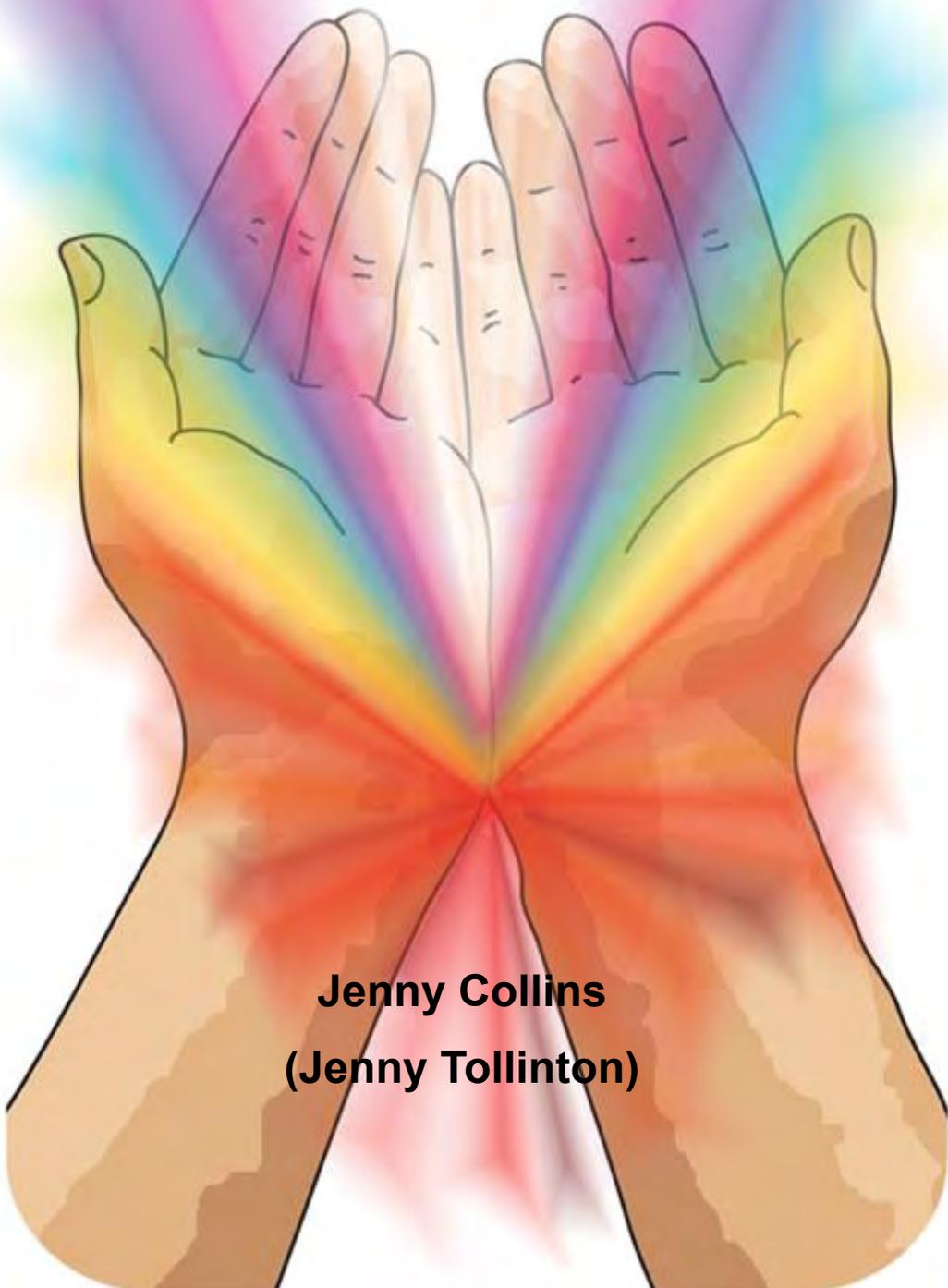


**TENO Hands
To
HEALING Hands**



**Jenny Collins
(Jenny Tollinton)**

Jenny Tollinton

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E-Book Edition June 2017
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I dedicate this book:

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THANK YOU

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Photos Jenny Collins (Tollinton)

FOREWORD

I have run the Bradford Repetitive Strain Injury (RSI) Support Group for almost 20 years. The group was set up in response to RSI sufferers that I met in my role as a Primary Care Occupational Health Advisor.

During these years, I have met hundreds of sufferers. The thing that they all have in common is their work ethic. They are usually hard working and proud to be so, they are the ones that go the extra mile at work, that stay late, do extra and strive to do the best they can. When they develop an RSI, I think it is extra devastating for them because many of them lose their status as workers.

Most of our members over the years have been young women who work using computers, women who are at a point in their lives where they are planning to have a family, women who have to put their lives on hold because of the debilitating nature of RSI.

There has been much controversy over the years about computers causing RSI. I am pleased that at last there seems to be some recognition that computer over use might play a part in causing these injuries, even though there has been legislation for over ten years aimed at protecting workers that use computers. I think that there are still people around who think that office work is not real work and this is unfortunate, any new technology can bring problems with it but it takes a few years to recognise what those problems are.

Maybe the fact that women are most likely to work in low paid repetitive jobs has some bearing on the debate, along with the fact that it is still women who do the majority of household tasks as well as working. The frustration that comes with not being able to do things for yourself when you have always been independent and capable often leads to a feeling of hopelessness and depression. What sufferers need is some understanding of their difficulties and some holistic care. That is what the Bradford RSI Support Group provides.

It is important that women like Jenny tell their stories so that a wider understanding of the condition can come about.

Carol Duerden

Tech IOSH, MBACP, MPCP, Dip Counselling – Human Relations

TENO Hands To HEALING Hands

Typing away on the computer I launched into another chapter. Wow, released from my disability! No longer in pain, I know I deserve to be well. Now I know, as this power is inside each and everyone one of us that my body does know how to heal itself if I will only stop and listen.

Coming from an active family life, as doors shut on that life I am living proof that it can be possible to overcome 'dis-ease'. Suddenly living becomes something I can do.

Filling up with petrol and screen wash, and checking the tyre pressures, I got my car ready for a trip down south. Vigorously brushing my teeth, fastening the tiny buttons of my fashionable blouse and styling my hair with a hot brush I got ready to go out for a meal. Using my knife and fork I cut into the duck as I sat chatting away at the table. Turning off the tap in the ladies I caught sight of myself in the mirror and thought, wow is that really me...

Shopping for myself I carried my own bags around the mall stopping occasionally to open the screw top on my bottle of water to take a drink. Travelling alone using planes, trains and buses I pulled my suitcase along carrying my lap-top computer in my other hand.

All excited and laughing away I swung the Nintendo Wii Console remote to serve the tennis ball towards my nephew's player on the screen. A few weeks earlier I had been at his birthday party, roller-blading...



INTRODUCTION

In the 1990's on the go morning, noon and night I was holding down five jobs totalling 32½ hours a week; an administration role, support assistant, dinner supervisor and a self-employed swimming teacher at my children's primary school, and a swimming teacher for our local swim scheme. I also helped as a volunteer for a local swimming club and was heavily involved in the local school's friends association. With three children under teen age and a house and home to run too; my life was certainly a busy one and I loved it.

In the summer of 1993 more swimming teaching and administration hours meant giving up the support assistant and dinner supervisor jobs but my working hours remained the same. Then in the New Year of 1995 whilst working 18 hours per week as an adult student co-ordinator, and around 14 hours per week as a swimming teacher I developed a work-related injury known as tenosynovitis (teno). The symptoms of teno took over all areas of my life with quite devastating effects. All I had ever done was work hard, but due to health and safety regulations being ignored I found that my injury was due to the illegal set-up of my visual display unit (VDU) workstation and, unbelievably - it could have been prevented! So when the effects of my injury intruded on my relationships with my husband and children, my family and friends it really did feel quite catastrophic at times. I went on to stumble through massively excruciating times for many years following diagnosis which included struggling against the agonising mental anguish that goes along with this kind of injury.

Tenosynovitis affects manual dexterity, grip and fine motor functions. It is one of a range of repetitive strain injuries known as RSI's. An RSI is not necessarily found just in the upper limbs either; the feet or knees may also be affected. These injuries are caused when a task requires small, rapid, repeated movements, often whilst maintaining a static posture. Teno has three stages, mild, acute, and chronic or end-stage as I was advised mine was.

How had all that happened? I had wanted to be able to type since my teens so when I was 30 I thought it was about time I did something about it, never imagining that not long after I would not be able to type again and I was only 36 – nowhere near ready

for the scrap heap.

Nobody in the medical profession ever put a timescale on when my injury would, if ever, get better. 'It could be ten years' they might say, may be never...nobody ever said 'it will go'. The gravity of my diagnosis at that time did not sink into my mind at all.

Occasionally, over the following years I would think about a friend of mine who had been diagnosed with multiple sclerosis. A few years after her diagnosis I remember asking her how she was coping and she told me that it had gone. She no longer had multiple sclerosis. I was so pleased for her and often thought "wow, what did she do?" I had read in books about people healing themselves of serious and even life threatening illnesses however actually knowing of someone in person was quite another thing. Could I do that?





DIAGNOSIS AND TREATMENT

On the 6th of February 1995 I visited my doctor with the most profusely excruciating pain in my right wrist. Since the 18th of January 1995 I had been having trouble with searing pain which would shoot through my wrist when carrying out varying manipulative hand tasks. My fine pincer grip was affected in such a way that I was dropping money and pieces of paper, finding it impossible to use the office stapler or grip scissors. My writing became illegible if I could even manage to write at all. I had trouble gripping a knife and fork or a cup of hot tea and once dropped very hot chicken fat all over the kitchen floor, narrowly missing burning both my thighs. When getting hold of my seat belt to pull it across my body pain would sear through my wrist and up through my arm, the same as when pushing open doors, amongst many other things. I also had swelling around the wrist and the pain carried right on up through my arm and into my neck. I was diagnosed with right-side, tenosynovitis of the radial border and initially my doctor suggested three things; a futuro splint, painkillers and sick leave.

