

## **Airing Pain Programme 35: Pain, policy and employment**

### ***The challenges of improving pain management in Northern Ireland, and raising awareness of chronic pain among businesses***

*A special edition of **Airing Pain**, covering the 2012 Northern Ireland Pain Summit, organised by the Pain Alliance for Northern Ireland. There we interviewed representatives from government and the voluntary sector, health professionals, and of course patients.*

*We hear about the needs of patients and provision of pain services in Northern Ireland from, among others, Chief Medical Officer, Dr Michael McBride, and Dr William Campbell, Consultant in Anaesthesia and Pain Medicine at Ulster Hospital, Dundonald, Belfast.*

*Patients attending the summit give us their stories and say what brought them there and Tania Kennedy, Director of Business in the Community, sets out her thoughts on how the world of business can better take account of chronic pain.*

*Dr Pamela Bell, Chair of the Pain Alliance for Northern Ireland, and Kate Fleck, national Director for Arthritis Care in Northern Ireland, conclude with their thoughts on the 'road map' for action following of from the pain summit.*

**Paul Evans:** Hello I'm Paul Evans and welcome to **Airing Pain**, a programme brought to you by Pain Concern, the UK charity that provides information and support for those of us living with pain. This edition is financed by Grünenthal.

**Pamela Bell:** At the end of the conference for me it is important that the Health Minister, the Health Committee and the Northern Ireland Assembly take on board the asks of the road map that's been developed and really putting pain up the health agenda throughout Northern Ireland.

**Evans:** In May 2012 Pain Alliance Northern Ireland organised a summit to raise awareness of the extent of the problem of people living with chronic pain. Janet Graves covered the event for Pain Concern; she started speaking with Chief Medical Officer for Northern Ireland, Dr Michael McBride.

**Dr Michael McBride:** We know how common chronic pain is; we know that somewhere in the region of 1 in 5 people in Northern Ireland suffer from chronic pain and I think it comes as a unique and indeed challenging opportunity because we're at, I suppose, a crossroads in terms of provision of health and social care in Northern Ireland. We have a new blueprint, a road map for the future direction of health and social care in Northern Ireland called 'Transform Your Care' which our Health Minister Edwin Poots has endorsed. We've recently launched a long-term condition strategy, both of which are very relevant in terms of how we improve because I think that's what it's really about, about improving the care that we provide people living with chronic pain.

I mean, how do we empower patients living with chronic pain, giving them the right skills and knowledge and information to manage their own pain better, to give them their sense of

control back over the management of their pain, which I think is vitally important I mean there's nothing as disempowering or as disabling as chronic pain. I think also its about how we ensure that we raise the level of awareness amongst those health professionals working in primary care. It's about ensuring that we have a phased approach to the management of people living with chronic pain: a better integration of services; a better integration between our GP practices and indeed the specialist treatment that can be provided in a hospital environment with all of the professionals that input into that.

Chronic pain is a challenge because of the diversity of people affected by and living with chronic pain because again it can originate from a wide variety of conditions, whether we're talking about arthritis, diabetes, people who have had, or are having, problems after a stroke, people living with side effects of a drug treatment, for instance, with cancer which can cause very painful neuropathy. So it impacts on such a wide range of conditions, that the co-ordination of that and the standardisation of a more methodical and integrated approach to supporting people living with pain and ensuring that they get access to the right services at the right time by health professionals who are both skilled and knowledgeable in terms of the management of chronic pain and, most importantly also, they can decide when they have reached the edges of their knowledge and skills and when it's appropriate to refer on to someone with more specialist knowledge.

And I think these are the challenges in Northern Ireland, how do we reduce the patchy availability of these services, how do we make the best quality of care and experience uniform throughout Northern Ireland and I think the challenges would be no different in my view than across the rest of the United Kingdom. I mean I don't think there's any doubt in what we all aspire to – whether that's someone living with chronic pain, whether that's someone caring for someone living with chronic pain, whether it's a doctor, nurse or health professional working in primary care, whether it's a voluntary sector organisation, whether it's a commissioner of services, or an official in a department or a minister – we all want the same thing, which is the best care we can possibly provide for patients living with chronic pain in Northern Ireland.

