

# **Minutes of the Scottish Parliament's Cross Party Group on Chronic Pain Thursday 20 June 2002, 12.30 p.m. at Quaker Rooms, 7 Victoria Terrace ,Edinburgh**

## **AGENDA**

- 1.Attendance and apologies
- 2.Minutes of last meeting\matters arising
- 3.Interactive website
- 4.Raising awareness of services- Evidence based complimentary services
- 5.Questionnaire -Audit of Pain Services
- 6.Adolescent chronic pain- not children/not adults- do we need specific funding?
- 7.What next for chronic pain -taking issues forward

## **ATTENDANCE AND APOLOGIES**

### **ATTENDANCE:-**

Dorothy-Grace Elder MSP (Convenor)  
Susan Aitkenhead RHSC Yorkhill  
Gordon Anderson,  
Dorothy-Grace Elder, MSP)  
John Currie RHSC Yorkhill  
Alison Elliot University of Aberdeen  
David Falconer Pain Association  
Nigel Hayward, Athena Medical Hayward P.R.  
Derek Jones Queen Margaret University College,Edinburgh  
Gerry Lafferty Glasgow  
Christine MacDonald Backcare Lothian Branch  
Liz Macleod Physiotherapy Pain Association(PPA)  
Bill Macrae Ninewells Hospital Dundee  
Denis Martin QMUC  
Paulo Quadros Possil Stress Centre\GGHB  
Mary Scanlon MSP  
Rosemary Showell Chronic Pain Management Clinic,Cumbernauld and Kilsyth Lanarkshire PCT  
Blair Smith University of Aberdeen  
John Thomson Glasgow  
Heather Wallace Pain Concern

### **APOLOGIES**

Janette Barrie Lanarkshire Acute NHS Trust  
Fiona Garrett Backcare  
Lord James Douglas Hamilton MSP  
Evelyn McKechnie  
Robin Harper MSP  
Henry McLeish MSP  
Ruhya Parris Glasgow Royal Infirmary  
Cathy Peattie MSP  
Terry Shevlin  
Jennifer Stirton  
Elaine SmithMSP  
Margaret Smith MSP

## **2.MINUTES OF LAST MEETING/ MATTERS ARISING FROM THE MINUTES**

**Dorothy-Grace Elder asked for corrections to the minutes of 27 February 2002.**

**David Falconer :-** page 2 “Pain Association has a role in funding” should read “Pain Association are low in funding”

**John Thomson :-** page 5- “ information that was unhelpful” should read “information from the private sector was unhelpful and had been for several years”

### **MATTERS ARISING FROM THE MINUTES**

**Gordon Anderson :-** had no information on Ministry of Pensions of Works. He recorded comments that were made to him or took on board comments on the minutes which were previously circulated. He asked if someone could speak to these issue.

### 3. INTERACTIVE WEBSITE

**Dorothy-Grace Elder** :- This Website is still current. She praised Alan Smart, Head of Broadcasting and his staff who had been an enormous help before and after the last meeting and Parliamentary members debate.

The Parliament intend to keep this website open permanently. Government Ministers are watching the postings. The website is also useful for patients to share information. CPG members should continue putting their comments onto the website : [www.scottishparliamentlive.com](http://www.scottishparliamentlive.com) It is the only interactive site of its kind.

The website has attracted 130,000 “hits” from 17 countries. The website also includes a message of support from Prince Charles, who is a back pain sufferer.

The Cross Party Group was first established in 24 April 2001 having met informally from July 2000

The parliament has adopted the campaign and included it in the video “1,000 days of the Parliament”.The video can be obtained by contacting the Broadcasting services via Gordon Anderson. One of the cpg members Ann Murray is featured in the video.

The Health Minister Malcolm Chisholm last year visited the Astley Ainslie Hospital, and regards chronic pain as an important issue.He has lent weight to the support shown by the Deputy Health Minister Mary Mulligan. The previous Health Minister Susan Deacon was not an enthusiastic supporter, but in fairness as the very first Health Minister she did have a lot of issues in which to contend with.

Dr Steven Gilbert put in the original petition on chronic pain ,and it was on the basis of this that the Health Committee voted unanimously to provide additional money for comprehensive pain services throughout Scotland. Only on two previous occasions has the health committee asked for specialist support.