So, this is what I did. I went straight to the chemist and was fitted with a futuro splint, but was never actually told how to use it. Apparently, you wear these kinds of splint for a few hours at a time, rotating the wearing at different times throughout each day. Until happening upon this information I wore the splint constantly, likely causing a weakening of the muscles.

I did not want to take painkillers but accepted a pain-relieving gel. After a week, I was pain free and I wondered how on earth this could be, surely if this gel acted so quickly it must only be masking the problem and would likely cause me to exacerbate the condition doing untold damage? I stopped using the gel and sure enough the pain returned with a vengeance.

I did not want to go on sick leave so I continued working as a swimming teacher and managed to work the 18 hours in my administration job without using a computer.

By now I was relying on my left hand for almost everything and I worked a further four days before being on a week's annual leave. By the 24th of February 1995 I was back at the doctors, now with pains in my left hand and arm, and up into my neck too. I

explained that after working only a further eight days without touching any computer my symptoms and swelling were the same in both my upper limbs. I mentioned to my doctor why I was not using the pain-relieving gel and he respected my feelings. He also said he would refer me to an orthopaedic consultant. The enormity of my situation did not sink in at this stage. I thought I would be all 'fixed' and back at work in no time!

As both my upper limbs were now affected my diagnosis became bi-lateral tenosynovitis. At this stage I was forced to go on sick leave from my administration job. I had only ever been on sick leave for one week in my life when I was 19, and I went on to find this time in my life extremely difficult. Although I had to take sick leave from my co-ordinator role I could carry on as a swimming teacher though some aspects of that role became quite challenging.

Fortunately for me I have not only the support of a doctor, but also an occupational health worker/counsellor at my surgery who both recognise the existence of work place injuries. I was advised immediately that working with a computer in my administration job was causing my symptoms. I was also offered counselling sessions at this time which were to become one of the mainstays of my recuperation over the next five years.

Numerous visits to people in the medical profession followed over those next five years. I saw a total of 12 different specialists in order to either be eligible for claiming benefits such as disability living allowance (DLA) and industrial injuries disablement benefit (IIDB), or to pursue a legal case. I have never been on incapacity benefit.

I saw an orthopaedic consultant on the 27th of March 1995. He initiated my treatment by sending me for physiotherapy. The treatment involved having sponge pads put on either side of my wrists and then electromagnetic pulses were sent through to stimulate the nerves. This was very painful and did nothing at all except aggravate my symptoms. I was signed off by the physiotherapist by mid-May. Towards the end of June my doctor offered me a few sessions of acupuncture.

At this stage I first heard about the governments Placing & Assessment Counselling Team (PACT), the old Access To Work scheme, from my counsellor and I self-

referred. PACT is a government run scheme that helps people back into work after illness or injury by providing any specialist equipment that is required for use in the workplace, and access to some treatments.

On the 22nd of June 1995, my orthopaedic consultant decided, in order to rest the wrists completely, to put both my arms in plaster casts for three weeks, though I refused to have them both done at the same time as he tried to suggest. This did not improve my condition so he sent me back for one last attempt at physiotherapy which did nothing at all except put my back out of line when during a treatment, they once put my neck in traction!

By the time, I saw the orthopaedic consultant again on the 26th of October 1995 he could offer me nothing more and I was signed off after just seven months. Left to my own devices at that time as far as any treatment from the National Health Service (NHS) consultants were concerned.

Once the NHS physiotherapy had ceased that October I was able, through the PACT system, to receive five sessions of adverse neural tension (ANT) physiotherapy. This is a very subtle and gentle form of physiotherapy that I had heard was the correct way to treat an RSI. My doctor stopped my acupuncture sessions at this time as he felt that maybe we were over stimulating the nerves by running the two treatments simultaneously. The ANT therapy wasn't painful like the other forms of physiotherapy that I had received and did appear to help but five sessions were nowhere near enough for any marked improvement of my condition to be noticed. As sessions were £25, which at two a week, would mean £200 a month for an indefinite period of time it was out of the question that we pay privately for any treatment at that time. We were unable to find that amount of money when we still had bills to pay and our children to feed and clothe.

I went on to receive a further five sessions of ANT physiotherapy from PACT in February 1996 and this time there were small signs of increased flexibility in my muscles but again five sessions were nowhere near enough to maintain any improvement in my condition.

During the early years of my teno I would use heat or ice packs at varying times to help ease the pain and had reflexology and aromatherapy massage from friends.

On the 30th of November 1997, my employment from my administration job was terminated on the grounds of permanent ill health due to 'having RSI in both upper limbs'. Two months after I had to take sick leave in February 1995 the pension scheme rules were changed allowing part-time workers to join the scheme. However, being a part-time worker prior to that date meant that I was not eligible for any retirement pension. As I continued to work a few hours a week my swimming teaching pay was what kept us afloat financially over the years.

Eventually four and a half years after my diagnosis, in the Autumn of 1999 I asked my doctor if he would refer me to a Professor in rheumatology that I had heard about at Leeds General Infirmary (LGI). When my appointment came through six months later, along came the beginning of the turning point in my very slow recovery. I could now receive some more of the ANT physiotherapy too. With the little knowledge that I had so far about my condition I found that most of what I had been doing to treat my teno myself, through trial and error since my diagnosis, was in actual fact their procedure. I was told that the problem was in the thoracic part of my spine and that this needed building back up. Nobody had mentioned this before so I started to feel and think that at last, maybe - I could get a little better...

In 2000 I received around 12 sessions of ANT physiotherapy rather than the initial six that are the norm and I would not let the physiotherapist sign me off until I felt confident that I could maintain and strengthen the improvement I had made. When that time came, I was advised by the physiotherapist that I could ring at any time if I felt the need to and simply by knowing that there was support at the end of the phone line made me stronger. From then on, I could incorporate my physiotherapy exercises into a toning table exercise routine, which I still do to this day, twice a week.



LIVING WITH TENO

Living with teno 24/7 did not only involve living with constant pain. It also meant living with all the restrictions that the symptoms had on my everyday life. The choices I made for myself and my family, and not least the way I was perceived by other people.

It was very hard to explain to those who asked exactly what it was that I had, and why I had got it. People who worked full-time on VDU's knowing that I worked part-time, made comments such as, 'why haven't I got it?' All I wanted to do was to be back at work and all the medics were telling me that was not an option for the foreseeable future, so already feeling very frustrated, those comments felt very cruel at the time.

Unbeknown to me, my teno symptoms were already present ten months before my diagnosis. One of the many consultants I saw diagnosed the onset of my condition to have started early in 1994.

For four to five months before being diagnosed with teno I was being bullied by a work colleague. The stress this caused to my health showed up in irritable bowel syndrome, migraines, and panic and anxiety attacks that at times bordered on paranoia due to the mental anguish I was suffering from the ongoing stress of the situation. As stress is often a contributory factor to an RSI this did not help my situation. Prior to my sick leave, I approached management about the bullying but to no avail. By the time, I actually went on sick leave management seemed to think that nothing more needed to be done about the bullying. It was important for my well-being to seek redress so I pursued this through the grievance procedure which took two and a half years.

In the spring of 1995 whilst trying to cope with my own work and health difficulties, one of my children was being bullied both inside and outside of school. Depression set in and I had countless counselling sessions with my surgery's occupational health worker. I remember, quite clearly, her saying very early on that my life was like a bowl of spaghetti, everything was in a tangle and it was going to take some time to unravel. I needed to allow myself that time whilst still trying to exist and look after my family and home. In retrospect, with everything that was going on it was no wonder that my body had shut down.

By the summer of 1996 in addition to my swimming teaching hours, about once a week I could do between five to ten minutes of one of the less strenuous household jobs such as dusting or washing up, or manage to make a very basic meal such as a ready-made quiche or pizza. The family diet was not very healthily as we had to rely heavily on microwave cooking and convenience foods rather too often.

Teetering on the edge there in those very dark days of my teno I spiralled into a very deep, dark 'black hole' depression and there were two occasions when my doctor would have liked me to have taken antidepressants, but I refused. Always very respectful of my wishes, he kept a very close eye on me on a monthly basis over those first three years. I felt that taking antidepressants to make life a bit easier would just add to my health problems. Everyone is a unique individual, with their own path to follow and so whilst I recognise this strategy is not for everyone, it is the way I chose to handle my situation.

(And maybe if the pharmaceutical companies could start looking at more natural/holistic substances for use in their drug trials then added complications from drug taking, particularly for pain, depression and anxiety would be minimised.)

Incredibly painful teno symptoms were by now part of my everyday life. Knowing that I had not banged, knocked or injured myself in any way I was completely baffled by my excruciating pain. The best way I can describe the pain is for you to imagine the tendons running from all your fingertips into your hands, up through both your wrists, forearms, elbows, upper arms to your shoulders and then fusing together in your neck as if they are guitar strings. Next imagine these strings being twanged vigorously in this confined space as they sear and burn right into the very core of your limbs. Along with other symptoms this is what I lived with for many years.