**Dr Pamela Bell:** I'm Dr Pamela Bell, I'm formerly a consultant in anaesthesia and pain medicine working at Musgrave Park Hospital for most of my career and I'm currently Chair of the Pain Alliance for Northern Ireland and that is a group that is focused on providing support for patients with chronic pain. The conference today is of real importance, the very first time that we have in Northern Ireland brought together those leaders and decision makers in health care, including the Minister for Health, Social Services and Public Safety and the Chief Medical Officer and the most senior commissioners, together with health care providers and clinicians, patients, their families and carers and the voluntary and community sector – and I'm particularly pleased since chronic pain is really about the impact on how we live and work that we also have representatives from business and the community talking about how work can be good for our health and how employers need to value patients or employees who have chronic pain but still contribute significantly to the workforce. So yes, a big problem for health care, a big problem for social care, but more broadly a problem for employers, for employees and for society at large.

So I see the Pain Alliance as being the catalyst for all of this, the bringing together of perhaps rather diverse interests and saying well the commonality, the thing we all join together in, is wanting to have improvements in those services for patients with chronic pain.

**Evans:** Dr Pamela Bell, Chair of the Pain Alliance for Northern Ireland, organisers of the 2012 Northern Ireland Pain Summit.

Now in terms of services provided for people with chronic pain in Northern Ireland, there are differences between what each Healthcare Trust provides, probably as you'd find across the whole of the UK. But there's one statistic that does surprise me. Dr William Campbell is Consultant in Anaesthesia and Pain Medicine in Belfast.

**Dr William Campbell:** Statistics show that there are perhaps as many as twice the number of chronic pain sufferers, probably mainly associate with spinal pain, in the North of Ireland compared to southern parts of the British Isles. This could well be associated with lifestyle – patients don't have the opportunity to get out just as much in Northern Ireland, could well be even as simple as the weather being much poorer, several degrees cooler, wetter weather but the ability to get out and walk and mobilise the spine can have two beneficial effects: one being that it actually mechanically helps move the spine much more readily to keep the flexibility up and, in addition to that, the psychological wellbeing of the individual, just to get out and about.

From the point of view of help from the various Trusts in relation to both funding and from the point of view of services that were available. From the point of view of funding, if they were taken into account with the Trusts' budget, it actually worked out at something in the region of 40 to 50p in every thousand pounds was spent on delivering pain services. Now that wouldn't take into account separate physiotherapy and rheumatology, nor would it be likely to take into account the likes of their analgesic budget from the pharmacy. But other aspects would be the availability of various services within each Trust. So although pain clinics and pain management programmes have developed and gradually built up in each of the Trusts within Northern Ireland, there is still scope for increased activity.

Ideally the Conference will highlight the fact that there is a relatively small amount of funding put into pain services, especially chronic pain services and that should be taken in context with the fact that one of the commonest causes to attend a general practitioner is with pain and musculoskeletal pain –it practically equals all the other problems added together. So whenever you consider that there's only roughly 50 pence in every thousand pounds spent on pain clinic services it's literally a drop in a jug of water, it's really really very little. At the end of the Conference we'd hope that over the coming months and years we would see an increase in the availability of both physiotherapists and psychologists to help provide multidisciplinary support for patients as well as some improvement in the facilities for medical staff to provide a better service for patients.

**Bell:** One of the reasons why a Conference like this is so important at this time is that, in the wider sense, health and social care is being re-drawn for Northern Ireland and following the publication of the Compton Report it is clear that it is the intention of our Department of Health that services will be available to patients much closer to their home and within their own communities and that this care will be focused on their individual needs. So when we look at the provision of Pain Clinics as such, mostly, in Northern Ireland, based in hospitals and widely scattered in the province with more gaps in provision perhaps than coverage, then we can clearly see that there is not enough local service.

Now, changing from where we are at present, into a situation where much of the care is delivered within your general practitioner's office or within your community, will require a good deal of education. Education not just of the general practitioners and other health care professionals within the community, so that their level of skill in managing and indeed diagnosing the presence of chronic pain will really be lifted to an extent where patients notice a real difference in finding it much easier to get the right treatment at the right time.

**Dr Jim McMullan:** My name's Jim MacMullan, I'm a GP in Tynan, just outside Armagh, and I've worked in the chronic pain service in Northern Ireland for over 10 years now. Pain is the third most common reason for a person to come to their GP and chronic pain sufferers are five times more likely to come to their GP than someone who doesn't have chronic pain, so that represents a huge burden and a huge challenge to general practice. What is sometimes lost in the ether is that chronic pain is a chronic disease, very much like diabetes or asthma or epilepsy and by definition often cannot be cured but requires management. This management requires a bio-psychosocial holistic approach to the person and sometimes prescribing a tablet is not enough for these people.

