

Arthritis Today
Article on *A Woman in Pain* hypothetical

Anna is a 58-year-old woman whose life is punctuated by passion, loss, love and economic hardship. A professional ballroom dancer in her teens, her dreams of retaining the Latin American championship crown for the third time running are dashed when her life-long experiences with pain begin at the tender age of 14.

Over the decades, Anna gets married and endures an abusive relationship; falls pregnant 11 times, only to lose nine of her children, and finds love again in her later years. Throughout the ups and downs of her life, Anna's one constant is chronic pain. She lives the best life she can, but Anna's pain brings with it a host of physical, emotional and psychological scars, throwing up some interesting challenges for a vulnerable woman living in a modern age.

While Anna is not her real name, this brave woman represents millions of women across the globe. Pain has a huge impact on every day of their lives, and many remain untreated and isolated from the flow of life around them. In a staggering number of cases, their pain issues see them sidelined into a life with significant emotional, social, psychological and economic hurdles.

The international burden of women in pain is a largely unrecognised government policy area. In March, the Australian Pain Society and Arthritis WA joined forces with the Bone and Joint Decade to highlight this crucial health care issue. Through the *Woman In Pain* hypothetical, with Anna's story at its nucleus, a robust dialogue was set up. Held at the Perth Convention & Exhibition Centre, it was organised to put the spotlight firmly on this often-trivialised area of public health.

On the panel were medical professionals and patients with a wealth of experience in dealing with pain, from both a personal and professional viewpoint. All of them women, they each highlighted the strengths and weaknesses of the medical system, the incredible bravery and strength of women living with pain, and the necessary steps that are needed to address a multitude of issues surrounding the topic of pain.

Anne McKenzie, consumer research liaison officer with UWA's School of Population Health, opened the hypothetical, telling those gathered that pain was often trivialised by society, and even the language employed when talking about pain, gave it an unimportant edge.

"Society treats pain in a very flippant manner," Ms McKenzie said. "Much of our slang talks about people being "a pain in the neck". It's very easy to flick pain off as being trivial. So it's very important to have meetings like this so pain is talked about openly and in an informed way."

Australian Pain Society President Amal Helou, a nurse practitioner for 25 years at Sydney's Royal Prince Alfred Hospital, said the *Real Women, Real Pain* awareness campaign aimed to empower women and highlight the realities of living with chronic pain. The campaign would give women a voice and give them avenues in talking to people about their pain.

City of Perth Lord Mayor Lisa Scaffidi said it was the responsibility of businesses and governments to spread the word that it was no longer acceptable to trivialise conditions such as Arthritis.

In 2008, the Global Year Against Pain in Women, barriers still existed for women seeking treatment for their conditions. Ms Scaffidi said Arthritis was a major national health issue, which in 2007 had an estimated annual economic burden of \$23.9bn.

“There are solutions out there,” Ms Scaffidi said. “We all deserve to enjoy the fruits of living in such a beautiful city.”

Finally, Suzie May, was the last speaker before the hypothetical kicked off. Ms May was diagnosed with Rheumatoid Arthritis at just 28, just as she was about to embark on a stellar legal career.

“That was my introduction to true pain,” Suzie said. “Before that I had experienced artificial forms of pain.”

The diagnosis was like “a blow inflicted on my soul” Suzie told those gathered. But the brave lawyer refused to allow her Arthritis and her pain to rule her life and she and husband Chris made the decision to have the child they had always dreamed of.

In trying to fall pregnant, Suzie faced the enormous challenge of having to cease all of her medications. “I no longer had the luxury of being able to reach for a pill when I was in pain,” she said. “I was carrying a tiny body that did not deserve to be pumped full of pain medication.”

After Oscar’s birth in June 2007, Suzie faced a new list of challenges as the intense pain of her RA returned. Determined to give Oscar the best start in life, Suzie overcame the unbearable pain in her hands, arms and shoulders to breastfeed in the early hours.

“Each morning I would be unable to move,” Suzie said. “Even trying to do up the press studs on Oscar’s suits was a challenge. But I would definitely do it all again – a baby’s smile can be a very effective pain management strategy.”

With the introductions finalised, the panel went on to examining Anna’s eventful life, with tips and explanations for why this plucky woman had endured such a protracted life of pain and health problems. Her experience is a valuable lesson to all on how to manage the wide-ranging impact of pain.