During the first five years when waking, my hands and wrists would be heavy and stiff. My inner wrists would often be throbbing with pain. Often my right elbow and neck were affected too. These symptoms persisted throughout the day and ranged from the hot, burning twangs to shooting pains in the fingers, pains up the forearms as if a knitting needle were stuck in there, pins and needles or a numbing sensation accompanied with the complete opposite of being really cold. The cold weather

aggravated my symptoms and it would take hours for my body to warm right through whenever I got cold. Not being able to exercise, I gained two stones in weight. Sleeping became absolutely unbearable. There was a period of seven to ten months when I would wake up at least five times a night due to pain. This sleep pattern re-occurred a few months later and lasted for a further five months. Trying to get into a comfortable position was nigh on impossible and there were many times in those early years where I would gladly have let someone chop off both my hands and arms.

On reaching the sixth year after my diagnosis my teno had not gone; I had just learnt how to deal with it. About an hour or so after waking, showering and dressing, my hands and wrists would, on most days, have loosened up. Sometimes there would be twinges of pain in the wrists and round the thumbs and fingers, sometimes on the back of my hands, sometimes swelling, pins and needles and/or tingling sensations. As I went through the day certain activities would trigger swelling around the base of the index and middle fingers and around the thumb area, some day's bouts of shooting pains in my wrists. My fingers have also been known to 'lock' on me from time to time.

As the cold aggravated my symptoms, in the winter time I was worse. It was very dangerous to walk out in icy weather because if I were to fall I would not be able to put my hands out to protect myself, or in a heavy snowdrift I would be unable to dig my car out. This also meant it was difficult to travel to my swimming teaching job on occasions.

For almost thirteen years there were many things that I just did not attempt. We take for granted many things but I stopped pushing the trolley around the supermarket, carrying heavy jars, bottles and tins, loading the shopping in and out of the car, carrying the shopping bags from the car to the house. I stopped washing the car, filling it with petrol, lifting open the bonnet, using the air pressure gauge, changing a tyre, even opening the doors to petrol stations. Doing D.I.Y. jobs, using shears to trim back bushes in the garden or weeding went out the window too, as did putting out the wheelie bin, (though not literally!) I stopped pegging washing out on the line, chopping and peeling vegetables, whisking, beating, mashing, draining hot liquids and baking. I even had to stop carrying an umbrella, as you need to sustain a grip and maintain the height at which your arm is raised when holding an umbrella.

Needing the physical support of another person took me by surprise as it is something I had not considered the need for when out and about. When travelling on public transport I needed somebody with me so that they could get up at the correct stop for me, and then when the vehicle had actually stopped I could stand-up and alight without having to hold on and have the jerk of braking jar through my wrists. On a couple of occasions, we had to travel around London and I found using the tube was a nightmare! When going on long walks I could manage a bum bag but it is also sensible to carry a snack, water and minor first aid kit. As even a backpack would add extra pressure across my shoulders, again a person was needed to carry the bags, the same as when out shopping for gifts too, particularly at Christmas time.

Turning keys in the locks to enter and leave the home was difficult and painful and when I was out I found it extremely frustrating that I would often be unable to open the heavy doors to shops and offices. Using both hands to prise open the door a couple of inches and then stick my knee into the door using force from my leg to open the door was one way of dealing with this situation. Just having to prise open a door a couple of inches would often make me wince with pain as it would jar on my wrists, and that's not to mention what other damage was being caused to my body by contorting it in that way.

I would also forget on occasions when in supermarkets that I could not carry more than two or three items and would end up with about five or six, albeit small things, in my hand, wishing I had never decided to pick up so many things. I would then also find myself fumbling with my change.

Not being able to exert the same pressure when cleaning my teeth meant I needed regular de-scaling treatment at the dentist. I found my long curly hair became increasingly difficult for me to manage. I was unable to use a hair dryer or tongs and extremely reluctantly I had my hair cut, and much shorter than I would have liked. Only in 2007 did I find I was able to manage having long hair again.

My daily beauty routine of cleansing, toning and moisturising only happened on the odd occasion when I felt I could manage it. I suppose not wearing make-up on a daily basis was a bonus at that time. The intricate movements required in putting on make-

up caused me pain so I would use the bare minimum when on the rare occasion, I would go out. I chose clothes without fiddly buttons and that required minimum ironing. I bought slip on shoes or boots with a zip so as not to have to fiddle with laces and I bought coats with hoods for when I got caught out in the rain. I bought coats with pockets too to avoid carrying a handbag. On the odd occasion when I saw an item of clothing that I really liked, but knew would be difficult for me to fasten; I would allow my 'bloody mindedness' to kick in and then have to ask for help from a family member when I wanted to wear the item. Most days, even the early hours of the long hot summer days, I wore gloves. Letting my hands get too cold would cause them to go numb and stop them functioning altogether.

Many people like to go out and meet up socially, perhaps for a drink in a busy pub but I would have to think about that. I would need to be near a table so I could put my drink down or ask whoever I was with to hold my drink for me. If out at an event I was not able to express my appreciation in a physical manner by clapping along with the rest of the audience as this would cause me pain. Turning taps or trying to flush a toilet was extremely difficult too.

Driving a manual car was very painful yet the only thing I remained stubborn about. Though long journeys would leave me in pain for anything up to a week afterwards I continued to drive because it would have been a complete and utter loss to my independence and my sanity not to.

As an avid letter writer, I reverted to telephoning friends using a phone with a headset. Also, I had no option but to stop using a computer.

This list is not exhaustive and if just reading all this is making you rather weary, imagine what this must feel like on a daily basis, year in year out, and add on top of that, a lack of sleep...

By the time, I was about ten years down the line I had reached a point where I knew what I could reasonably do and I would push myself to the limit. If I was not careful on days when my mind was really active and I wanted my body to be the same, I would push myself so hard that I would get flare-ups that would last anything from an hour to

weeks. Why did I do this? Well, there are days when you just do not want to be dependent upon other people all the time. So, attempting jobs boosted my confidence and made me feel I was living a worthwhile existence. More often than not by this point in my life the mental feeling of accomplishment was well worth the pain of a flare-up.

A flare up would mean being back up in the high pain threshold and forced to rest. Over the next eighteen months I had about nine of these, the longest lasting for three weeks.

In November 2004, I found out about the government's warm front scheme which provides free heating, insulation and draught proofing in your home provided certain criteria are met. This scheme had been out for five years and being in receipt of DLA meant that I was eligible to receive this. Cold being an aggravator to my symptoms our home had to be kept warm. As I was at home more often at that time being on sick leave from one of my jobs this meant our heating bills increased exponentially. Had I known about this scheme earlier it would have had a great financial impact. Not only would the scheme have helped to reduce our heating bills over the previous five years, it would have also have paid for the new gas water heater which we had had to have replaced six months earlier at a cost of £500.

Despite my teno symptoms I could continue to work part-time as a swimming teacher passing additional swimming teaching qualifications along the way. In 1996 I also became treasurer for the Bradford Occupational Health Project (BOHP) remaining in that role for the next nine years. When an offshoot of the project, the Workers' Health Advice Team (WHAT) first began in 1999 I became a volunteer worker for a couple of hours a week and in 2000 I became a paid worker for a couple of hours a week as well as a volunteer.

Then at last came a time when I could type again! In April 2002, WHAT were able to offer me a few more hours paid work and I was able to resume computer work using Dragon NaturallySpeaking voice recognition software. WHAT is only a small, independent voluntary organisation, but through using the Access To Work Scheme at a nominal cost to them, they could acquire the voice recognition software for me. I

went back to college too, where using voice recognition software I completed the European Computer Driving Licence (ECDL) certificate and passed the intermediate word processing exam that I had been entered for at the time of my diagnosis seven years earlier.

The tutors at Shipley College were wonderful and could not have been more helpful. This was the only college of three that I had approached who were willing to provide me with the Dragon software, which meant that I could take any of the keyboard skill courses that I wanted to without discrimination. The college staff also gave me full support with the examination board, who, after some dispute, accepted that I could sit their exams if I had my certificate endorsed saying that I had used voice recognition software instead of a keyboard.

No longer did I have to sit and dictate while someone else typed for me. It was a wonderful feeling! Using the voice-activated software enabled me to write my short autobiography "From Hand to Mouth" which with the back-up and support of the WHAT I self-published in February 2004. I was then asked if I would recite my book for a local radio station, Bradford Community Broadcasting, BCB 106.6 FM which was broadcast as their first dedicated stand-alone programme. Having achieved all this was a boost to my confidence and when our local newspaper published an article on my book, along with a photograph of myself, I had to tell myself, 'yes, you are allowed to smile you know' - for a long time I did not believe that I was.

Out of writing my first book arose the opportunity to speak about my experience at various events. These ranged from a communication workers' union AGM to an MP's education day down in London at the House of Commons and various other employer seminars and events. I would always have an employer's angle in my talk too in order to raise awareness of RSI prevention and to make employers aware of the devastating effects of RSI, not least on family life.

I was greatly helped over the years by the dedicated, unwavering support and trust of my colleague at the WHAT. Carol whom I initially met when she was my occupational health worker/counsellor back in those early years of my teno has supported and encouraged me along the way. It was through her that I became involved with the

BOHP and started to work for the WHAT where I regained my self-esteem and confidence whilst gaining so much diverse and valuable knowledge.

Fortunately, there is an RSI support group in existence locally which became my vital lifeline for many years. Nobody questioned my RSI as the people there knew exactly what I was going through and offered a safe haven of support. During my years of recovery, the group gave me a focus, an outlet through which to vent my anger and frustrations. I chaired the group for many years until March 2007 and on behalf of the group have campaigned for the prevention of RSI's in the workplace to be put on the agenda. Yet still, in 2008 new people, often in their very early 20's come to the group with injuries that have been caused in their workplace and I am still baffled by why this is as we do not live in the prehistoric age.

