

Committee Secretary
Standing Committee on Health
PO Box 6021
Parliament House
Canberra ACT 2600

Friday, 17 July 2015

Dear Committee Secretary,

Chronic Disease Prevention and Management in Primary Health Care.

I welcome the opportunity to comment about best practice in chronic disease prevention and management in primary health care.

Specifically, I ask you to fund research into Fibromyalgia and cater for patients who require home care, visits and support from medical professionals and alternative therapies.

Australia could be, but is not leading the World in the research with Medical Marijuana for the possible treatment of Fibromyalgia, MS, ME & CFS.

I would be prepared to sign a waiver form that I fully understand it could help or hinder my health. We all get to the point where we believe our life is not worth existing in, we want to live not exist in pain! I cannot stress enough how I would jump at the chance to part of Trials on Medical.

This is my story

I am 54 years of age and until a few years ago I reasonably healthy & active person that ran a busy Camping Store with my husband for 25 years.

Over the last few years I have existed in life with chronic daily pain. I suffer from Osteoarthritis, degenerative disc disease and Fibromyalgia and in the past Thyroid problems.

My conditions mean I cannot stand for more than around ½ hour, I cannot sit for more than about an hour. This depends on where my pain is and its hourly level. There are some days I cannot sit, stand or lay down pain free. There are the odd days when I don't have major pain, but my lumbar still limits my activities.

I suffer depression from not being the same person I was and believe the Thyroid problem and medication, was the trigger for the Fibromyalgia. I blame that squarely on the doctor's lack of training in treating me. He was a Heart specialist, not a Thyroid specialist. This was because I was unable to get into see one for 6 months. People trust doctors, especially specialists to know what they are doing. Apparently the Thyroid specialist tells me; my bloods should have been monitored every week until stable and then removed from the drugs.

My daughter currently does my housework. My husband is 14 years older than myself and I was expecting to look after him, he now is my carer. We have limited income from his part pension and small superannuation funds.

I am not on a disability pension because I cannot mentally cope with the hassles of Centrelink paperwork and the looks I would get if asked what I was doing with myself these days. When I do go to town it's because I am having a good morning and that's all people see, not what I go thru every day. We have chosen to cope as best we can with what we have.

My current methods of help and coping are:-

1. Lyrica 75mg, twice daily. This helps a little with the severity of pain from the Fibromyalgia. I did find the 150mg more effective, but it turned me into a couch potato unable to do anything at all which made my depression critical.
2. Currently I am seeing a Phycologist/Hypnotherapist who is helping me work thru my grief of loss from the person I used to be, looking for a way to not feel totally useless and relaxing more instead of stressing but what I cannot get done each day.
3. Sleeping pill, daily. Cannot sleep at all from aching back, hips, legs, joints, shoulders (depends on the day and how much I am able to push myself).
4. Tens Machines, sometimes helps a lot, sometimes not depending on what is hurting
5. Long hot spa with 2 cups of Epsom salts that I purchase in bulk.
6. Fisiocrem purchased in bulk and loaded up before bed

When chronic, like I have been over this “Artic blast”, I have other pain relief pills and potions that have their own bad side effects. Picking the lessor of 2 evils that will dull the pain enough to one that I can cope and live with is not always effective.

I stress about the drugs I am on and what if their potential side effects happen to me.

Despite an estimated one million Australians living with Fibromyalgia, there are limited services, support and information available. The gaps between research and daily care are unacceptable.

I ask the Federal Government to provide:

1. Access to quality services and medical Trials for all Fibromyalgia sufferers including people in rural, regional and remote areas.
2. Access to education and training for health professionals in particular as it relates to early intervention, multidisciplinary team practice and the early identification of Fibromyalgia.
3. A public awareness campaign to address discrimination, misunderstanding and stigmatisation of people with pain within the community, including in the workplace and in welfare and compensation systems.
4. Funding to provide community support services including consumer information, self-management education and telephone support (crisis help line).
5. The development of a national research agenda to address gaps in knowledge about Fibromyalgia and improve clinical practice in pain management and immediate access to Medical trials for Regional and Rural areas.
6. Research into possible Genetic links; I have 1st cousins with MS & CFS & Hemochromatosis and Vitamin B deficiencies.

I trust that my submission is useful in informing the Committee’s consideration of best practice in chronic disease prevention and management in primary health care.

Please do not hesitate to contact me should you have any queries or require additional information.

Yours sincerely,

Mrs Kim Crowe