

WBNA Pain Management Survey

Background

The West Berkshire Neurological Alliance (WBNA) currently represents 25 organisations, representing over 30 conditions

In July 2009, the West Berkshire Neurological Alliance (WBNA) organised a one-day conference, *Brains, Pains & Gains*, on pain and pain management.

Whilst organising this event, it was decided that it would be good to get some information on patients' experiences of pain and pain management in the West Berkshire area.

In the spring of 2009, the WBNA therefore carried out a Pain Management Survey of people living with pain who are living or working in the Berkshire West NHS area of Reading, Wokingham & West Berkshire.

Survey Overview

The survey consisted of 8 questions, many with multiple answers. Survey respondents were also asked and encouraged to make comments as part of the survey, in order to better illustrate the bare results.

The survey was uploaded to the online survey management system provided by SurveyMonkey.com.

The survey was publicised through the WBNA member organisations and through local publicity, such as distribution of information cards to local pharmacies.

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Survey Results

Sixty-seven people started the survey and, of these, only 57 completed the full survey. In order to ensure that survey respondents fulfilled the required criteria, they were first asked to confirm that they were living or working in the Berkshire West NHS area of Reading, Wokingham & West Berkshire and that they experienced either acute or chronic pain. If they did not answer yes to both these questions, survey respondents were unable to continue with the survey.

Acute pain was described as temporary pain that is expected to resolve, e.g. pain from a recent injury. Chronic pain was described as lasting 3 months or more whether intermittent or not or whether including flares of acute pain or not. Ninety-five percent (n=64) of survey respondents suffered from chronic pain, with 7.5% (n=5) suffering from acute pain.

Survey respondents suffered from a number of chronic conditions causing pain, including:

- Arachnoiditis
- Arthritis
- Cerebral Palsy
- Diabetic Peripheral Neuropathy
- Fibromyalgia Syndrome
- ME/CFS
- Multiple Sclerosis
- Myofascial Pain
- Polymyalgia Rheumatica
- Post Polio Syndrome
- RSI
- Sciatica
- Scoliosis
- Sickle Cell Disease
- Spinal fusion
- Spinal Injury
- Stroke
- Transverse Myelitis
- Trigeminal Neuralgia
- Vulvodinia

The most prevalent conditions suffered by survey respondents were arthritis (20%, n=13) and Fibromyalgia Syndrome (33%, n=21). Eleven percent (n=7) of survey respondents said that they were undiagnosed.

Survey respondents were asked "To what extent has pain impacted on your life in the last month?" with the options of "Great Impact", "Moderate Impact", "Little Impact", "No Impact" and "Don't Know". Sixty percent of respondents (n=38) said that pain had had a great impact on their life in the last month, with 37% (n=23) saying moderate impact and 3% (n=2) saying little impact.

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Forty-seven survey respondents commented on this question, with remarks such as:

“Pain and weakness is draining and prevents me from doing what I would otherwise do.”

“My pain has affected the quality of my life and my relationships.”

“Previously an extremely active person with a busy social life, now as my husband says I have become a withdrawn individual frightened to be away from the comfort of my home”

“It limits how much I can do, how far I can walk and interferes with my sleep”

“Although pain has had only a moderate impact on my life in the last month, in the last few years pain has, at times, had a severe impact on my life”

“I cannot walk far or stand for long, this causes weight gain and causes more recurrent pain and tiredness.”

Survey respondents were then asked “How satisfied are you with how your pain is managed?” with options of “Very satisfied”, “Satisfied”, “Moderately satisfied”, “Slightly satisfied”, “Not satisfied at all” and “Don’t know”. Twenty-seven percent (n=17) of respondents were not satisfied at all with how their pain was managed, 37% (n=23) were slightly satisfied, 18% (n=11) were moderately satisfied, 11% (n=7) were satisfied and only 3% (n=2) were very satisfied with how their pain was managed.

Forty-one survey respondents commented on this question, with remarks such as:

“Being on a cocktail of prescribed and over the counter medications barely manages the pain”

“After 14 months of chronic pain a new GP has referred me for pain management”

“Progress is extremely slow, with no real diagnosis.”

“No medication appears to get rid of the pain. It only eases it very slightly.”

“My GP is very good and helps a lot but access to pain management is too limited.”