In July 2007 I re-signed as a swimming teacher but remained at the WHAT a few hours a week. As part of my role at the WHAT I attended numerous local authority building consultation meetings and disability events and as they are one of the City's largest employers I would persistently bring issues to their attention to promote the prevention of RSI's in the workplace. I would also do my best to help get accessible doors, handles, keypad fobs and lever taps high on their design stage agenda.

Throughout my ten years I would see a little light go on in the head of RSI sceptics – hmm...stress, bullying, legal, compensation 'itis', hmm...and I know because I had it all thrown at me – wrong in my case. As mentioned earlier, one of the many consultants I saw diagnosed the onset of my condition to have started early in 1994 which was a good six months or more before the bullying incidents even arose but only a few months after my hours and workload had increased.

In actual fact, in 1995 the stress from the bullying resulted in an added medical condition that also lasted for several years alongside my teno. This was a condition known as temporo mandibular joint dysfunction syndrome (TMJDS). This is a condition related to the jaw. Initially my jaw was locked for ten days during which time eating, drinking, talking, yawning, teeth cleaning, etc. were all extremely painful as my mouth could only open no more than an inch. Once my jaw unlocked these problems remained difficult and painful. My face also drooped to the right by a good half inch or

so and remained drooped until being released only in recent years by my acupuncturist. During those first days prior to my diagnosis I thought I had had a stroke. This was another slow healing process...

By not taking the tablet route things may have taken a little longer but at least I never added to my physical problems. By living through the pain and anger and working through the vast frustrations and mental challenges I became a much stronger, happier, more confident person, no longer allowing myself to be bullied, rather to be politely assertive.

On the eve of Halloween in October 2006 I went over on my left ankle on an unlit kerb. The excruciating pain that seared through my body was reminiscent of my early teno days. My husband and my eldest son had to help me into casualty where I waited for my ankle to be x-rayed. Fortunately, it was not broken but the tendon right next to the ankle bone was very severely sprained. The doctor wanted me to use crutches, how on earth could I do that! Twice I explained about my teno and the reasons why there was no way I could manage if I had to rest on crutches. When I went to see the consultant three days later he said I had been advised to use crutches and said, "I see you are not, why." At the best of times many people feel intimidated when going for hospital appointments and as medics will be aware there are many disabilities which are unseen so perhaps their words could be a little more carefully chosen. Maybe I could have been asked 'have you a medical reason for not being able to use crutches?' Being in one of my more assertive moods that day, again I explained about my teno and replied politely with a smile "I see the reason has not been explained in my notes".

Whilst having to cope with my own health and well-being, life still went on, and around me were lots of other family issues for me, my children, family and friends. One of the other positive effects to come out of all those years was that I had found the courage to battle on through in adversity. All the strength and knowledge that I gained during those turbulent times helped me immensely particularly when my Mum became seriously ill.

As we found out to my Mum's cost it is never wise to sell your home to pay for care costs without first seeking out some legal advice. The government has a scheme

known as Continuing NHS Healthcare whereby all the care costs of an individual are paid for by the government if a person's primary need is health-related. In March 2007 after a long struggle to have this awarded for Mum, though sadly retrospectively, it was successful. It was very distressing for all the family as realisation dawned that had Mum been assessed initially under Continuing NHS Healthcare she would have been able to have provision in place to be cared for in her own home, never having to go into a nursing home. When that realisation along with the enormity of what had been achieved hit home, I kept bursting into tears. Not only was this success a huge thing to have achieved I went on to do it again and had Continuing NHS Healthcare awarded once more for another relative towards the end of 2007.

In 2007 I only had one flare-up, in the January, which lasted for two to three weeks and was work stress induced. After a refurbishment in my place of work I was left unable to access the building. Even though, via a consultation process prior to that refurbishment I had communicated important information in relation to my condition and equipment, still non-communication at the design stage of building refurbishment occurred. Having already been through this and worse, 12 years earlier I never expected to be put in a similar position again, and by the same employer though I can appreciate it was hard for staff to understand where I was coming from. They were not the ones living with this condition on a day to day basis and so could not possibly comprehend the pain and mental turmoil, humiliation and frustration that I was going through. Disability awareness is not about waiting for a need to occur rather it is about anticipating needs before they arise and one way of doing this is by having preventative measures in place so now here I was, struggling yet again for justice, this time regarding a situation that had been identified to my employer over a year earlier.

Happily, being a lot more clued up now after years in the voluntary sector and having the Disability Discrimination Act (DDA) to fall back on I was able to get my issues dealt with this time in order not to have to go through another grievance process, though it was touch and go there for a while. I like to think that lessons have been learnt there too.



FAMILY LIFE

In March 1999, my husband, Barry was asked to describe how my injury affected our lives. Here is part of that text - "Since Jenny was diagnosed as suffering from tenosynovitis I have had to play a large part in helping her cope with her disability, both in terms of emotional support and also assisting her with many tasks she can no longer do on her own, if at all.

During the six weeks Jenny's arms were in plaster casts I had to help her wash, wash her hair and help her get dressed. I also had to make her meals and cut up her food. She still needs help with some aspects of personal care even today. For example I frequently help her to wash her hair in order to give her scalp a good massage. She still often needs food cutting up as she cannot put enough pressure on her knife to do this herself. This can also happen whilst we are dining out.

Jenny used to carry out routine maintenance on her car, but she is now unable to even lift the bonnet of the car. She finds it impossible to open filler caps for the oil and water etc. and very difficult to operate an air pump to inflate the tyres. In addition she cannot operate a petrol pump because of the sustained grip that is required and she is also unable to open the door in order to go and pay for the petrol.

Jenny finds it difficult to carry things and can only manage to carry one or two small items in her arms but is unable to carry anything of appreciable weight in her hands. If she attempted to lift a bagful of shopping this would cause a great deal of pain, therefore Jenny is unable to go shopping alone and needs to be accompanied by another person.

Prior to Jenny's diagnosis we shared the household tasks, but since the onset of her condition, I have had to take on the lion's share of the domestic chores. As Jenny tried to do more around the house she did so with the assistance of aids. For example, she used a rubber gripper in order to help her unscrew bottle tops though she still has difficulty opening new bottles and often needs help with this.

I have also given Jenny support at medical appointments by accompanying her on all

but a few appointments in order to offer moral support, opening doors, carrying any documents she needs with her and, if necessary, to take notes.

Jenny relies on me for help with scribing and typing as since becoming ill she has had to send many letters and produce many documents in relation to her condition. Most of the burden of typing has fallen to myself, with our children helping out wherever they can. Jenny was provided with a scribe during a recent exam in order for her to update her swimming qualifications and the very large log book which had to be filled in was done by myself, as per Jenny's instructions. I also had to input her swimming record sheets on a very regular basis.

My wife has always been a fiercely independent person and finds it very difficult to be so reliant upon others. Jenny has adapted bravely and imaginatively to living with her disability but still finds it very hurtful to stand and watch whilst others carry things out for her, or has to ask someone to cut up her food.

Jenny's life has changed dramatically since getting tenosynovitis, as have those of her family. Friends too, have had to be very patient and understanding. At times the enormity of her situation has caused Jenny a great deal of anguish, particularly in the early days, when she learned that her tenosynovitis wasn't simply going to 'go away'. I have had to watch Jenny swing by turns from anger to depression and back again; making the best of the calm time in between."

It was not only me who was suffering greatly as a result of my disabling injury.

Although I continued to work as a swimming teacher throughout the years I had teno I was not able to increase my swimming teaching hours as I needed regular periods of rest. Financially things were not easy, especially with three young children. My need for regular periods of rest also meant that lost earnings could never be recuperated as working full time was no longer an option. Not only had I lost a monthly income but, as I had been advised, to pursue a compensation claim I had to make crippling legal aid payments too. As my children went into their teenage year's family treats became few and far between which would otherwise not have been the case.

Over five years after my diagnosis I did receive an out of court settlement from my employer and though it can never compensate for all the distress suffered it did feel like an acknowledgement on their part. My settlement was a quarter of my full loss of earnings up until I am 65. Never claiming incapacity benefit because I was still managing to work a few hours a week as a swimming teacher means my state pension is affected because the national insurance contributions I had made over the years I had teno fall short of the governments requirements for eligibility for that period. Lack of recognition of my teno condition meant I could not be exempt for that period either. The fact that I had been receiving DLA and IIDB during the time in question did not have any bearing on the situation. I did take this matter up with the Department of Work and Pensions (DWP) though to no avail.

After receiving the compensation, I was able to buy a car with an automatic gear box which really did help to make my life a whole lot easier. Though the compensation I received could never replace the lost years with my children. By now they were young adolescents and not into 'family' things. Adolescence is a hard-enough time for any child without the added pressure of seeing their Mum become incapacitated and all that goes along with that too.

Trying to keep the family home clean was impossible in the early stages of my teno. Things such as making beds, hoovering, dusting, cleaning windows, shampooing carpets, they all require the use of the gripping action, ironing school uniforms too.

It was an extremely hard and very upsetting time during those years and I had no choice but to relax my perfectionism. The tears I shed, many a day sat staring at the dust wondering when if ever, I was ever going to get better. My husband still had to go out to work and the children still needed to be cared for, go to school and live their lives. I really feel for my children. They had not done anything wrong so why did they have to suffer too. Missing out on treats because we did not have the money was not their fault. And just because my life seemed to have ceased somewhat that did not mean that theirs had to too.

Activities with my three children, such as going bowling, cycling, ice-skating, ball games and whatever else you can think of all became spectator sports for me, except

when on our annual holiday to Scarborough where my 'bloody mindedness' kicked in again and I would join my children in just one game of crazy golf before going home at the end of the holiday.

