

## My Story as a Nurse, & as a Mother & Carer of Someone with CRPS (Complex Regional Pain Syndrome)

*As my beautiful daughter slowly limps up the hallway, I stand and wait for her to reach me so I can envelop her in a motherly hug (because, as we all know, a motherly hug can fix most anything), but as she stops in front of me and I reach out to hug her, she flinches and says, "Don't touch me."*

*My heart drops and I turn away so she cannot see the disappointment in my face; all I would like to do is give her that big, motherly hug that will take her pain away. But on days like this, it would only hurt her more.*

*I know that today is going to be one of those days where my little girl is locked away from me, locked in her room in the dark with her pain. I know there is little I can do to take that pain away from her. The only thing I can do is be there when she needs my help, whether this is to get in and out of the shower, to dress or undress her, to help her get into or out of bed, to help her get up from the couch, or one of the other many little things she asks of me. On days like these, the only other way I can be there for her is to gently hold her when she needs a hug, even though these hugs are filled with pain for her, or to just sit with her as she lays her head on my lap; sometimes that is all either of us can do.*

This all started when my daughter was doing her VCE studies. She was tired, and continually complaining of pain in her right hand and arm. We all put it down to stress and all the extra writing she had been doing for her VCE revision and exams. A muscle strain was the most likely thing – writer's cramp. When she left school her symptoms progressively increased and worsened. She had left home and was determined to live independently; she was working, and maintaining a unit and yard, but was finding it increasingly difficult to continue working and taking care of herself.

As her pain and symptoms began to increase and spread further up her arm, going into her shoulder and back, she started to have difficulty sleeping, or to even hold a cup in her hand. Many trips to different doctors and multiple, varying tests ensued; Neurologist, Pathologist, Chronic Pain Specialist, General Practitioners; Pain Management Program, physiotherapy, occupational therapy; EKG, ECG, MRI, multiple blood tests, ultrasounds, x-rays. But nothing helped to ease her pain, or gave us a way to cure it.

For quite some time we had suspected CRPS; we had many sessions in front of the computer looking up this horrible affliction, looking for something that didn't mean a lifetime of pain, something that wasn't as frightening. But when the diagnosis of CRPS was confirmed, we redirected our focus on finding an effective treatment that would give us our lives back, a treatment that rids us of those days that would give us back our daughter, the daughter that I could hug with no pain for either of us.

After two years, she moved back home, her pain becoming too much to cope with on her own and because she needed help with basic tasks. This has been disheartening and difficult for my daughter as she had sought to strike out on her own, to be independent.

Since she has been home, to regain a degree of independence, she has taken on part-time work one day a week, and tries to help around the house, as she is able. My husband and I encourage her to do as much as she can, when she can, helping her as she needs.

We recently joined The Purple Bucket Foundation Inc.; they are helping to raise awareness for CRPS, and provide support for the carer and sufferers affected by CRPS.

As a nurse, I have looked after many people with chronic pain, myself being one, having developed chronic pain from the wear and tear of years of nursing. But I had not known about CRPS (having been known as RSD – Reflex Sympathetic Dystrophy), until my daughter developed the condition. Like a majority of people out there, I had no idea how sporadic and varied this condition is, how extensive and painful the symptoms are.

In researching this condition, I have found that there is a long list of symptoms just as varied as the sufferers themselves. There is more to it than just the painful sensations of burning, stabbing, and stinging pins and needles in the sufferers affected limbs/areas. In some cases, CRPS sufferers can have their condition spread into other limbs – generally, if the condition does spread, it will either spread vertically or horizontally; in rare cases, however, it will spread diagonally into another limb. When the condition spreads further throughout the body, other areas may be affected, from stomach cramps and nausea to memory loss and cognitive issues.

CRPS sufferers also experience pain that changes in intensity, often feeling worse than may be expected; spontaneous pain that can occur with or without a trigger; muscle spasms; coordination difficulties; loss of fine motor control; loss and impairment of special awareness. They can experience stiffness of, and in muscles and joints; changes in hair and nail growth – lack of or excessive hair growth, brittle nails, sometimes with stunted growth – on the affected limb/s; weakness; swelling; the temperature of the affected area can sporadically become cold or hot – for some people this is constant.