When they come to me in secondary care clinics a lot of our patients expect an intervention, an injection, a drip, an operation, a scan, something, you know, very much on the medical model and, as is often the case after a full assessment, it transpires that there's much more going on in their life than just the pain – there's the social issues, there's the financial issues, there's the psychological issues and the mental health issues.

There was an article that the BBC news covered a few days ago of the Scottish experience in treating all chronic diseases with chronic pain included in primary care head on by the Dundee and Glaswegian professors of general practice. And they pointed out that these complicated complex individuals with multiple medical problems are often managed in a disjointed and fragmented way and that, rather than investing in more and more specialists for these people, perhaps there should be a case for more generalists to look after the whole patient, rather than neurologists for one bit, orthopaedic surgeons for another bit, rheumatologists for another bit etc. etc., gynaecologists, urologists – more generalists required for the joined-up thinking overlooking the entire process for the entire patient rather than focusing on one anatomical bit as it were.

When the patient gets explained to him what is going on here and what the evidence is for their condition and that injection therapies and extra drugs may actually not help the condition and technically could make them worse with side effects and that there are other things out there that does not involve taking extra drugs, if they're willing to engage with the pain management programme, with the psychologists, with the physios, with the OTs, with the nurses and doctors that at the end of that there they almost invariably will feel better. A lot of them, a little light comes on and they say 'Yeah, I'll have a go at that.' Then of course there are some people who are very resistant to this and seem to think that all you're saying it's all in my head doctor, which is absolutely not the case.

But, it's almost self-selecting – those who are willing to embrace this whole concept of acceptance and self-management and looking after themselves will always do much better than those who are in denial and who sit back and want to be referred on for another investigation or another injection or another test. They have not reached that level of acceptance and the real challenge is getting the resistant people to accept that there are

things out there other than more drugs, more interventions, more injections, more drips or more scans.

**Evans:** Jim McMullan.

Now, before we continue I'll just remind you of our usual words of caution that whilst we believe the information and opinions on **Airing Pain** are accurate and sound, based on the best judgements available, you should always consult your health professional on any matter relating to your health and wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Back to the 2012 Northern Ireland Pain Summit – and as you heard, delegates included representatives from every sector of the pain community, from Government, health professionals, the voluntary sector and of course, patients. Kate Fleck is National Director for Arthritis Care in Northern Ireland.

**Kate Fleck:** One of the examples I gave at the conference this morning was the impact on parents living with a child who's been diagnosed with arthritis and the impact on the whole family is immense. You already are a parent of probably one or two or three children so it becomes more complex, you've got to deal with health professionals, hospital visits, you have also the priority of your other children – the ones who are not living with a long term chronic condition – whereas your child with a long term condition who very often has pain; and there's nothing worse for a parent seeing their child in pain and feeling helpless.

Again part of the work we do in Northern Ireland, we've got a really good parent support group and we run very positive programmes for children: positive future body image; take them away on physical activity weekends and say 'yes you can', even with arthritis and even if you hurt you can actually take part in these things as long as they're geared and done in a safe environment. So I think for parents and families with children with arthritis it has a real impact and I think the other side of that then is the family member who becomes a carer. And, again, it is difficult for people living with long term conditions to see their spouse or a family member becoming a carer, having to give up their independence, having to maybe give up their work to look after that and really guilt sets in and for the carer, you know, they lose part of themselves in that whole caring role. Most of the carers don't mind but it changes the dynamics of the family and the relationships.

**Nancy Toner:** Hi I'm Nancy Toner from Belfast. I was diagnosed with rheumatoid arthritis when I was 16, a very scary prospect at that age. I have since then been through lots of hospital appointments, medications, operations. A long-term condition, rheumatoid arthritis, it never really leaves you. I've had 17 joints replaced and they're all working well but I know there'll be more.

When I was 16 I didn't fully understand what it was going to mean to me. My Mum understood more and became quite upset. I now know why, it's with you every day; it's affected all parts of my life, my working life, and my social life. I have a family now and my children don't know me to be pain-free; they know I need help in all areas of the housework. My husband has been a great support: he knows by looking at me if I'm in pain, if I'm having a bad day or if I'm having a good day. I've been in pain longer than I haven't been in pain because I'm now 61 – but I've grown up with it and it's always been with me as a sort of

companion. Sometimes it can be a difficult companion but I have learnt to cope with what I have and self-manage my situation and I feel that I am in control of it most of the time.