At that time my children were still relatively young being 13, 12 and 10 and it was really difficult for them to understand the magnitude of what was going on. What was happening to their Mum? Their Mum who was always on the go and full of life, laughing and joining in their games, now suddenly she was crumbling in front of their little eyes in heartrendingly painful sobs. In recent years, I spoke to my children about what it was like for them at that time. My daughter, Wendy told me she had felt sad that I could not play tennis with her anymore...and yes, that hurt!

When my sister, Linda and her husband Paul's children were born I really wanted to help them out by sharing their childcare with them in some way whilst they went out to work. Throughout those ten years I had to become creative and inventive to find ways around doing things. One thing I would do was to use my feet and toes instead of my hands and fingers to carry out tasks such as switching on plugs. So, I was able to look after my niece, Rebecca and my nephew, Dominic one day a week, by working out a routine which included me having duplicate baby items to save me having any weight to carry, though I could never take them out in a pushchair. Children bring me so much laughter and happiness, and fun along the way, not to mention the times that I spent with Bex and Dom helping me immensely emotionally. It meant a lot to me to be able to share in that precious time.

In May 2001, my Mum became very ill and spent many months in a community hospital before moving into care. That was a difficult time for all the family as Mum became wheelchair-bound and for me it was especially hard, as because of my teno I could not push her. It was hard seeing some of the looks I got, not to mention how that made me feel inside though I did on occasions resort to helping her out by pushing her wheelchair with my stomach.

Since my early teens, I have been involved in differing types of voluntary work so in 2002 when I was asked by the Matron of the community hospital if I would be a voluntary patient representative for the essence of care benchmarking in care for the

elderly I happily accepted. This was a government initiative by the Department of Health and it gave me the opportunity to get my teeth into something, using valuable knowledge and skills that I had but without having an adverse effect on my health. In February 2003 I attended a conference with two other colleagues where we gave a tabletop PowerPoint presentation on nutrition. I thoroughly enjoyed this role for three and a half years.

Mum spent her latter years in a nursing home and sadly passed away on the 22nd of December 2005 but her legacy remained, as being a voluntary patient representative lead on to me becoming a member of the Consumer Council for our local Primary Care Trust (PCT) until the amalgamation of the PCTs in October 2006. For 18 months around that time I was also a voluntary quality visitor for social services in the City's local care homes which involved me carrying out a monthly regulatory inspection and writing a report for the Commission for Social Care Inspections (CSCI).

Through my voluntary work with the Consumer Council I heard about the Expert Patient Programme (EPP), a course for anyone living with a long-term chronic health condition, which teaches you ways in which to manage your condition on all levels. This is a free 15-hour course spread over a period of six weeks. I self-referred and attended a course in October 2005, the best I had ever been on. A lot of the techniques taught on the EPP were similar to my own as I had already learnt ways of managing my long-term chronic health condition on a day-to-day basis but still I gained so much, as their techniques richly enhanced my own. The skills I learnt enabled me to prioritise how I planned my life. It took my confidence level up yet another notch and I walked out of those sessions 'walking on air'. It was very, very empowering.

One beauty of the course for me was that it was not disease specific. So instead of getting 'bogged' down in your own condition, it concentrated on the core problems experienced by everyone so that huge benefit was gained by both the participants and the tutors. The realisation that the core problems of my condition, i.e. fatigue, stress, shortness of breath, pain, itching, anger, depression and sleep problems were common to other chronic health conditions was astonishing – it was so obvious yet I had not thought of it like that before. This realisation in turn opened up my mind to a whole range of other areas and ideas that would help me. It made me think outside

the box.

Even years after my diagnosis, scepticism still prevailed around my condition. The EPP made me finally accept that my chronic health condition was as relevant as anyone else's. I realised how far I had come when everything I had learnt for myself was backed up by the course. I gained great emotional positivity and was in good shape mentally. It put a whole new perspective on everything in a way that I never imagined it could. I am fortunate in having a very good support network of family and friends, and the EPP strengthened these relationships. There was lots of fun and laughter too which has to be a must in anyone's healing process. I had accomplished so much from attending the EPP, a positively powerful course which is available to anyone living with a long term chronic health condition. By making others who live with one of these conditions aware of the EPP it will mean that others will not have to learn the hard way as I did.

At the same time as attending the EPP and after about five years of deliberating whether I would be able to manage it or not Barry and I joined a Salsa class. For the first six months or so until my strength and stamina was regained it would leave me feeling very tired with achy arms and hands, and my fingers would throb but as dancing also releases those 'feel good' endorphins the effects were short lived. Although we had to modify the hand holds, particularly for spin turns I greatly enjoyed the classes, had lots of fun and what a great feeling it was to have some excitement in my life again.

By the end of 2005 my humour had returned – and more!



RECOVERY

The beginning of the turning point in my very slow recovery came after getting the right help from the Professor in rheumatology in 2000, five years after my diagnosis. Knowing that I had instinctively been doing the right things myself through trial and error during those years was a big boost to my morale.

I chose to use a more natural route back to health and I found many of the complimentary medicines to be of great help; again, it was trial and error. Always on the lookout for anything that I thought might help to release me of my teno symptoms I would go to complimentary medicine festivals and mind, body, spirit events around Yorkshire. I find these great places to visit to get a good look at what therapies are around and maybe sample one or two, as often the practitioners will give taster sessions for a nominal fee. Whatever I feel drawn to try is usually the right thing for me at that time. Feeling comfortable with the practitioner and feeling a benefit from a therapy is my gauge as to how well something works. It will also depend on where I am at emotionally at the time.

Towards the end of 2003 a friend recommended a fantastic Japanese acupuncturist and although the method she uses, felt to me quite torturous, it works! As it was quite expensive for me at that time I could not go too often but it was not long before I knew that if I could keep going as many times as I needed whether that be 10, 100 or a 1000 times I would see an improvement. Although my doctor also offers acupuncture on the NHS unfortunately PCT funding does not allow him to give unconditional amounts of treatment. As a client, I feel this is one of the ways in which I was very badly let down by the NHS. Having the correct treatment on the NHS via access to ANT physiotherapy and unconditional acupuncture sessions, amongst others forms of treatment in the beginning would have prevented many of my years of suffering.

Having had those few sessions of acupuncture with my doctor in the very beginning and spurred on by the effects of the EPP I returned to my doctor at the end of 2005 with a request for more acupuncture sessions as backup alongside the sessions I was paying for. I was able to have a few more sessions and the difference those started to make became apparent when the sessions stopped. To me however, it proved that

I was doing the right thing. Something the EPP taught me was - who's the Expert Patient? You are! Who lives daily with your condition, who knows your condition best? You do! So, unless you can have the correct amount of treatment, until you either recover or reach your best possible outcome it becomes nonsense, neither is it cost effective.

During 2006 I participated in a six-month period of research on Enabling or Disabling Governance which was jointly funded by the Economic and Social Research Council and the Office of the Deputy Prime Minister. A 20,000-word report is to be produced on this. After all the researcher's extremely hard work I hope that the government will respond to the findings of this research appropriately in policy and practice.

The research involved me taping a daily diary on cassette then every fortnight I would receive a phone call from the researcher to discuss any issues, questions or problems either of us might have. She would also check that I was coping with the process.

This daily diary was a fabulous way of offloading and regularly dealing with issues as they arose. I remember saying at the beginning of the research that it may even help me along in my healing process. Indeed, it did. I am proud to have been part of that research project about disability issues and knowing I had an obligation to someone else meant I was committed to staying the course, it was a good feeling and well worth doing.

Still searching for anything that I thought might help to release me of my teno symptoms it was during the time of this research that I found bio-mechanics. It was whilst watching Wimbledon on TV in the summer of 2006 that it made me think, how were athletes able to go back to work within a matter of weeks after sustaining severe strain injuries like mine? One tennis player was talking about having had tendonitis and yet, two months later, here she was actually playing again. I wondered how that worked - regular sessions of intensive forms of physiotherapy perhaps but paid for by whom.

I began to wonder why I had never thought to look at sporting injury treatments before and guessed it was probably because of where I was at emotionally and financially.

Strangely within a matter of days of watching that Wimbledon the same friend of mine who had told me about the acupuncture told me about a chap who does bio-mechanics. What was that? I looked it up on the internet and it appeared to be a treatment people with sporting injuries would use. On thinking about it for a moment, sports people are back up and with the programme within a very short space of time so how come after more than 11 years I was not?

Bio-mechanics is a form of manipulation that works with your muscles and soft muscle tissue via the central nervous system which is where I had always felt the core damage was initially done. I wondered why bio-mechanics not been suggested to me by anyone I had seen in the medical profession. Did the NHS not provide such a service - I later found out that apparently, they do but as is often the case within the NHS people do not know the service exists and not everybody can access it.

I had just one treatment of bio-mechanics at the end of July 2006 and six months later the effects were still apparent. My circulation was vastly improved and whilst I still needed to wear my gloves my hands would not get as cold as they had previously. Other symptoms I had suffered with throughout, like migraines and vertigo all ceased after that first session too and a headache is now a non-occurrence. Even my doctor asked me for the chap's number as he wanted to recommend him to a patient or two.

During the following ten months, I proceeded to have various holistic treatments alongside the acupuncture.

In recent years as I became aware that my body did know how to heal itself I really started to listen to it and slowly but surely, I learnt not only how to, but to act upon my body's needs particularly when it wanted to rest. I learnt how to distinguish 'pain' pain from 'fatigue' pain.