This condition is debilitating and complex, with each person exhibiting a different combination of symptoms in varying degrees. Each person having different triggers and tolerance levels to varying stimuli. Because of this, it is very difficult to diagnose and treat. Along with physiotherapy, occupational therapy, and other physical/movement based therapeutic activities, analgesic and nerve pain medications, and anti-depressants are used to treat and manage this still widely unknown condition.

With early diagnosis and a tailored approach to treatment, a sufferer is more likely to go into remission, though many are not diagnosed within the recommended timeframe of 6 months. Remission or a reduction in pain levels from the right treatment becomes more difficult to achieve the longer someone has CRPS, and is more likely to spread, “with 35% of those affected, reporting symptoms throughout their entire body.”

The cause of CRPS is still unknown, though it is associated with dysregulation of the central nervous system and autonomic nervous system. CRPS is not necessarily caused by any psychological factors – i.e. the pain is not just in their head – although high stress has been attributed to the onset of this condition. The constant pain, reduced mobility, and restricted/altered lifestyle often lead to depression and anxiety – anxiety is often bought about from the fear of causing more pain, or being in a situation that may trigger more pain (going out into the cold, being in a social situation you are unfamiliar with or that is stressful). In this, CRPS is associated with the **psychosocial effect**. With the increase of pain, there is often a decrease in social and physical activities of most sufferers, which can lead to depression and the feeling of isolation; for some sufferers, this can lead to the misdiagnosis of a mental health problem.

There is no one diagnostic test for CRPS. It is based on a persons’ medical history and relevant symptoms in relation to the CRPS “check list”. Many tests can and should be carried out to rule out any other possible conditions – MRI, blood tests, x-rays – bone scans (in some situations), CT scans, etc. These tests can also show what other systems can and are being affected by CRPS: the early onset of arthritis, a vitamin D deficiency, etc.

As not all health care professionals are aware of CRPS, or may not fully understand the varying degree of symptoms associated with the condition, there may be a delay in its diagnosis and treatment. Unfortunately, this is to the detriment of some sufferers.

With the right sort of treatment, some people do recover from CRPS, but there are other CRPS sufferers who have ongoing symptoms and pain. These sufferers have pain that can linger for years, sometimes increasing and spreading throughout this time. Some of these sufferers may go into remission for a period of time, then relapse, and so on, throughout their lifetime.

It has been suggested that some anesthetics reduce the risk of CRPS occurring during surgery; these anesthetics could also be utilized for CRPS sufferer who must have surgery to reduce the risk of the condition spreading into the area being operated on. Some sufferers in rare cases, with severe swelling and complete lack of movement look to have the affected limb amputated, as a way of improving their life.

Until more is known about CRPS, carer and sufferers like myself and my daughter can only live day by day. We wait, we continue to talk to others, research, and hope that a cure can be found for sufferers like my daughter.

## Things to Remember and Do:

CRPS is a painful and debilitating syndrome that can affect anyone.

Currently, there is no cure, and there is no simple treatment.

Support, patience, and understanding is important.

Many sufferers can and do recover, this may be permanent or sporadic.

Support from family and friends, along with counselling and psychological staff can enable the sufferers to get through the day.

We as medical staff need to be aware that touch is often one of the most painful things that any sufferer is living with; soft touches can feel like you have hit them with a hammer, cotton sheets can feel like sand paper, and so on, each sufferer being different in their tolerance levels.

When a CRPS sufferer comes into hospital, it is usually as a last resort because their pain has gone beyond their control.

## Remember to:

1. Ask if they are happy to be touched?
2. Ask if they can tolerate the pressure from a blood pressure cuff? (Particularly if they have multiple limbs affected. They may be able to tolerate it on one arm over the other, or they may be able to tolerate a cuff on their leg.)
3. If they can tolerate a physical exam?
4. If they can give blood? Can they tolerate a normal sized needle? What is the best place to draw blood? (Remember, a small needle prick to us, for a sufferer, can feel like having a four-inch nail stuck in their arm.)
5. Listen to them and their caregivers. (Don't assume it is all in their head or that they are just looking for drugs.)

**This is a very real and debilitating condition.  
A trip to the hospital is the last thing a sufferer wants or needs.**