**O' Loughlin:** I'm Naomi O' Loughlin, I work voluntarily with the MS Society on the Northern Ireland Council and I'm Vice-Chair of my local branch. When a family member suffers from chronic pain it doesn't just impact on the individual, it impacts on the whole family, sometimes you end up with a partner, spouse or whatever taking on a role of carer; and that's not something that they signed up for. It can have a lot of emotional pressure, a lot of financial pressure to, your career is impacted, sometimes you have to give up your work – you've got that loss of earnings.

With a condition like MS it can strike at a young age; I was 24 when I began to exhibit the symptoms of MS. I mean, we'd just taken out a mortgage, we'd just bought the house, I had two children of 2 and 3 years old – your whole world just implodes around you, you try and make sense of that, it's very, very difficult and there's an awful lot of pressure on your relationships and a lot of times people even just slightly outside your family group don't see the pressure. I suppose you have to learn to ask for a wee bit more help and explain your circumstances because a lot of people just think 'oh I can manage this on my own'. But wee bit by wee bit by wee bit you know, they do get eroded, your self-confidence goes and you do sometimes just need a wee bit of help.

**Evans:** Naomi O' Loughlin, a volunteer with the MS Society.

Tanya Kennedy is the workplace director with Business in the Community. It's a not-for-profit business membership organisation promoting corporate social responsibility. So where does the world of big and small business fit into the management of chronic pain?

**Kennedy:** It is well proven now that it is the responsible businesses that are the most successful and part of being responsible is looking after the well-being of your employees and being an inclusive and a happy work environment so people are productive. So in terms of that, what employers and workplaces want to do is identify people with chronic pain and find solutions so that they will be happy and productive at work; it's good for the person, it's good for the business.

I think it's very important that we have this conference in Belfast today because when I was asked to talk about the impact that the workplace can have with chronic pain, I was absolutely astounded at the lack of information that was available to employers, yet workplace as a setting is a huge opportunity to make a real difference to people's lives in terms of their health and well-being and that includes chronic pain.

There's a startling statistic that the cost of chronic pain to a business is likely to be higher than the cost of diabetes and heart disease put together. Yet at this point in time employers are investing huge amounts of time and money encouraging people to improve their lifestyle habits. Now if they can take the same approach to what will change attitude towards chronic pain and encourage and support people with chronic pain to remain at work, the return on investment for that could be phenomenal and employers really can make a difference to the lives of people with chronic pain because 45% of people with chronic pain don't work at all. However, those who are in work don't at this point in time have the confidence it appears to discuss with their employers what their own personal needs are. Yet employers want skills

into the workplace, particularly at the moment that people with chronic pain can offer them simply by making some adjustment.

**O'Loughlin:** I think it's a brilliant idea to try and encourage employers to bring skills into the workforce. There's an awful lot of people out there that don't conform to the traditional 9-5 – they can't – but they would so love to be part of it and everybody has their own unique skill-set and being able to give something back... you need a focus, you need a purpose for life and that's part and parcel of managing your condition – whether it's for financial gain or not, but you need to be doing something that makes you happy and makes you feel as if you have a purpose so your bringing home money at the end of the week too, that's an added bonus, but it's a lot to do with how you feel about yourself as a person and your self-worth as well.

**Kennedy:** There is a lack of understanding I would suggest at this point in time of what chronic pain can be and we heard from great speakers today who live with chronic pain as to people's reactions to the adjustments that are made for them so it's up to employers to educate the people in the workplace. It's good for them too to help and be sympathetic towards people with chronic pain and to appreciate how good life is without it.

There's a big gap at the moment in my experience in the workplace and that is with line managers and supervisors. We all start work in one form or other when we work and then perhaps we're promoted and we don't know how to take responsibility for people because it doesn't come naturally in most of us. So employers need to look at that part of their population, educate them in everything around diversity, including chronic pain – there are lots of different reasons that people are different, so that they can empathise and make the work experience for *everybody* at work the best it can be. It's a change in attitude more than a cost. There may be some costs involved with some individuals, however, it's a shift in attitude and it's a shift in workplace culture to one that's accepting and that doesn't cost anything and not only that, in shifting that culture it will probably add to the success of the business.