The Health Committee felt that the chronic pain services were patchy and inadequate and this was admitted to by Highlands Health Board to the Health committee.

### 4. RAISING AWARENESS OF SERVICES- EVIDENCE BASED COMPLIMENTARY SERVICES

**Bill MacRae**:-As regards the issue of New money very concerned at the perception on the news of extra money being allocated by allocated by the Chancellor for England and Wales – The perception by patients in Scotland is that extra money is available when the reality is that Ninewells Hospital, for example are experiencing a 2% cut. This is very frustrating.

**Dorothy-Grace Elder**: This money is not through the system yet.

**Blair Smith**:-The problem is that there are not enough qualified health professionals.

**Paulo Quadras**:-It is difficult to have enough therapists. The Health Minister Malcolm Chisholm knows about this as I have written to him concerning alternative based therapies in counselling, physiotherapy and massage.

In my experience most people have stress or conditions caused by stress. There is a need to put more and more of these centres together. The Possilpark centre has 100% funding but in other cases GP's have to find funding for these services from other sources.

**Liz McLeod**:-Complementary therapies make an enormous contribution and should be developed .Patients are at risk if they do not understand that Chronic Pain is a condition in it's own right. Patients in most circumstances have to pay for therapy and shouldn't do this.They should be a multi-disciplinary assessment and timely treatment and then patients may not have to go to see alternative therapists. Education is important. Difficult to recruit people with appropriate skills.

**Denis Martin**: Lack of physiotherapists who have the right skills. Education and training is the big issue. Shortage of people with the right skills.

**Rosemary Stowell**:-The local clinic in the Cumbernauld and Kilsyth closed due to lack of funding and was overturned due to lack of campaigns.

**Paulo Quadras**: Has had similar experience of clinic closure.

## 5. QUESTIONNAIRE - AUDIT OF PAIN SERVICES

**Dorothy-Grace Elder:** Don't know precisely the range of services. The return for health boards are sketchy. We need to cooperate amongst ourselves to get an audit done. Questionnaires can be prepared for health boards. Denis Martin met SPICE (Parliament Information Centre) Researcher about this.

A further paper was circulated to members from the Health and Community Care Committee by Gordon Anderson

**Denis Martin:** Has circulated questionnaire. Wednesday 26 June is the next date for the Health committee any further delays means that the questionnaires are being dealt with much later due to the Parliamentary recess. Seems to have taken on most of this, but will feed in comments.

Any other ideas and suggestions should be passed to Denis Martin

**Action: all members**

**Unknown person:** It would be an idea to send this information to the head of the health boards but it may only result in superficial answers being received.

**Note see paper on Information on pain clinics running within Scotland**

The list is not comprehensive and needs suggestions and additions.

**Action:- all members**

For example Astley Ainslie Hospital is excluded as it is already known. Is there a chronic pain service taking place in an area then the name and address should be included.

**Blair Smith:-** Spoke with reference to **Paulo Quadras'** suggestions on research proposals which he rejected. Need to know the size and impact of a problem. How many people are there with chronic pain. How many people would benefit. It is difficult to extrapolate based on specific areas.

**Dennis Martin:** It is strange that we didn't know the extent of problem.

**Paulo Quadras:** There is not a cohesive integrated way of assessing services. What is effective and what is ineffective. It would be useful to have Centres of alternative medicine.

**Dorothy-Grace Elder:** We need to concentrate on the format of the questions. People should speak up now or send emails in order that it can be forwarded to SPICE.

**Bill Macrae:** People in health boards are still working on a 1950's model on pain. A model that was developed in 1640. This model of pain is based on Descartes' writing from the 1640's. People are still thinking that if a part of the body hurts, it simply means that there is a problem with that part, whereas we know that between that part and the feeling of pain lies the nervous system. Problems within the nervous can give rise to pain. In these patients it is the pain itself that is the problem. We need to educate people at all levels.

Unless we can move people forward and understand brains and spinal cords that will remain the case. We have the problem that we are asking administrators who have no knowledge of chronic pain but because they are in administrative charge they are the ones who "tick the boxes" as regards priorities.

**Mary Scanlon:** From her experiences, cancer patients are expected to die in pain. Patient expectations are that they have to tolerate pain and didn't know that they could obtain pain relief.