By September 2006 I was physically able to take on a few more swimming teaching hours which meant that as I had a little more money coming in I was able to seek out more holistic treatments. At the end of January 2007 I started seeing a naturopath to help me with my weight. I was surprised to find that the nutritional diet advice she gave would also help my terno swelling and inflammation too as there are certain foods

that aggravate these symptoms and by eliminating them from my diet my body would benefit greatly. She also administered a herbal mix for my teno symptoms which meant that along with everything else I was doing I was now treating my body in a holistic manner. Over the following year, I managed to lose more than two stones in weight with the added bonus of feeling much healthier and in far less pain.

I had tried Reiki healing in the past and got nothing from it but at the end of April 2007 I came across Seichem Reiki with Quantum touch and had a mega two-hour session. This was powerful stuff! I happened to be already booked in for a second session of bio-mechanics the following week too.

At that second bio-mechanics session when speaking about the rehabilitation process that I had been going through I was told to carry on as I was doing as I was showing quite a marked improvement since my first visit a year earlier. It was suggested that I could now try to start using stress balls to exercise my hands too. We spoke about my work and how I loved teaching children; seeing their little faces when they finally swim on their own unaided is priceless. But whilst swimming teaching was also very good for my morale during my teno years, I was told that in actual fact the hot humid, atmospheric environment would have exacerbated my condition.

A week later I had another mega two-hour session of the Seichem Reiki with Quantum touch and I decided that I would like to do the Seichem Reiki level I course myself. I did this at the beginning of July 2007 and a week later I was amazed by the improvement in my condition, and how good I was feeling. And nobody was more shocked than me.

I suddenly realised that my right forefinger which had been hooked since my diagnosis could now move freely. I could actually push it back with no pain or after effects. I could get my fingers round my wrists and I seemed to have my grip back too...

I never said anything to anyone, hardly daring to believe it but a week later when it was still the same I told Barry. Three weeks later I told my acupuncturist and she said 'you are not dreaming!' Although I still had right elbow, bicep and shoulder pain troubles this was an amazing improvement in my condition, so I went to see my doctor.

Whilst pleased he was also wary that I take things very slowly. Though I was still not attempting lots of tasks, I now knew that in time I would. As we went into the colder months I did not reach for the gloves until mid-November and then I did not need them constantly. It was at this stage that I knew I was on the road to recovery - I CAN DO IT! After all, it is what I would always say to the children at swimming...

In October 2007 after giving another talk on RSI, where incidentally I was very pleased to have produced my very first PowerPoint presentation too, I suddenly realised that I had more than likely been living with a twisted spine since the day my neck had been put in traction way back at that physiotherapy session in 1995 and that the bio-mechanics spinal MOT in July 2006 had put that back to rights.

No longer having a disability, at the end of 2007 I contacted the DWP to cancel my DLA. Wow, what a statement!

The bulk of my recovery process happened through my own tenacity of spirit by choosing to follow the holistic route in using a combination of holistic treatments. Apart from my doctor and counsellor, the Professor at LGI and the EPP course I had very little actual physical support from the NHS. There is no centre of excellence for the treatment of RSI in the UK. So, my road back to health was successful despite a lack of physical help from 'health'. Although my doctor is extremely good and capable, he was not backed up with resources from the PCT to enable him to give me the full all round support that I had needed to aid my recovery. It is such a pity that we are not allowed the opportunity, even though we mandatory pay into the system via national insurance contributions, to heal holistically through our NHS.

Nobody in the medical profession ever putting a timescale on when my injury would, if ever, get better meant that mentally accepting those things that I could no longer do was one of the hardest things for me to have to endure during all those teno years. Asking for help was a massive blow to my independence and at times when that help could not be forthcoming for whatever reason, I had no choice but to accept that fact. But knowledge and the mind are powerful things. When people say, things are all in the mind, in one sense I feel this can be said to be true, though never forget that excruciating pain is agonisingly real. Because nobody ever told me, 'it will go', I had

in my mindset that I was disabled and never going to get better. I do not know at what point it was along the way but once I changed that mindset to one of a positive nature regarding my condition then things really started to shift. Maybe it was listening to the tennis players...

Whilst sad to now have left the WHAT I am also happy to be moving onto a new phase in my life. I am taking a much-needed sabbatical, after which as a practitioner in Seichem Reiki healing now myself, I will use this healing for others wherever my path in life leads me.

This time around it is a good feeling knowing that my book has been written using a mixture of voice recognition software and keyboard use. All the countless and varied new skills I have learnt during my time at the WHAT along with many fond memories will always stay with me. I have met many wonderful people along the way in the voluntary sector, many who share my enthusiasm and passion for a cause, not least the members of the Disabled Peoples Forum (DPF), a group run by and for disabled people, who raise awareness of disability issues through a collective 'Stronger Voice'.



HEALING

My dear friend, Christine, recommended a book to me around the time of my diagnosis, 'You Can Heal Your Life' by Louise L Hay. A couple of years later I eventually went out and bought this amazing book. To me Louise is the Master of All in the self-help field. Her story and continued success is an inspiration to us all. For many years, her book was my companion, always near my side but it was taking me an awful long time to break out of my spaghetti tangle. Slowly but surely as I started to 'see' she became my inspiration for the writing of "From Hand To Mouth". I CAN DO IT! I sent Louise a copy of my book after I published it and was SO thrilled to receive a reply from her. I will always treasure her letter.

I had known for around 15-20 years now that I was supposed to be working in some sort of healing career helping others yet I could not see how I could ever do that when I was in need of such great healing for myself. How could my hands be channelled to become healing hands when they were in so much constant pain, surely that would not help others. When in April 2007 I so desperately wanted to be able to support my family and friends through their healing processes I finally found the right people to help and I went on to take the Seichem Reiki courses myself. From then on everything turned around at a fast pace and in helping others I have in turn been able to help myself to heal too.

It is my belief that our bodies do know how to heal themselves. As I accepted that I deserved to be well my life became free from depression and pain. Although the slightest thing could set me back I persevered in finding a way through my 'dis-ease'.

People ask me what I think has brought about my healing. It was not any one thing in particular rather it has been an combination of everything from my early counselling sessions and my referral to the Professor in rheumatology along with my holistic approach in using Louise L Hay's self-help books and tapes; to finding and using the complementary therapies of reflexology, acupuncture, bio-mechanics, naturopathy, Seichem Reiki with Quantum touch; to using toning table exercises adapted to suit my needs; to attending the EPP and being involved in the research project which both played a large part towards my mental recovery; onto the Seichem Reiki levels I and

II to the ThetaHealing DNA 1 & 2 and ThetaHealing 3 & 4 advanced courses that I have taken.

Also, silent help from a friend; as for many years after my diagnosis I would on occasions think about that friend of mine who had been diagnosed with multiple sclerosis and who no longer had the 'dis-ease'. I would often ask myself, 'wow what did she do?' and felt myself that if she could do that, so could I. Reading in books about people healing themselves of serious and even life threatening illnesses is one thing however actually knowing of someone in person is quite another. It was always there floating around in my head, if she could rid herself of multiple sclerosis then I could surely be rid of my teno. I know that she used various holistic treatments however I often wondered how she had cured herself. Now I know.



CONCLUSION

Before I had RSI, I was a strong, extremely independent, self-confident and out-going person, on the go morning, noon and night. After diagnosis, I found coming to terms with the gravity of my condition a struggle. In years to come the devastating effects of living with my RSI condition affected all areas of my life. Physically I experienced constant debilitating pain which limited the choices I could make in my life. The severity of my condition created a need for dependency on others which restricted my independence. The emotional and mental anguish which accompanies a RSI affected my relationships with family and friends, and made it hard for me to cope with everyday life. The practicalities of running a family home became difficult and financially life was a struggle. All I had ever done was work hard. Yet had health and safety regulations been adhered to in my place of work my RSI could have been prevented.

I became crushed inside and was really lost for a while during the thirteen years I had my RSI. Yet I found the courage to battle on through in adversity focusing on my recovery and raising awareness nationally of RSI's. Despite tireless campaigning over the years however, RSI's remain prevalent in the workplace today.

People ask me what I think has brought about my recovery. It was not any one thing in particular. Physically I learnt to listen to my body and act upon my body's needs. Mentally, I changed my mindset from thinking I was disabled and never going to get better, to believing that I could get well. Practically my recovery was down to perseverance and my own instigation as I stumbled, through trial and error, in finding various treatments that aided my recovery. As there is no centre of excellence for the treatment of RSI in the UK my road back to health was successful despite the lack of a full treatment programme from the NHS.

I would on occasions think about that friend of mine who had been diagnosed with multiple sclerosis knowing that she used various holistic treatments and often wondered how she had healed herself. Having used a combination of holistic treatments myself, now I know it is possible to recover. 'I DID IT!'



EPILOGUE

By early 2008 I was filling my own petrol tank again, ha ha ha...trivial I know, but massively exciting for me. I have even cut back the bushes in my garden using the garden shears and done some D.I.Y. - painted my front door. I can fasten buttons again and I am able to wear anything that I like so even my femininity is back! At last I have my hair long again which really makes me feel good. Now people I meet comment on how great I look. I feel great, ten feet tall.

Before my teno, my life was full of sporty, energetic activities and though it was a long time in coming it is now Fantastic to have my hands back. I now live free from persistent pain and instead I have tears of joy and laughter as my whole body has come back to life. I no longer just exist. And now I have my exciting, thrilling, exhilarating life back I want to live it. Recently I passed the PADI scuba diver course and I am currently on the verge of completing the open water diver course and all that this has entailed, not to mention the boost it has given to my inner confidence - you just cannot imagine how good that feels; skiing course next... And recently travelling alone meant I had to negotiate mini-buses, airports and planes managing a suitcase and laptop on my own, 'I DID IT!'

