



**PUBLIC PETITION NO.**

**PE01460**

### Name of petitioner

Susan Archibald on behalf of Scottish Parliament Cross Party Group on Chronic Pain

### Petition title

Improvement of services and resources to tackle chronic pain

### Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to (a) hold a debate on the matter with a vote or voting rights (b) transfer more of the management for chronic pain into primary care (c) provide more social model care instead of medical model (d) change its policy to provide direct funding to ensure radical improvements to the service can be made including establishing a residential unit in Scotland to prevent Scottish pain patients being sent to Bath in Somerset for treatment

### Action taken to resolve issues of concern before submitting the petition

Raised awareness in Cross party working group Scottish Parliament with MSP's and organisations from all over UK for over 12 years.

Submitted a petition to Scottish Parliament for improved services on 28.05.2001

Won support from 130,000 members of the public by email to the Parliament calling for urgent help for chronic pain in February and March 2002.

Gained backing from the Health and Community Care committee in May, 2002.

MSPs have asked many questions over the last 12 years. Links to sample of questions raised in Scottish Parliament from Mar 2000 – Jan 20

[http://webmail1.mail.aol.com/37105-111/aol-6/en-gb/mail/get-attachment.aspx?uid=29002988&folder=OldMail&partId=3&saveAs=mary\\_scanlon\\_parliamentary\\_questions.doc](http://webmail1.mail.aol.com/37105-111/aol-6/en-gb/mail/get-attachment.aspx?uid=29002988&folder=OldMail&partId=3&saveAs=mary_scanlon_parliamentary_questions.doc)

[http://webmail1.mail.aol.com/37105-111/aol-6/en-gb/mail/get-attachment.aspx?uid=29002988&folder=OldMail&partId=4&saveAs=jackie\\_baillie\\_-\\_parliamentary\\_questions.doc](http://webmail1.mail.aol.com/37105-111/aol-6/en-gb/mail/get-attachment.aspx?uid=29002988&folder=OldMail&partId=4&saveAs=jackie_baillie_-_parliamentary_questions.doc)

### Petition background information

Chronic pain can be described as 'pain that has persisted beyond normal tissue healing time', which is taken, in absence of other criteria, to be 3 months. It is defined by British Pain Society for Chronic Pain as being a continuous, long-term pain of more than 12 weeks or after the time that healing would have been thought to have occurred in pain after trauma or surgery. It can be caused by a huge range of common conditions, including arthritis, osteoporosis, irritable bowel syndrome, cancer and endometriosis or by other factors such as injuries or operations.

The petitioner has suffered from chronic pain for 13 years.

Chronic pain does not fit neatly into one discipline and as a result the journey of someone with chronic pain through to correct diagnosis and adequate management can be fragmented and costly.

Chronic pain is estimated to affect 770,800 people in Scotland causing significant costs to individuals, families and carers but also to the healthcare systems and the economy (see below). It is very difficult to define the true scale of the problem and therefore we do not feel it has been afforded the same priority as other health concerns.

The previous health secretary, Nicola Sturgeon, accepted two Reports - in 2007 and 2008, called GRIPS reports "Getting to Grips with Chronic Pain" and written by the NHS's Quality Improvement Scotland, which contained 6 action points in relation to improvements in pain services - but these are still not implemented. Ms Sturgeon refused any direct Government funding.

[http://www.healthcareimprovementscotland.org/programmes/long\\_term\\_conditions/programme](http://www.healthcareimprovementscotland.org/programmes/long_term_conditions/programme). There is a chronic pain steering group that meets 4 times a year and plans for better services but without direct government funding or health boards helping no radical improvement is foreseeable. Pain patients feel cheated out of real help.

Government investment is currently £60,000 for two days weekly work by a lead pain consultant. As the present lead consultant Dr. Steve Gilbert stated in a petition to this parliament in May 2001, "it has been impossible to persuade many Health Boards to fund services adequately". If Boards did not fund services properly ten years ago, they are less likely to do so during the current recession and Government direct action is needed.

Current Government policy is to take the Managed Clinical Network approach, inviting health boards to set up planning groups, with non recurring money for two years only but no direct investment in services. Out of 14 Health Boards, currently one has a Chronic Pain Managed Clinical Network, a further two have applied and secured funding and another two are awaiting a funding decision. That is the slow take up rate by Boards since MCNs were first suggested in 2005.

a) Having a debate in Parliament with voting rights would urge the Scottish Government to end Scotland's few chronic pain treatment centres being understaffed and confined mainly to areas such as Glasgow, Dundee, Edinburgh, Dunfermline and Aberdeen, let people in pain have more than current post code access and patchy and inadequate services for a common condition with thousands on waiting lists. Raise awareness of chronic pain and how it affects people, allow MSP's the opportunity to fight for better rights for their own constituents as, to date; so many people in Scotland have no access to pain services putting them at a disadvantage to others. There have been two previous debates, in February 2002 and in June 2011 but both were confined to member's debates without a vote. Despite that, 130,000 people emailed the Parliament in February and March 2002 demanding urgent help for chronic pain after the first debate. This showed the public's priorities – which the Parliament claims it heeds. But subsequent action has been minimal and patients are still waiting for radical improvement in underfunded services.

b) Transfer more of the management for chronic pain into primary care is really the key as to date if you visit your GP they give you medication and some may move you on to a pain specialist, this in itself takes many months and once again produces a negative effect on the patient as no one is trying to help them cope with their pain or emotions, doctors seem to analyze, dissect a person and put them into categories. More staffing in Scotland's few specialist clinics and bringing chronic pain more into primary care would make the doctors see the bigger picture, and not just the pain part but treat the whole person as obviously it has a huge effect on their physical and mental health and their social, economical and working lives. The depression and suicide rates are high among pain sufferers at the worst levels.