**Rosemary Stowell:** Add in detail on how patients are actually referred.

**Denis Martin:** Suggested – what is the aim of the service; title, expected outcome. Is it valid or a 1950's model? We may need full survey with focus groups. We need questions to address these points.

**Liz McLeod:** Expressed concern that people who manage money may be putting chronic pain services at risk if they do not understand chronic pain is a condition in its own right.

**Denis Martin:** There are examples of good practice as a benchmark.

**Dorothy-Grace Elder:** Concerned that the Scottish Executive are deciding just now about spending and so things are becoming urgent.

**Mary Scanlon:** The new money does not come into effect until April 2003. The Epilepsy services are a useful example, there were no services last year in the Highlands so it is better. Anything that is of benefit is to be welcomed. Added value is what is being sought after. Ministers have made a commitment for audit of services so it is up to them to make sure that the Scottish Executive know about gaps and to review services.

Anything that you want to say we will support it.. Give us your best ideas. Dorothy-Grace Elder has cross – party support and it is an important time to build on that.

**Dorothy-Grace Elder:** Heather Wallace has arranged a meeting with the Deputy Health Minister.

**Heather Wallace:** The agenda will include:-  
How chronic pain is recognised  
Looking at the implementation of CSAR  
Chronic Pain is not ring fenced. Should there be better service.  
Four people are attending and people are welcome to attend as observers

**Dorothy-Grace Elder:** Personal inclination that when approaching Ministers that MSP's do not attend but the health professionals attend.

**Derek Jones:** The meeting was arranged some time ago. Chronic Pain needs to be identified as a condition. Services need to be comprehensive and need to involve primary care services.

There are education issues- some clinicians need more education and training than other newly qualified clinicians.

**Dorothy-Grace Elder:** The people going to this meeting are not representing the cross party group.

**Heather Wallace:** This forthcoming meeting is following on from a meeting with Malcolm Chisholm when he was the Deputy Health Minister.

**Dorothy-Grace Elder:** It is very good that someone has arranged a meeting with the Minister.

**Dennis Martin:** We are giving the same message and there should be someone there from the Cross Party Group.

**Liz McLeod:** Item 7 of the agenda today includes The Way Forward, we need to discuss this. Professionals are being represented at the meeting with the Deputy Minister for Health and it would be helpful to ideas and opinions from members of the Cross Party Group.

**Mary Scanlon:** Dorothy-Grace Elder has moved chronic pain forward and a meeting is all part of this process.

**Dorothy-Grace Elder:** There is a danger of under-pitching and not asking for enough. Dr Asbury has come with figures of £9.2 Million as being needed to tackle the 1% of chronic pain population. Are there any comments on this figure?

**Mary Scanlon:** Did the Minister promise an audit of chronic pain?

**Dorothy-Grace Elder:** Yes and No. The Health Committee decided to set out it's own questionnaire and audit. SPICE (Scottish Parliament Information Centre) are in the process of compiling a questionnaire.

Malcolm Chisholm's timescale for funding is September. Professionals from the cross party group should be at this meeting. There is a momentum of goodwill and a need to build on this prior to May 2003 before this is lost.

**Mary Scanlon:** There are no "sign" guidelines as yet.

**Rosemary Stowell:** Primary care clinics – the ideal perfect clinic is £40k per annum in the Cumbernauld and Kilsyth with a population of 80,000 which would be a multi-disciplinary nurse-led service, comprising of District Nurses with a holistic assessments Patients have to have confirmed results and diagnosis in order to assess which professionals are needed for them. These costs include staff.

**Dorothy-Grace Elder:** the £9 million estimate by Dr Asbury- how does the cross party group feel about it?

**Blair Smith:** I could not put a figure on this.

**Derek Jones:** This is the same money as primary care services, arguably

**Dorothy-Grace Elder:** Dr Asbury's estimate is worth presenting.

**Bill Macrae:** This was done in 1999 and one would have to add in inflation and psychology and physiotherapy services. Everyone needs a team approach.

**Denis Martin:** Some costs for education suggested along with a “before” and “after” link for a tracking measure. Some costings to support voluntary groups linking to the social sector. Figure of £9 - £10 Million, perhaps even £40 MILLION.

**Blair Smith:** Need research. There is no audit of services and how it works. Research has to be built in at the outset.