**Evans:** Tanya Kennedy, the director of Business in the Community.

Now the 2012 Northern Ireland Pain Summit was organised by the Pain Alliance for Northern Ireland and as part of their work and key to the Summit, was the development of a road map for action. Pamela Bell again...

**Bell:** We hope that by listing things that might be achievable, that in fact we can look back and see what progress is being made. So, given the changes that are likely to occur, we feel that education – education for healthcare professionals and perhaps, particularly for those healthcare professionals in the community, is going to be key to patients seeing the early changes. So that may mean that when they go to their General Practitioner, rather than simply being given a prescription for yet another painkiller, that they might be signposted to a community group for support – exercise or walking group – that they might get to a physiotherapist who can help them overcome fear of movement and thereby help with their rehabilitation.

**Fleck:** Given some of the statistics that were given out at the conference this morning around the lack of pain services in Northern Ireland, it's essential that clinicians get more training on pain; that they also learn I think to work in partnership with the voluntary sector

who have lots of expertise in running self-management programmes and refer to us. I mean I can talk from a personal experience where I had a consultation 11 months previous for a condition called bursitis and 11 months on I only got injections in my hip – 5 minute injections but an 11-month wait. You know, that really is kind of unacceptable treatment and I am not the only one by a long shot waiting on those sorts of times for treatment and medical intervention.

**Bell:** There's much change going on and someone needs to lead that change. So one of the other things that we have suggested would be the creation of a lead clinician for chronic pain, perhaps similar to the lead clinician role in Scotland, so that someone has oversight, someone can keep the train on the tracks through all this change, someone can look at the gaps in the services and say 'well this is perhaps where we ought to invest and this is perhaps where we can let things sit because they're doing quite nicely thank you'. But key to successful change is good leadership and in the absence of good leadership I'm not quite sure how effective that change can be. One of the other aims in our road map is to encourage patients in their self-management of their condition.

**Fleck:** The message from me really is around the self-management agenda, the importance of that, if we're going to have waiting times and people are waiting longer, there are things that people can do for themselves. They can pick up new skills, new ways of managing pain that don't mean always rushing for the pill bottle. It's about learning breathing techniques, relaxation techniques, a little light exercise, getting out in the fresh air, trying to encourage socialisation, not sit back in isolation because there's nothing as bad as feeling isolated, despairing. You do need contact; if you can learn and be supported to learn how to self-manage I think it's a great bonus to someone living with pain.

**Evans:** Kate Fleck, National Director for Arthritis Care in Northern Ireland and before her Dr Pamela Bell, Chair of the Pain Alliance for Northern Ireland, organisers of this 2012 Northern Ireland Pain Summit.

And before we end this edition of *Airing Pain*, I'll just remind you that you can still download all editions of *Airing Pain* from [www.painconcern.org.uk](http://www.painconcern.org.uk) and you can also get CD copies from Pain Concern. If you'd like to put a question to our panel of experts or just make a comment about these programmes, then please do so via our blog, message board, email, Facebook, Twitter or pen and paper. All the contact details are at our website once again [www.painconcern.org.uk](http://www.painconcern.org.uk).

We'll end this edition of *Airing Pain* with the views of Nancy Toner and Naomi O'Loughlin.

**Toner:** There are some very positive messages coming out of today. I think that a lot of the people here today maybe are only realising the importance of it as they go away today and take the information away with them.

**O'Loughlin:** I have a rheumatologist who said to me once 'I would like you to speak to students, because you know more about rheumatoid arthritis than I do' – and this was a rheumatologist. I was quite shocked, but he said, 'well you're living with it, I'm not'. So these conferences are good at bringing awareness to politicians, GPs, everyone here today has learnt quite a lot about chronic pain and how the public have to live with it.



## Contributors

- Dr Michael McBride, Chief Medical Officer for Northern Ireland,
- Dr Pamela Bell, Chair of the Pain Alliance for Northern Ireland.
- Dr William Campbell, Consultant in Anaesthesia and Pain Medicine in Ulster.
- Jim MacMullan, a GP from Tynan, Co. Armagh
- Kate Fleck, National Director for Arthritis Care in Northern Ireland.
- Nancy Toner, patient representative.
- Naomi O' Loughlin, volunteer with the MS Society.
- Tanya Kennedy, Director of Business in the Community

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