CPG meeting as time is critical.

Kenneth Macintosh MSP/Michael McMahon MSP - Agreed

Blair Smith - A half way house suggestion would be a delegation to meet him along the same lines as recent meeting with Mary Mulligan and cross party group on chronic pain.

Kenneth Macintosh - Is it medical advice that is stopping the money?

Ian Gibson - There is no medical civil servant interpreting issues.

Bill Macrae - There is a need to dispel the misunderstanding of chronic pain. Probably no single person who understands.