Scenario 1: Anna’s first experience with pain occurred at 14, when she injured her back while working part-time in a shop. After 12 months of back and leg pain, and much failed treatment (physiotherapy, injections and exercise), a kindly surgeon performed a laminectomy (A surgical procedure on the spinal cord). Apparently, Anna was cured.

Polly Delaney, 30, consumer: “I have heard the term “cured” many times. In the five years since I started having chronic pain, I’ve had four different diagnoses. I’m not holding my breath for a cure. When a treatment regime doesn’t work, that when things start to get difficult, when you don’t fit into the “cure” model.”

Nicola Cook, Rheumatologist: Women living with pain need to have realistic expectations. We are doomed to disappointment if having a “cure” is the only thing that’s going to provide a satisfactory outcome.”

Scenario 2: Anna was married at 18 – for next few years she was literally “barefoot and pregnant” most of the time. She and her husband lived up North, where medical services were thin on the ground. Anna had 11 children, including four sets of twins who did not survive beyond 30 weeks, a baby girl who died a few days after her birth, and two sons, both of whom survived. Doctors did not tell Anna why she lost all these babies, but she never asked. One doctor suggested Anna “go on the pill” but her priest would not condone this – he advised Anna and her husband to use the rhythm method – but she had already tried that and it had not worked!

Professor Nicky Leap, midwife: “Even today women still experience such profound loss when giving birth. It’s a terrible indictment (on the medical system) that Anna should have had all of those losses without knowing what was going on. What stays with women during their childbirth experiences are all the kind, and especially the unkind, things that people have said. There is a lot of research that shows that it’s not the pain of childbirth itself that stays with women, it’s the experience that accompanies it which leaves a lasting impression.”

Scenario 3: Anna’s marriage did not work out – her husband turned out to have a violent and sadistic side. Anna took her two children and left him when she was 25 and ended up in a women’s refuge. A bout of serious depression followed and Anna sought psychiatric treatment. Two ladies who appeared to be “ripping the place off” were running the refuge. As Anna was already studying accounting, part-time, the management asked her to take over its running. After five years working in the refuge, Anna learnt a lot about life – to say the least. Her next job was as a credit officer with a building society – Anna was the first female to work in credit.

Stephanie Davies, Pain Physician: “When women experience these kinds of events in life, there are three things that help them cope – work, hope and love. Finding some worth in being employed and the support of family can never be under-estimated.”

Petrina Lawrence, consumer: “My family is always keeping me grounded. I went from the family home into an abusive marriage for 17 years and the support I received from my family was wonderful.”

Polly Delaney, consumer: “I wouldn’t be here if it wasn’t for my family. They still help my husband and I even now. They have been phenomenal in acknowledging that just because I suffer from chronic pain, it hasn’t stopped me from being Polly. There

is such a thing as being normal and you don't have to have the pain at the forefront of your mind all the time.”

***Scenario 4:** Anna's life was now back “on track” until 1982 when she was a passenger in car accident. Anna's injuries were mainly spinal – she was left with severe low back pain, neck pain and loss of feeling in her left arm. Anna also suffered from headaches and blackouts. Thoroughly investigated by a neurologist, she was eventually referred to a pain specialist.*

Helen Slater, Physiotherapist: “When dealing with something such acute spinal pain, it's very important to be looking at the big picture of management through a multidisciplinary approach. Participating, being active and taking part in regular exercise has a really significant part to play. There are three types of pain: acute, which lasts less than three months, sub-acute, which is a slightly grey area and chronic, which lasts for six months and beyond.

***Scenario 5:** Through a limited understanding of pain, Anna received two cervical epidural injections and two “facet” blocks. Both made her pain worse! She vowed she would never have any more injections and for the next two years, Anna battled on with Panadeine forte and Valium. She also used hot packs and hot shower to alleviate her pain.*

Barbara True, Rheumatologist: “When a patient is refusing to have certain types of treatment, it's time to sit back and listen to what that person really wants until they ask for other treatment options. There's a need to define what's possible and reasonable.”

Allyson Browne, Clinical Psychologist: “It strikes me that Anna is someone who has suffered tremendous loss – she has lost a lot of children and has experienced a host of other difficulties. She has shown a great deal of resilience and despite all of her experiences, has been motivated to seek treatment. What's important is the type and the frequency of the support she receives – these can be critical to the success of the outcome. Interestingly, patients are not always focussed just on pain reduction, they are seeking improvements in their quality of life and they want to learn to manage their pain in a more effective way. Many employ value-based goal setting and have the mindset that “my pain is not going to get in the way of what's important to me.”