Throughout all the turbulent times back there I am fortunate that I was still able to give my children, Paul, Wendy and Nicky my love and I am SO immensely proud that they have all come through this period in their lives to become wonderful, beautiful, loving adults who I love very much. Over the years when they were a young age, particularly during their early teens I, and they, missed out on so much by my not being able to participate in all of the fun activities and games they played, so imagine my delight, when in November of 2007 I was able to join in fully at Bex and Dom's birthday parties. I was so 'chuffed' with myself for roller-blading! And **THE VERY BEST OF ALL**, as we glided round the floor; Holding the hand of my daughter Wendy!

AFTERWORD

2017

Out of writing my first book arose the opportunity to speak about my experience at various events. I would always have an employer's angle in my talk to raise awareness of RSI prevention and to make employers aware of the devastating effects of RSI, not least on family life.

Twenty-two years on since that diagnosis, even after having given a talk at an MP's education day in 2004 at the House of Commons where there were over 50 attendees I am astounded that RSI's caused in the workplace continue to be diagnosed, and after all the knowledge that we have, preventative measures are still eluding some workplaces.

My experiences, not only of my 'teno' year's but of recent years' challenges not being addressed by the NHS and governmental bodies / 'services', I believe, shows an even greater need than ever for a holistic approach to well-being being adopted in this country. One where all medical and natural healing practitioners work alongside each other in unison for the greater good of the mental health and wellbeing of the client.

On a personal level I have gone from strength to strength in being able to 'goffer', 'gaffer, labourer on house renovation – loved it! My first time ever in this field bringing out 'untapped' interior design creativity; a mass of new DIY skills gained; helped provide paid work for 6 young people and gave me the satisfaction of knowing that I have well and truly healed the 'teno'.





WORKPLACE

The added stress of bullying was certainly an aggravating factor that undoubtedly did not help my RSI but that was caused purely by the very bad ergonomic set-up of my work station. Everything was amiss from the heating, to lighting, space, furniture, lack of certain items of equipment, oh and minimal training.

A Workplace Foundation report published in the autumn of 2007 seemed to advocate that people need to get back to into work as soon as possible after illness or injury, 'work is good for you' they say. Whilst I would not disagree that keeping your mind active and staying mentally alert can be a good thing and that it could be argued that possibly there might be a case for certain types of employees to be in work, employers do need to be very careful about the actual situation that they will be placing an already injured employee back in to, as these photographs show.



The office that I worked in had intimate space that was used by up to four people at any one time and there were numerous untold Health & Safety hazards in there too. Though these photographs only show my workstation after my diagnosis when the cupboard and desk had been switched around, they do show the height at which I had been working with a mouse! As you can see there is no support there for the elbow, so with my arm in suspension, the height at which I had been working with a mouse was the likely cause of my hooked right forefinger.

The office window had a one inch gap between it and the outside wall which meant that I regularly worked in a draught with frozen hands and fingers and my jacket wrapped around my knees. With everything in the office still as cramped as before, all that switching the cupboard and desk around would have done for me, would have been to take me out of the draught. There was no mention of fixing the problem with the window. I was later told that working in these cold conditions meant that there would have been no circulation getting through to my wrists, hands and fingers so it was no wonder no end of untold damage could occur.

Why did I work in these conditions - I had only just learnt to type, what did I know about computers? So, I worked in these conditions because I was never given any health & safety training regarding the use of computer equipment, ergonomics, breaks or a variation of tasks. Without this very basic training I could not possibly know any different at that time.

I hope the memory of those photographs stay with you, and that if you are an employer that it will make you stop and think for just one minute when staff come to you with concerns relating to their work, equipment or the slightest of aches or pains about what you might say and do for them. Do not let others suffer. RSI starts very simply with little things like dropsy or simply saying my hands hurt but the pain is very real and prevention **is** the only answer!

TENO HANDS



AFTER TENO





RSI IN THE WORKPLACE IS PREVENTABLE

Nowadays, people are a little more accepting of RSI's in that at least they may have heard of these conditions. When I was diagnosed thirteen years ago, nobody really knew what RSI was, even though it has been around for many years within the factory and manual labour force.

The crazy, scary part for me on finding out that I had an RSI caused by computer use was that **nobody** need even develop these injuries through their work and whilst I know things have improved since 1995 there is still an awful long way to go yet. One of my consultants remarked, back in 1995, that "these injuries ought not to be occurring as we approach the 21st century".

So, I am amazed, and I still find it hard to comprehend that even now after all these years there are still many employers out there who just 'do not get it'. I like to tell it how it is and it does not have to be like this. Everything I have written, about how my disabling teno affected not only me but my entire family and support network need never have happened. It is time employers stopped blaming the work force and 'got with the programme'.

Employers have a duty of care so it is vitally important that they ensure that their employees feel at ease in their place of work and that they feel safe to speak their minds when discussing work related issues without any pressures of feeling intimidated, bullied, guilty or 'sent to Coventry', and yes, being sent to Coventry still goes on in the workplace even today, as we know only too well from our experience at WHAT. Disturbingly, as late as October 2007, a HM Revenue & Customs staff survey said that only one in five employees feel it safe to speak their minds at work. Only this year in 2008 did I take a call from someone who has worked for one of the country's largest employers for five years, the second person from that same company with RSI to ring within two months, who didn't know anything about Access to Work nor did they even know what an accident book was!

With all the technology, there is today there are no excuses. Instead of blaming the workforce it is far better to treat the workplace as 'sick', rather than the worker. There

are a number of different systems and equipment which can be better used in today's workplaces. Ergo Sentry for instance, which physically stops you from using the computer for a set period of time, and even gives you exercises to do in the interim. These days' voice recognition software is a lot more usable, accurate and compatible with more office applications, making this a fantastic option. As voice software is quite specialised it is well worth investing in training from a specialist company to ensure that all the correct systems are put in place. There are also improvements to hardware such as ergonomic keyboards and mice. Technology is advancing all the time and there is no reason why manufacturers could not make every single piece of equipment ergonomic as standard. Doing this will also minimise the risk to the future working generation, our children.

In today's world, children are heavy users of VDU equipment and risk permanent painful injury using computers that are set up for adults. A lot of teachers and parents still seem unaware of the dangers in schools and homes with relation to the ergonomic set up of their children's workstations. RSI's are a particular risk to children as their muscles and bones are still developing.

In my earlier book, I wrote about Professor Peter Buckle of the Robens Centre for Health Ergonomics at the University of Surrey who says there are some measures put in place to minimise adult risk but little attention is paid to students and schoolchildren. He says field research involving more than 2,000 youngsters show 36% of 11 to 14 year olds are suffering serious ongoing back pain and that children who suffer back pain at school are more likely to suffer in adult working life, therefore the current picture of children working in systems that appear to affect current and future health is a disturbing one. I personally would add that constant texting and mobile phone use pose a risk too not to mention today's game boys, Nintendo DS and Wii Consoles, fun as they are.

Crippling our children of the future need not happen. By applying the principles of ergonomics at the design stage of new technological equipment for use in the classroom it will minimise the risk to children. At the very minimum, basic typing skills and health and safety regulations on the use of computers and computer equipment ought to be taught as mandatory along with the three R's on the school curriculum.

The government have put minimal legislation in place to tackle the RSI issue and could do a whole lot more by enforcing activity under the Display Screen Equipment (DSE) regulations. Our children have a right to work in a safe and healthy environment.

Employers will have a happy, healthy, stress free workforce in their company or organisation when they put preventative ergonomic measures in place for all their employees in the first instance. It will make a difference. As will giving employees the opportunity to voice their opinions openly and honestly. Following through with proper feedback and the correct backing if somebody asks for certain types of equipment or training or asks for a specific issue to be resolved will save not only time and money but wear and tear on employee's health too. As an employee taking the correct breaks and having a variation of tasks within your job will help towards making you feel more comfortable in the workplace. The use of qualified risk assessors is very important too. There is absolutely no point in an employee carrying out their own risk assessment if they do not know what they are looking for. In following the European directives by keeping working hours in the week short it will enable employers to get more out of their workers resulting in a more productive workforce.

It is the workers on the shop floor who actually do the work and work with the equipment so it is extremely important for the worker not to be bypassed. Workers actually do need to be included in any kind of surveys or planning meetings that happen when employers are looking at revamping or opening completely new sections of business. **Consultation is a two-way process** – not a means for the employer to tell the employee what they have done.

One hard lesson I had to learn, when we had very little money coming in, is one I am sure employers can learn from too and that is 'that at the end of the day it is not the cost but your health that matters'. Money over health does not equate. My payment was a drop in the ocean to my employer and though many people fall by the wayside which lets many companies off the hook, even today firms are still paying out on RSI claims. If preventative measures in the workplace are adopted, then compensation claims will become a thing of the past saving millions of pounds. Believe me, though it is their right, nobody relishes the thought of having to pursue these emotionally difficult and traumatic, long winded claims. As for me it was never about the money.

If it was I would have given up long ago, not relentlessly strived throughout my ten years in pursuing for best practice and RSI prevention to occur for the highest and best good of both employees and employers across the country.

Instead of looking in the short term financially I would like to see employers, educationalists, the NHS and the government looking to the long-term. By spending more initially on getting things right it will then be financially viable in the long-term, not to mention the dramatic effect that it will have on the health of the nation's workforce. The government would also see a massive reduction in sickness absence statistics; seems common sense to me...



WHAT IS RSI?

RSI stands for Repetitive Strain Injury. It is a term used to describe a range of painful conditions which affect the musculo-skeletal system, i.e. the muscles, tendons, tendon sheaths, joints and nerves. Many researchers now suggest that RSI is a misleading term for these conditions as repetitive movements may not be the most important risk factor. There is also a lot of controversy about the term arising from some well-publicised statements that RSI does not exist. The term Work Related Upper Limb Disorders (WRULDs) is often used as an alternative. However, this is not an ideal term either as the lower limbs may also be affected. Our group use the term RSI as we believe that people are more familiar with this name.