“Pain is brushed under the carpet while other things are looked at because to the doctor they are more important as they are easier to deal with”

“Have had to search for information and treatment myself”

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“My pain could be better managed through higher doses of medications and more lifestyle adjustments, but at the moment, neither of these is possible and I have to suffer as a result - alternatives are not easy to access”

Survey respondents were then asked: “Have any of these people helped you to control or manage your pain and if so, how much have these people helped you?”. The question then gave a list of healthcare professionals, from NHS Pain Consultants to Private Osteopaths, and the options of “No help”, “A little bit of help”, “A reasonable amount of help”, “A lot of help” and “N/a or don’t know”.

If we look at the results for each category of healthcare professional, excluding those that responded “N/a or don’t know”, the results are as below.

Type of healthcare professional	No help	A little bit of help	A reasonable amount of help	A lot of help
NHS Pain Consultant (n=24)	33% (n=8)	42% (n=10)	13% (n=3)	13% (n=3)
NHS Neurologist (n=17)	65% (n=11)	29% (n=5)	0%	6% (n=1)
NHS Neurosurgeon (n=9)	56% (n=5)	11% (n=1)	11% (n=1)	22% (n=2)
NHS Rheumatologist (n=13)	46% (n=6)	23% (n=3)	23% (n=3)	8% (n=1)
Other NHS consultant (n=14)	36% (n=5)	43% (n=6)	7% (n=1)	14% (n=2)
NHS GP (n=47)	11% (n=5)	45% (n=21)	21% (n=10)	23% (n=11)
NHS Pain Nurse (n=6)	50% (n=3)	0%	33% (n=2)	17% (n=1)
NHS Physiotherapist (n=17)	53% (n=9)	29% (n=5)	12% (n=2)	6% (n=1)
Pharmacist (n=11)	45% (n=5)	18% (n=2)	18% (n=2)	18% (n=2)
Private Consultant (n=13)	31% (n=4)	31% (n=4)	8% (n=1)	31% (n=4)
Private Physiotherapist (n=16)	31% (n=5)	25% (n=4)	13% (n=2)	31% (n=5)
Private Chiropractor (n=12)	42% (n=5)	33% (n=4)	25% (n=3)	0%
Private Osteopath (n=16)	19% (n=3)	31% (n=5)	31% (n=5)	19% (n=3)
Private massage therapist (n=15)	20% (n=3)	33% (n=5)	20% (n=3)	27% (n=4)

Healthcare professionals and therapies mentioned by survey respondents in the comments that were not otherwise listed included: hypnotherapy; acupuncture; speech therapy; yoga; exercise; Chinese herbal medicine; Palliative care consultant; McTimoney chiropractic; reflexology; shoulder consultant; private CBT (Cognitive Behavioural Therapy) from a psychologist; Trauma & Orthopaedics consultant; MS Occupational therapist; Trigeminal Neuralgia Nurse; and Post Polio Consultant at St Thomas' Hospital.

Other comments on this question by survey respondents included:

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"Pain consultant was sympathetic but said he didn't know how to help."

"As my pain condition is an enigma, sadly in the 21st century nobody in the medical or healthcare profession has been able to diagnose the cause"

"I paid for acupuncture was good but could not continue as the cost was becoming too much."

"I have seen different people, but unfortunately they are only interested in their own speciality and are not prepared to listen when it comes to the whole problem of pain. They tell you that you are there because of your back, or knee, or face: they are not interested in the whole body."

"I have never been referred to any of the above."

"I also have reflexology & this helps a lot, but I can only have this for 4 months of the year, due to cost as I go to a local training college. It starts in February, ends in June. By October I am in so much pain I cannot function properly"

"My NHS GP is brilliant, but actually, all the suggestions and specialist therapies that keep my pain under control have come from private practitioners - my NHS GP helps by issuing the prescriptions that my private consultant suggests"

The survey respondents were then asked "Overall, have you experienced prompt and effective help from the NHS with managing your pain?". Only 14% (n=8) of the survey respondents replied "Yes" and 74% (n=43) replied "No".

Comments from survey respondents on this question included:

"I had a very good GP who was really helping through it, but she has left. Don't feel quite so supported with new GP."

"Still very slow progress after 15 months."

