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Minutes of meeting of Cross Party Group on Chronic Pain
Wednesday 27 February 2002 at 1.00 p.m
Quakers Meeting Rooms, 7 Victoria Terrace, Edinburgh

1. Attendance and Apologies

see sederunt attached

2. Convenor's Opening Remarks

Dorothy-Grace Elder, MSP opened the meeting.

She thanked her staff Evelyn McKechnie and Gordon Anderson for their assistance in organising this meeting. She went on to express her appreciation for the help and support of the various organisations and individuals who assisted-many of who are here today.

She went on to introduce the Scottish Parliament Head of Broadcasting Unit Alan Smart who was thanked for his help in publicity and arranging for the interactive web-page which has attracted emails and hits from California and Detroit.

One woman who logged on from California had the same symptoms as a woman who logged on from Fife- an international bond.

Dorothy paid tribute to Ann Murray and John Thomson who inspired her to set up the Cross Party Group after approaching her at a local surgery in July 2000.

3. Annual General Meeting

Dorothy-Grace Elder handed over the chair to Janette Barrie who called for nominations for the following positions which were elected unopposed:-

Convenor	Dorothy-Grace Elder, MSP
Deputy Convenor	Jamie Stone, MSP
Organisers	Evelyn McKechnie, Parliamentary Researcher Gordon Anderson, Parliamentary Researcher
Treasurer	David Falconer, Pain Association

4. Funding of Research

There is a shortage of funding bodies At present the Chief Scientific Office is the main funder. Down south in England there are various organisations which act as sources of funding for research. There are complex issues on chronic pain and there needs to be a number of funding bodies whose priorities agree with the Chief Scientific Office's priorities such as for example, cancer.

Pain goes across the priorities. There is a need to change the way of thinking.

Charities and Voluntary Organisations:- There is a need to bring them together as umbrella organisations.

The Pain Association has a role in funding and they are partners in research with the Queen Margaret College.

Dorothy-Grace Elder ran through the main points in her speech that she was giving in the debate in the Parliament later on the subject of The Plight of Chronic Patients.

A number of additional points were suggested.

One has to differentiate from Acute and Chronic Pain.

Palliative care items were to be removed as there is a Cross Party Group on Palliative Care.

Nurses have to deal with chronic pain training over and above. Clinics that are set up have to find their own resources as there are no resources for training. This is not to take anything away from chronic pain as there is an issue of time management and simply trying to cram everything. Much of time is taken up mainly by goodwill.

There is funding by drug companies but one is not obliged to use their products.

Physiotherapy Services in Lothian:- A good model and example that is funded by Primary health care and allows physiotherapists to be recruited and to work for around 6 months and to practice their skills.

There is patchy funding elsewhere particularly where nurses see and need and aim to do their best - all of which is very ad-hoc indicative of the little amount of funding for chronic pain issues.

It is important to have linked up strategy with a geographic spread. The first port of call is local practices (who don't have the knowledge and expenditure). Local practices can be preventive. Patients who don't have chronic pain have had early interventions.

Acute pain is not adequately addressed.

Yorkhill Hospital in Glasgow is very lucky in being able to develop services.

One needs health boards to develop expenditure.

One wants to see further expenditure on child services, yet Yorkhill Hospital sees the majority of children in Scotland.

Dundee Hospital sees patients from all over Scotland and England and is able to have a multi-disciplinary pain management programme by both coercion and goodwill.

One needs pressure for national bid for funding.

In Dundee they don't have In – Patient Beds. There needs to have resources and support in order to allow families staying overnight. One would like to see managed clinical network.

One would like to see Pain Centre for Children even although there is a Pain Management programme.

Even Great Ormond Street Hospital don't have this service as it is unique in the UK with a 4-6 week waiting list taking up to 99 patients.

In the first year this service was funded by the Scottish Executive.

Adolescent Management:-Need to develop treatment from children to adults. In Dundee there is an upper limit of 14 years for people taken in. If they get to Dundee before 14 years of age they will be taken on.

Pain Association Scotland needs an extra £20,000 from the Scottish Executive-this point agreed.

5. Citizens Permanent Jury

This jury could monitor what is done. A sitting panel of citizens could hear the evidence before them in order to discuss issues and to make formal reports. In order to do this there should be official funding from the Parliament or SPICE (Scottish Parliament Information Centre) in order that the Scottish Executive could respond. The costs could be in the region of £20,000. It was agreed that Elaine Smith, MSP or John Farquar Munro, MSP could help progress this.

Funding of Voluntary Sector:-Expert pain management programme including pain management component and the Challenging Arthritis Programme. All need finance.

The Department of Health in England published a report in partnership with the voluntary sector.

This could be broadened out to include other LMCA

Dorothy-Grace Elder agreed to write to the Minister on points not able to be included in the debate in the Scottish Parliament

Chronic pain is a health and social welfare issue. Dealing with chronic pain also takes pressure off the NHS.

Health problems do not stop when one leaves a doctor as it still exists at home.

Mark McCann stated that in his area the biggest problem is to get health boards to agree to a project in order that it can obtain Lottery funding. Fundraising has been going on for over three and a half years, but

£0.5 million is needed but the Lottery Board won't fund it until the health board agree to it.

Lochaber :- 12.5% of the population suffer pain.