Petrina Lawrence, consumer: “I have always tried to find outlets for my pain – even if it's relief for five hours here, or two hours there. It can be as simple as going to watch a movie, or enjoying a cup of coffee.”

Allyson Browne, Clinical Psychologist: “There is a growing recognition that pain is just one part of people's lives. Treatments are now moving in the direction of having tailored, individualised programs, so that people living with pain are given the tools to move other parts of their lives forward.”

Stephanie Davies, Pain Physician: “Pain is just one of a myriad of problems in these people’s lives and sometimes there is a tendency for the over-simplification of pain.”

Scenario 6: Anna fostered an interest in yoga and meditation when she picked up a book on the subject. Using yoga, she perfected her own technique of self-management. Most of the time Anna could manage her pain – but once or twice a year she was admitted to hospital for a rest and a short burst of opiates – by injection and by mouth. During this time Anna developed a serious relationship with Mike – a bus driver – whom she had known at school. Anna also commenced a full-time course in naturopathy at the College of Natural Medicine, wanting to formalise her knowledge of massage and other “alternative” treatments, but her health problems cut the studies short after six months. When Anna started to experience bouts of severe chest pain she was in and out of hospital but did not feel she was being taken seriously. One cardiology registrar (a woman) told Anna that she was taking too many painkillers. Anna thought she was being written off as a junkie.

Helen Slater, Physiotherapist: “Treatment programs should be arrived at in collaboration with the patient. They should be asked – ‘What are your goals?’ and be encouraged to develop self-management strategies. Active coping strategies are really, really important.”

Barbara True, Rheumatologist: “In my experience, there are often traumas for patients that have been inflicted by other medical personnel, which makes things twice as hard. Firstly, you need to work through those with the patient. Some people (medical professionals) are better than others at dealing people and understanding the impact of their statements.”

Scenario 7: Anna eventually had a valve replacement and a two-vessel coronary bypass. Her condition worsened and she was told that her heart had “crashed and burned. A priest was called in to administer last rites. Anna felt she had lived a good life and accepted the inevitable. Suddenly, she was rushed to Royal Perth Hospital, where Anna woke up connected to a “washing machine” – an artificial heart used as a bridging system while people awaited heart transplantation. Due to her enforced immobility, Anna’s spinal pain worsened and a pain medicine specialist was called in. Anna refused to take drugs, but with some reluctance Anna was commenced on Oxycontin twice daily and used Oxynorm for breakthrough pain that could not otherwise be managed.

Nicola Cook, Rheumatologist: “This is where taking ownership of the problem is paramount. Sometimes taking drugs amounts to being the lesser of two evils. Nobody should take medications that don’t work, so people have to make their own choices in setting out what the pros and the cons are. Of course, medicines are not the only way to help the pain process.”

Polly Delaney, consumer: “Taking certain drugs is a difficult decision – some of the side effects are awful, such as slowed reaction and thinking times, but at the same time, I don’t want to have a massive drug load.”

Stephanie Davies, Pain Physician: “There is a lot of evidence to suggest that some medications with low doses do help with pain without being addictive. Using drugs with a low side-effect strategy in conjunction with things such as exercise and meditation can have great impact. It’s a matter of choosing the times that you are going to take medications.”

Scenario 8: After nine months spent on the bridging system, Anna had a heart transplant and was prescribed high-dose cortisone. Her partner Mike was himself experiencing more heart problems but ignored the warning signs while he helped Anna recover. Three years ago Mike had a heart attack and collapsed. Following Mike’s death, Anna went back onto an antidepressant.

So, how is Anna now? Still dealing with the grief of Mike’s death, Anna is doing her best to manage her pain and her health problems. She is still taking opioid on a regular basis, along with glucosamine for her aching joints and fish oil supplements to lower her cholesterol. She sees a dietician, attends Weight Watchers and has joined a health club. Anna misses her dancing. In its place, she has her music.

“You feel a little bit isolated at times when you are in pain if you haven’t got a partner – sometimes you think, who can I talk to? You know, you cope with a lot but sometimes you just need someone to talk to or say to someone – is there anything new? What alternatives are you using? If there are none, I’ve just to get on with it.”

For more information on self-management courses, alternative pain therapies and getting access to pain clinics run as part of the Federal Government’s Better Health Initiative, contact Arthritis Western Australia on 9388 2199 or by email: general@arthritiswa.org.au.