"I've just been told that "there is not much we can do about it"."

"I have had to rely on my company's medical insurance and funding physiotherapy myself."

"Because of the undiagnosed cause of the severe pain I am suffering it would be a fair comment for me to say the NHS has been of little help"

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“All the NHS did was offer me amytriptilene which after 5.5 years made me into a zombie. My family thought I had a form of dementia until I stopped taking it and very slowly recovered”

“Advice from the Pain Clinic was basically 'get used to it'. My GP is prompt at dishing out the drugs but they don't work, and every time I'm referred to a specialist it seems to take forever waiting for an appointment”

“Under NHS care, my pain was severe, debilitating and very poorly managed. I had to go private to get the help I needed to enable me to live my life.”

Survey respondents were then asked: “Of these services, how many are you aware of and how many have been referred to?”, with the question then giving a list of services that are specifically used for pain management and the options of “Referred and found useful”, “Referred but didn't find useful”, “Aware of but haven't been able to access”, “Aware of but have not wanted to access”, “Not previously aware of” and “Don't know”. Excluding those responses of “Don't know”, the results were as follows:

	Referred and found useful	Referred but didn't find useful	Aware of but haven't been able to access	Aware of but have not wanted to access	Not previously aware of
NHS Pain Clinic locally (n=43)	19% (n=8)	16% (n=7)	16% (n=7)	9% (n=4)	40% (n=17)
NHS Pain Service out of local area (n=41)	10% (n=4)	5% (n=2)	10% (n=4)	5% (n=2)	71% (n=29)
NHS Physiotherapy (n=44)	25% (n=11)	27% (n=12)	20% (n=9)	23% (n=10)	5% (n=2)
Complementary therapies on the NHS, e.g. acupuncture, TENS machines (n=46)	9% (n=4)	26% (n=12)	26% (n=12)	15% (n=7)	24% (n=11)
NHS Counselling (n=42)	10% (n=4)	7% (n=3)	19% (n=8)	19% (n=8)	45% (n=19)
NHS Cognitive Behavioural Therapy (CBT) (n=39)	0%	18% (n=7)	23% (n=9)	21% (n=8)	38% (n=15)
Hydrotherapy (n=42)	10% (n=4)	2% (n=1)	24% (n=10)	12% (n=5)	52% (n=22)
Exercise schemes for people with chronic health conditions (n=41)	2% (n=1)	10% (n=4)	20% (n=8)	5% (n=2)	63% (n=26)
Expert Patient Program	20% (n=8)	10% (n=4)	5% (n=2)	20% (n=8)	46% (n=19)

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(also known as the Living Well course) (n=41)					
Prescription medications for pain relief (n=50)	64% (n=32)	22% (n=11)	8% (n=4)	6% (n=3)	0%
Over the counter medications for pain relief (n=34)	44% (n=15)	41% (n=14)	3% (n=1)	6% (n=2)	6% (n=2)

Comments from survey respondents on this question included:

“There are a number of things that I know would help me better manage my pain - such as hydrotherapy and specialised exercise programs - that I haven't been able to access at all.”

“I have paid privately for acupuncture, physiotherapy, and two sessions of CBT. All these were very expensive and now because for me a hydrotherapy pool is beneficial I pay £65 a month to go somewhere in Wokingham which takes me nearly an hour to get there. This is all very expensive when you are on a pension. I find it more difficult to access things as although I live in West Berks my surgery is in South Oxon.”

“I am now appalled to find how many other options I could have had. I spent over £1000 on private acupuncture treatment unaware that it might be available on NHS. This has really [annoyed me] to know that I could have been getting more help”

As the above table of results shows, none of the survey respondents who had been referred to CBT or Cognitive Behavioural Therapy on the NHS had found this service useful. One quote from a respondent on this subject was:

“Referred for Blues Begone programme. Found this to be ineffective due to inadequate nature of DVD. Felt like I was being fobbed off by GP and organising staff, as if the process of giving me the DVD was to their mind a tick in a box rather than an effective treatment.”