The Healthcare Quality Strategy for NHS Scotland:  
The Scottish Government, May 2010

Success will mean that, for the first time, people in Scotland will have:

“the opportunity to comment systematically on their experience of healthcare and its impact on their quality of life; an assurance that NHS Scotland services will be further improved in the light of what people tell us about their experiences and outcomes; support to engage in shared decision-making about their care; the whole of the NHS committed to patient safety and, in particular, to avoiding infection and harm, using consistent and reliable improvement methods;

personalised care plans for those people with the most complex care needs; and  
A guarantee that their NHS Board will prioritize quality in its agenda, including the use of a new early warning system”.

However, patients with chronic pain remain dissatisfied with services and treatments.

c) Looking at providing more social model of care instead of medical model:

The Medical Model of health tries to treat people through the use of medicine and science, and it doesn't take into account the social and emotional factors of how the injury, illness, or disease was caused or what effects it has on the person.

The social model of health looks at holistic approaches to helping people overcome their conditions and work their way through recovery, like pain management, and takes into account of how society and our environment affect our everyday health and well-being, including factors such as are social class, poverty, poor housing, diet, pollution and income. There needs to be more psychologists involved from the beginning of the treatment to look at the underlying Issues and help the patients work through them, this will also help with the added pressures that effect people when chronic pain comes crashing into their lives as to date no one considers how peoples mental health is affected.

Changing from medical to social model of care would also have a huge effect on preventative spend as there are so many drugs being returned to pharmacies that have not been used, due to many different factors but mainly patients felt they did not work or were always included in repeat prescriptions. Patients should receive the right medicine at the right time and be appropriately treated.

d) Need for a change in Government policy with direct funding to ensure radical improvements to the service are made.

A chronic pain Cross Party Group member from the Association of British Pharmaceutical Industries raised the comparative good news of work in diabetes compared with chronic pain. He mentioned there were Managed Clinical Networks for diabetes, which appeared to be successful.

The background is that there is a twin approach with diabetes: Scottish Government direct funding as well as MCNs. All 14 Scottish health boards have diabetes MCNs. Chronic pain has three confirmed, with two more applying since first the first offer of MCN help in 2005. (Source: deputy health minister, Michael Matheson, July, 2012)  
Diabetes, like other big issues in numbers - heart, stroke, etc. gained MCNs without the long struggle endured by the lead pain clinician and others over the years. There was a refusal of any direct funding for pain service improvement by the previous health secretary. While the two conditions in themselves aren't comparable, the principle of twin track support we are calling for is the same.

Set up a residential unit in Scotland to manage chronic pain to prevent Scottish patients being sent to Bath.

This was identified in the Getting to GRIPS with Chronic Pain in Scotland, NHS Report, and July 2008 as Action point 5 but has not yet been put in place.

“Scottish Government to review current SG funded provision of Pain Management Programmes provided out with Scotland and consider investment in the development and provision of Scottish regional and local pain management programmes, including a residential facility for patients unable to attend as outpatients”

All the money in Scotland should be used to provide better services for the people of Scotland and not be used to pay for English services, this has to be redressed. Bath has a total of 2 part time consultants, 5 psychologists, physiotherapists, occupational

therapist a nurse and an administration team. Initially, there would have to be premises sought in one health board in Scotland maybe a building that is under review for sale that could be looked at for savings and redirecting staff accordingly.

Although being referred to a unit such as Bath for treatment might appear to be a good thing, I would ask you to please consider how difficult it is for a patient suffering from chronic pain to endure a journey Patients are sent to Bath from all over Scotland - for instance, from the Tayside area it's a return journey of 906 miles. One was sent from Shetland - return journey of 1,626 miles and horrifically taking 23hrs one way. This is because of lack of a residential service in Scotland and shortages in local day clinic services.

By the time they get to Bath, I am quite sure It will take a few days to overcome this horrendous journey. They get treatment - then they have to undergo this whole nightmare of a journey back home again. I usually work to turn negative things to positive but this actually makes a positive experience very negative for a person suffering from chronic pain.

Over £1 million pounds has been spent over the last few years (£1.1 million for 119 patients according to latest Scottish Government figures, September 2012) in sending people with chronic pain to Bath for treatment. How hard is it for someone with chronic pain without the added journey of sending them on a 900 mile round trip? This should be redressed ASAP. Wales has a residential pain service – why not Scotland?