**Dorothy-Grace Elder:** We will want to know. Suggestions will be important to send to the Minister.

**Derek Jones:** Emphasise savings and welfare, keeping people in employment and is part of wider social exclusion.

**Dorothy-Grace Elder:** Helps lower family break up

**Denis Martin:** The Pain Service in Oxford is thought to have the same services with costs that are twice as much. The figure of £50 Million should be taken and turned into a savings of £100 million that would be achieved.

**Dorothy-Grace Elder:** There are no discussions on figures in order to hook into a debate.

**Denis Martin:** What if £50 Million was asked for at the Parliament’s Health Committee.

**Dorothy-Grace Elder:** It would be the Finance committee and not the Health Committee which would Decide what would be a large figure.

**Mary Scanlon:** The Health Committee are not in the business of allocation of resources but is about ensuring an equity and consistency of services.

**David Falconer:** Look at the inter-relation, what does it cost to run service and what would it cost to run at an ideal level.

**Dorothy-Grace Elder:** Do we have any estimates of operating costs?

**Bill Macrae:** Inappropriate operations are costly and damage people. By treating people properly at the beginning we could prevent a lot of unnecessary operations. This would not only save money by not doing the operation, it would help patients because these operations often make patients with chronic pain problems worse.

**Blair Smith:** 46% of Scots have chronic pain according to an article in the Lancet magazine. 7% have high intensity of pain. Look at this in the context of spending £50 Million

**Liz McLeod:** How can the education of patients and professionals be put into best practice and measured against “CSAG guidelines” if that is a useful measurement tool. Specialist services and staff in Primary Care are available for other chronic illnesses e.g. diabetes . Patient support network can and do pick up on these patients and continue to support them in the community.

How would specialist centres speak to other services?

**Susan Aitkenhead :** Multi disciplinary courses are being set up with money from HEBS(Health Education Board for Scotland). Will send in details.

## 6.ADOLESCENT CHRONIC PAIN- NOT CHILDREN/NOT ADULTS- DO WE NEED SPECIFIC FUNDING?

**John Currie:** There is a national bid for adolescent chronic pain dealing with issues such as where do they go when they finish school? Late teens are a group which finish school and become part of the workforce.

They are likely to fall between paediatrics and other services. There are around 10-15 kids in the group

**Liz McLeod:** The issue of SEASAG (Clinical Standards Advisory Group Services for Patients With Pain) should be part of the discussions

## 7.WHAT NEXT FOR CHRONIC PAIN -TAKING ISSUES FORWARD

**Bill Macrae;** Hospitals should appoint a person in charge of pain services. There is a need to work with different specialities together. Someone in each health board area should be responsible to make it happen.

**Liz McLeod:** How would that work from a GP perspective?

**Blair Smith:** It is most important for chronic pain to be recognised as a speciality. There is a current move towards “gypsies” – GP’s with specialist interests., these are generalists who sub-specialise and give added value. Fife, for example has a “cancer supremo”.

**Dorothy-Grace Elder:** Letter from Malcom Chisholm to Mary Mulligan on chronic pain is based on the old fashioned advice of the Chief Medical Officer.. Do we want group representation with the Minister?

How do we want this raised? Do we want someone else to attend or a written submission?

**Heather Wallace:** It is good for the cross party group to make written submissions and/or arrange a meeting.

**Bill Macrae:** Suggest that the cross party group will make a submission soon

**Heather Wallace:** Lobbying has to come from every angle.

**AGREED:** Dorothy-Grace Elder or Gordon Anderson attend as observers from the cross party group at the meeting with the Minister.

**Blair Smith :**Would be willing to “translate “ the minutes into the form of a written submission

**AGREED**

**Action: Blair Smith/Gordon Anderson**

**John Thomson:** Wished to cite his own case where he had to go to Liverpool from Glasgow for one week- the travel time would have caused more pain than the treatment would have relieved.

**Bill Macrae:** The city of Bath has a good in-patient management programme.. There are several centres in England have good pain management programmes.

**Liz Mcleod :** There are similar skills and experience in Scotland but in small pockets.

**Bill Macrae:** . Patients going for in-patient treatment have to travel long distances to England. This is stressful for the patients and expensive.

Meeting closed at 2.30 p.m.