The survey respondents were also encouraged to comment at the end of the survey and these comments included:

“I haven't driven a car, or sat down properly since January (it is now May) - I have stood up to use my laptop, to eat any food, to do any writing. The pain has been so bad at times that I have considered suicide. Now, several months down the line, I happen to pick up a card in

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my pharmacy and do this questionnaire only to discover that something could have been done much sooner to deal with it. I have ended up on anti-depressants and fear I will lose my job because I can't manage the pain. WHY is all this kept secret? WHY don't you tell people about what is available? I'm a very self-directed patient but I have somehow completely missed the majority of treatments on offer. How can this happen?"

"It feels as though it has been a battle from the start. There seems to be very little specialist knowledge around. Doctors seem to think the pain is a minor side effect rather than the real problem that stops me doing the things I really want to do."

"I have been told that there isn't much that can be done. I'm aware that there are other drugs/treatments available, but I haven't been offered anything. Perhaps I've made too little of my discomfort, as I do try to carry on as normal, and if I pressed more I might get further, but my overall impression is that GPs are not all that knowledgeable about Fibromyalgia and how to deal with it."

"All I can ask is when a person presents with multiple problems the doctors do not just give up and say "sorry I cannot help you because there is too much damage" or say "you are here because you need a left knee replacement, so that is all I can talk about right now. If the right knee is hurting or your back is hurting then make another appointment". That really does get me annoyed"

"We need faster access to pain clinics. We need the ongoing use of hydrotherapy pools . This is very difficult as there are so few available and I don't see this changing as the NHS cannot cope with demand at the moment. We need quicker access to physiotherapists before conditions which are acute become chronic."

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Conclusion

The survey results have highlighted the fact that chronic pain affects people with a wide range of different diagnoses. Although the conditions are different, the experiences and needs of patients are often similar.

Awareness of options for pain management, the accessibility of those options, and their effectiveness varies widely. Some survey respondents were quite upset by the number of options available that they had not been made aware of.

Almost all of the respondents were aware that prescription medications for pain relief, over the counter medication for pain relief and NHS physiotherapy are options. But awareness of other services varies considerably, with less than a third of respondents being aware that there are exercise schemes for people with chronic health conditions and that there are specialist NHS Pain Services out of area. So being a patient in pain does not mean that you are made aware of all the services that may be helpful in managing your pain. Researching options is something that many patients have to do for themselves, but this is not easy, particularly if you are new to needing healthcare or are in a lot of pain. Some of the respondents were actually quite upset to find out that there are so many options that they didn't know about. Further work is needed in making it easier for patients to find out about all the pain management options that are available.

The survey results showed that even if patients are aware of services that may help with pain management, they may not be able to access them if they want to. The struggle to access services was something that many survey respondents commented on, saying that they did not have the energy to always be chasing up other options.

The survey results also highlighted the fact that the more easily accessible treatments are not always the most effective, especially as perceived by the patients in the context of quality of life, rather than just pain levels.

All survey respondents were aware that Prescription medication for pain relief was an available option and most respondents who wanted to could also access it. Of those who did access this option, a majority also found it useful. Most survey respondents were aware that Over the Counter medications for pain relief were an option and were able to access this option if they wanted. However, only 52% of those that did access this option found it useful. Many respondents also commented that medications could not control pain effectively on their own, or that higher doses of medications could provide greater pain control but often at the expense of quality of life.

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The survey results showed that NHS Physiotherapy and Complementary Therapies on the NHS have low levels of usefulness compared to relatively good levels of awareness and accessibility. Hydrotherapy on the other hand has relatively poor levels of awareness and accessibility, but 80% of the respondents who managed to access Hydrotherapy found it useful. And exercise schemes for people with chronic health conditions had relatively low levels of awareness, accessibility and usefulness amongst respondents.

The importance of focusing on the patient's quality of life was highlighted by a survey. Patients want to have options and to feel in control of their pain management. Pain management options that impact negatively on quality of life (e.g. if higher doses of medications means significant adverse effects) are often available but are not welcomed by patients.

Discussion

Problems with the online survey system, almost entirely down to inexperience, contributed to the low numbers of respondents, as there were a few occasions when the survey was found to be offline as it had timed out.

On some questions, the low number of respondents mean that the results were of little value. However, overall themes were identified and some of these were extremely interested. Further research is needed, especially into the cost-effectiveness of options in terms of patients quality of life. If a relatively inexpensive option is considered to be a waste of time by a majority of patients, then it is still a waste of resources despite the low cost.