Pain Management clinics will not just help patients learn to cope with their pain but in the long run they offer alternative answers to the basic medications and, through this, will bring preventative spend, as it has been proven 8/10 people have so much medication to control their pain but say it's not working. Some 5/10 of people are returning half their medicines to pharmacies. After six months, some patients' medication doesn't work as effectively as it did in first place.

We have to look at both cost and effectiveness over all the problems that chronic pain causes the individual as, to date; only the pain is being treated unsuccessfully.

“We believe this is incompatible with the Human Rights Act 1998 and other equality legislation in relation to the provision of services and treatment”.

#### Voluntary sector lack of help

The Scottish Government “recognised chronic pain as a condition in its own right” in 2009, fine words. But, beyond the major issue of no direct Government help for NHS chronic pain clinics, even the voluntary sector has had no benefit from this “recognition”. For instance, the Long Term Conditions Alliance Scotland (LTCAS) still has no specific fund for chronic pain. They were set up from 2006 to aid the two million people in Scotland suffering from many chronic conditions. But despite chronic pain accounting for an estimated 770,800, the Alliance distributes no funds specifically for chronic pain. Their staffing and premises cost £563,000 a year. They also have a £2 million a year Self Management Fund from the Scottish Government, which they currently distribute to 81 voluntary projects. But none of these, to date, is specifically for chronic pain and LCTAS recently failed to accept a funding application from the charity Pain Association Scotland – which runs self management pain projects within health board areas. So the Government designation has not resulted in practical help at any level. LTCAS is now known as the Health and Social Care Alliance.

#### \*Links to further information

UK Is bottom of the list of 15 European countries in terms of the negative impact that chronic pain has on people's lives. Ref <http://www.webmd.boots.com/pain-management/news/20110110/almost-half-of-people-with-pain-failed-by-nhs>  
PainEurope.com, Pain in Europe Survey - UK, 2005

The UK spends nearly £4 billion every year on incapacity benefit payments to those diagnosed with the condition

Scotland spends around £2bn in MSK and benefit payments to those diagnosed with

the condition every year (Societal Impact of Pain Symposium 5 May 2010 delivered by Professor Blair Smith on behalf of Dr Pete MacKenzie the then Scottish Government Lead Clinician for Chronic Pain)

Chronic low back pain costs the NHS nearly as much as coronary heart disease, (CHD) while chronic pain costs society more than twice as much as CHD in benefits and lost working day

Long-term absence from work cost the UK economy £3.7bn in 2009; 180 million lost working days, with back pain alone accounting for tens of thousands of lost days at work. Back pain was the most commonly identified cause of long-term absence for manual workers (56% of cases) and was to blame in over one third (37%) of absences in non manual workers.

[http://www.healthcareimprovementscotland.org/programmes/long\\_term\\_conditions/programme](http://www.healthcareimprovementscotland.org/programmes/long_term_conditions/programme)  
Coronary heart disease costs the NHS £1.73bn a year, diabetes £1.77bn and chronic back pain £1.63 billion (but with £10.67 billion on informal care and societal costs):

Source: NICE National Institute for Clinical Excellence speaker reported at Pharmaceutical Field Magazine:

<http://www.pharmafield.co.uk/blog/index>

PainEurope.com, Pain in Europe Survey - UK, 2005

UK Is bottom of the list of 15 European countries in terms of the negative impact that chronic pain has on people's lives. Ref <http://www.webmd.boots.com/pain-management/news/20110110/almost-half-of-people-with-pain-failed-by-nhs>

GRIPS Report 2008

([http://www.nhshealthquality.org/nhsqis/files/GRIPS\\_booklet\\_lowres.pdf](http://www.nhshealthquality.org/nhsqis/files/GRIPS_booklet_lowres.pdf))

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Ref 5

GRIPS Report 2008

[http://www.nhshealthquality.org/nhsqis/files/GRIPS\\_booklet\\_lowres.pdf](http://www.nhshealthquality.org/nhsqis/files/GRIPS_booklet_lowres.pdf)

### Unique web address

<http://www.scottish.parliament.uk/GettingInvolved/Petitions/chronicpain>

### Related information for petition

**Do you wish your petition to be hosted on the Parliament's website to collect signatures online?**

**YES**

**How many signatures have you collected so far?**

1

**Closing date for collecting signatures online**

10 / 12 / 2012

**Comments to stimulate online discussion**

The current treatment for chronic pain in Scotland is a bit like post code lottery. "Most of the few pain specialists in Scotland work part time between anaesthetics and pain."

In Greater Glasgow and Clyde they have 16 consultants as 8.5 full time equivalents. Where as, in Fife, they only have 3 Consultants, other places like Orkney have none or Western Isles have one. So many people living with chronic pain state that the medication they are using has little or no effect on their condition, leaving them suffering, frustrated and at their wits end with a vicious circle of more prescriptions but no support.

The people of Scotland deserve better improved, services open to all no matter where they live, that will give them the opportunity to try new treatments, learn to cope with their pain and finally the ability to move on with their lives.

To STOP patients being sent on 8 + hour journeys for treatment in England when there could be a facility in Scotland that they can be sent to; there has been no consideration of the how stress and the inhuman treatment of the trip have on the patient's overall mental and physical health.

Please support this petition