23% - (233 people)- get hydrotherapy and have to go to Dingwall for one week of hydrotherapy treatment. That is a round trip of around 250 miles costing around £700. This could be done cheaper in Lochaber.

Doctors don't know what hydrotherapy is.

£3 million is spent on pain relief.

Dingwall is at a capacity and cannot cope.

22 children in Lochaber are in wheelchairs.

John Farquar Munro stated that Lochaber is not in his area but agreed to bring this matter into his speech in the Parliament tonight.

Abuse of medication abounds as people don't use or understand their medication.

In Lanarkshire £7.3 million is spent each year on prescriptions.

There is a lack of knowledge ,education and training.

Physiotherapy training is changing and there is a shift of people's perspectives.

This is a massive problem and the system will always struggle to keep up. Chronic pain is treated as a "symptom" and not considered "condition" and dealt superficially in pockets. Research is treated similarly. One needs to think of it as a specialist area of medicine. Treatment is condition based.

Nicola Stuckey stated that it is crucial to think that pain "falls through the holes". There is a need to hang it on existing structures to get it up the health agenda. Every health board needs to say what their strategies are.

The main problems are the physiological and social effects of pain. There are number of sufferers and one needs to add on the number of friends and family members who indirectly suffer.

Chronic pain sufferers need someone to take time and listen who has contacts with specialists and to be able to listen and identify with them as nobody listens.

Doctors and health boards don't listen. They are not treating the cause only the symptoms

G.P's prescribing but are not telling about side effects. Hospitals are the best centres for pain control but the problems remain actually getting in to the hospitals.

Heather Williams spoke about Palliative Care. CSTB are trying to address skills for dealing with people with terminal ill.

There needs to be caution about the notion of trying to bring down the drug bill. Newer drugs all the time are more expensive ,perhaps what patients need is the bill to go up.

What is needed is the nurturing of patients.

Their first contact would normally be the GP's not single but issue multi-disciplinary education. This should be put on the agenda for the Chief Executive of the NHS.

There is link with palliative care and chronic pain management. Cancer pain is in many cases related to chronic pain. One should start to use the Cancer networks and "cancer clout" to highlight issues.

Amanda Hepburn stated that education is a huge problem as chronic pain is not seen as an issue. The problem is that non-malignant issues are overlooked.

Doctors prescribe medicines due to a lack of knowledge that may need.

Anne Murray stated the Glasgow North University Trust are getting £14 m and the management are taking on board the problem of pain management and education. Politicians do not realise the enormity of this.

The Ministry of Pension and Works are interested in people with acute and chronic pain and getting them back to work. They have a report ongoing at present but it may be sidelined once it is presented.

Generic medicines are cheaper substitutes but if brand names are not sold there is no money for investment. There is not enough money for investment in research.

Many doctors are researching back pain and arthritis. Some pain management techniques help such as manipulation but this is under-used and under-funded.

John Thomson stated that information given to him was unhelpful as a pain sufferer as he could not do his job of work.

Elaine Smith stated that there was no way that all the points and issues raised today could be raised in the parliamentary debate. There is a need to raise awareness and the use the debate as a starting point. She went on to congratulate Dorothy-Grace Elder for her work in getting the debate in parliament.

Dorothy-Grace Elder closed the meeting and thanked everyone for attending.

CROSS PARTY GROUP ON CHRONIC PAIN
WED 27 FEB 2002 1.00 P.M.

ATTENDANCE

Susan Aitkenhead	Pain Management Service,Royal Hospital
Gordon Anderson	Scottish Parliament
Janette Barrie	Lanarkshire Primary Care Trust Hairmyres Hospital
A.Brazenhall	Bishopbriggs Pain Clinic
John Currie	Yorkhill NHS Trust
Dorothy-Grace Elder ,MSP	Scottish Parliament
Fiona Garrett	Backcare
Steve Gilbert	NHS Anaesthetist,Queen Margaret Hospital
Amanda Hepburn	NAPP Pharmaceuticals
S.Lafferty	Glasgow Royal Hospital
Mark McCann	Lochaber Hydrotherapy
Liz MacLeod	Pain Association,Astley Ainslie Pain Association
Yvonne McEwan	University of Edinburgh
Evelyn McKechnie	Scottish Parliament
Denis Martin	Scottish Network Chronic Pain Research
Rosalind Stuart Menteith	General Osteopath and Osteopathic Council
Jeremy Stuart Menteith	Osteopath
John Farquar Munro,MSP	Scottish Parliament
Anne Murray	Glasgow Pain Association
Kate Niven	University of Stirling
Jamie Scott,MSP	Scottish Parliament
Shirley Sen	SRN Senaloy
Rosemary Showell	Lanarkshire Primary Care Trust Hairmyres Hospital
Phil Sizer	Pain Association
Elaine Smith,MSP	Scottish Parliament
Nicola Stuckey	Lothian Primary Care Trust,Astley Ainslie Hospita
Anne Murray	Glasgow Pain Association
John Thomson	Glasgow
Heather Wallace	Pain Concern

APOLOGIES

Blair Smith	
James Douglas,MSP	Scottish Parliament
David McFarlane	
Bill MacRae	
Nora Radcliffe,MSP	Scottish Parliament
Michael Walton	