RSI covers a number of different conditions affecting the musculo-skeletal system although there is disagreement amongst the medical profession about what ought to be included under this general definition. However, it is now generally accepted that RSI falls into two broad categories, although these may overlap. These are

- localised conditions
- diffuse conditions

Some of the most common localised conditions are;

- Tenosynovitis
- Tendonitis
- Bursitis
- Carpal tunnel syndrome

Localised conditions have a specific medical name, are better understood and can be diagnosed relatively easily. They are usually confined to one part of the body and the symptoms are experienced in that area only. Inflammation may be present. The conditions can be grouped as follows: those involving inflammation of the muscles, muscle-tendon junctions or associated tissue (e.g. tenosynovitis); those involving inflammation of the tissues of the hand, elbow or knee (e.g. bursitis); those involving compression of the nerve (e.g. carpal tunnel syndrome); and those involving fatigue of muscles because of excessive load or awkward posture.

Diffuse conditions are less localised and may spread through several areas of the body. They are much less well understood and may be hard to diagnose. They are often associated with intensive keyboard work. They are characterised by pain, muscle discomfort, burning and tingling sensations. Because the symptoms are diffuse it may be difficult to identify the site of the problem. There may be no clearly visible injury.

HOW DO I KNOW IF I HAVE SYMPTOMS OF RSI?

Symptoms of RSI include;

- pain
- numbness
- swelling
- muscle weakness, e.g., inability to grip objects firmly
- crackling in the joints (crepitus)
- tenderness
- pins and needles
- loss of or restricted movement

RSI involves progressive, long-term conditions characterised by three stages (although the symptoms experienced by each individual do not necessarily fit exactly the pattern outlined here):

Stage 1 (Mild) Pain, aching and tiredness of the wrists, arms, shoulders or neck during work, which improves overnight. This stage may last weeks or months, but is reversible (threatened overuse injury).

Stage 2 (Moderate) Recurrent pain, aching and tiredness occur earlier in the working day. Persist at night and may disturb sleep. Physical signs may be visible, such as swelling of tendon areas. This stage may last several months.

Stage 3 (Severe) Pain, aching, weakness and fatigue are experienced even when resting completely. Sleep is often disturbed and the sufferer may be unable to carry out even light tasks at home or work. This stage may last for months or years. Sometimes it is irreversible and full use of the affected part is never regained (established overuse injury).



WHAT CAN I DO IF I SUFFER FROM RSI?

Because it is the soft muscle tissue that is affected with RSI's, having seen consultants both in orthopaedics and rheumatology my personal opinion and advice about where to get the right help if suffering from an RSI, is to get a referral through the rheumatology route in the first instance. Ask lots of questions and seek out the correct treatment for your diagnosed condition as early as possible. Try to find out how health and safety is organised in your workplace and what the arrangements are for raising health and safety issues. If your place of work has a union safety representative speak to them and make sure that your injury is recorded in the accident book.

Your employer has a duty to consult employees about health and safety matters. There are different regulations according to whether there is a recognised trade union in your workplace or not. Where there is a recognised trade union members have a right to elect union safety representatives. These representatives have wide ranging legal rights under the Safety Representatives and Safety Committees Regulations, including the right to be consulted on health and safety matters which affect their members. If there is no union the employer must still consult employees under the Health and Safety (Consultation with Employees) Regulations. This may be done directly or through representatives elected by staff.

Make sure you know who your representative is and that you use him or her. If there is no representative, try to ensure that one is elected. They don't have to be a technical expert. You want someone who is enthusiastic and who employees will trust. You can have an input into the process and be able to raise health and safety issues which concern you. If you do have a trade union safety representative, you are in a stronger position because they have legal rights to take matters up on your behalf. Union safety representatives have legal rights under the Safety Representatives and Safety Committees Regulations;

- to be consulted about any health and safety matter including any proposed changes in the workplace and the health and safety training of employees
- to investigate potential hazards in the workplace
- to investigate complaints by employees about health and safety

- to make representations to the employer
- to inspect the workplace at least every three months
- to inspect health and safety documents held by the employer
- to inspect accidents in the workplace
- to represent members in consultations with HSE inspectors
- to receive information from inspectors
- to attend meetings of safety committee
- to paid time off to perform functions
- to paid time off for health and safety training
- to facilities from employer to perform functions

Find out if there is an occupational health department and whether or not your employer offers a fast track physiotherapy service. Find out what adjustments could be made in your place of work to better able you to continue in your role, involving the Access To Work scheme who you can contact via your local job centre.

EXERCISES TO PREVENT HEALTH PROBLEMS FROM VDU USE

Sitting at a VDU workstation all day can be hard on a body however simple exercises can prevent stiffness and help to maintain good circulation. The exercises shown below are best carried out regularly throughout the day to prevent the onset of fatigue and aches and pains.

1) Warm Up

Just before starting work flex the fingers and wrists. Rub your hands together to warm up the muscles.

2) Lateral Neck Rotation

Face straight ahead; *slowly and keeping control*, turn the head to the left, holding there for a count of five. Slowly turn the head to the right and hold there for the count of five. Slowly return to the central position and drop the chin to the chest, holding there for a count of five. Raise the head and repeat the process.

3) Shoulder Shrugs

Slowly and keeping control, raise and lower the shoulders, trying not to compress the neck.

4) Seated Calf Raises

Raise both heels whilst seated, holding for a count of five. Relax and repeat.

5) Arms

Reach the arms up straight over the head and stretch. Repeat.

6) Back

Move slightly forward on the chair, then straighten up raising your chest upwards and out. Hold for a few seconds and then relax. Repeat.

7) Wrists and Hands

Flex and rotate the wrists, spreading the fingers wide. Repeat.

8) Eyes

Make sure that you do not forget to blink whilst staring at the screen otherwise the eyes will become dry. To exercise your eye muscles and prevent eye strain, regularly look away from the screen and focus on an object in the far distance which is either at the extremes of the workplace or outside if possible.



ABOUT THE AUTHOR

Jenny Tollinton holds varying qualifications across the teaching, mental health and voluntary sectors in the UK. The author of '*From Hand To Mouth*' ISBN: 0-9547113-0-0; '*Because Mental Health Matters*' article; and '*Coming Out Of The Spiritual Closet*' #emergingproud blog.

A teacher, writer, healing channel, Jenny is the owner of BELIEVE Holistic Therapies / PosiTone® - SoulStar Cards, where she practices as an Intuitive Soul Coach and Guide / Specialised Exercise Coach; Swimming Teacher; Energy Healing / Reiki Seichem Practitioner; and Ear Candling Therapist.

Jenny believes so much damage is done in society by misunderstandings. In recent years, experiencing more personal challenges that saw both her and loved ones' encounter stigma, abuse, apathy, condemnation, homelessness, foodbanks, debt...amongst the harrowing process of being caught in a 'health system' where the true nature of how 'labels', 'illness' and 'dis'-ease impact upon our mental health and well-being are often misunderstood at the core root level. Wondering why, as certain conditions are recognised by society as 'illness / dis'-ease', why then does the 'system' condemn those whom have been 'labelled' as such.

One key area of concern she believes to be is a lack of training in the fundamental basics of mental health first aid. She feels that not only both her and loved one's experiences, but that of the masses show a great need for a holistic approach as paramount for everyone's health and well-being and looks forward to the day 'services' unite in offering a quality, continuity of care for all.

www.positone.co.uk



FURTHER READING

Self-Publications (not for profit)

“From Hand To Mouth” by Jenny Collins, written using voice-activated software is a short autobiography of personal experience of living with RSI and was written to help people better understand the nature of debilitating injury from computer use. **ISBN 0-9547113-0-0**

Hazards Publications

RSI Hazards Handbook November 1996

VDU Work and the Hazards to Health. August 1993

London Hazards Centre, Hampstead Town Hall Centre, 213 Haverstock Hill, London NW3 4QP

Tel: **0207 794 5999**

Labour Research Department Publications

RSI: A Trade Unionist's Guide Feb 2000

LRD Publications, 78 Blackfriars Road, London SE1 8HF Tel: **020 7928 3649**

TUC publications

TUC Guide to Assessing WRULDs Risks Dr Peter Buckle & Joanne Hoffman, University of Surrey

TUC Guide to Litigating WRULDs Cases TUC and the Association of Personal Injury Lawyers

TUC WRULDs Campaign Pack

Work-Related Upper Limb Disorders Conference Report, July 1993

Treatment for Upper Limb Disorder Sufferers Conference Report May 1994

TUC Publications, Congress House, Gt Russell St, London, WC1B 3LS Tel: **020 7636 4030**

Trade Union publications

Most unions now have a publication on RSI. Here are some of the latest publications:

RSI Hazards Handbook UNISON, 1997

Physiotherapy and Repetitive Strain Injury CSP, 1992

Work Related Upper Limb Disorders USDAW, 1992

Repetitive Strain Injury - a TGWU Guide TGWU, 1992

Work with Display Screen Equipment NCU, 1992

HSE publications

Working with VDUs (free leaflet) IND (G) 36(L)

Work Related Upper Limb Disorders - a guide to prevention 1990

Understanding Ergonomics at Work (free leaflet) IND (G) 90 (Rev2)

Seating at Work

Upper limb disorders in the workplace (02)

HSE Books, PO Box 1999, Sudbury, Suffolk, CO10 6FS Tel: **01787 881165**

Free leaflets can be downloaded from **HSE** website on www.hse.gov.uk

CONTACTS

Disabled People's Forum Tel: **07807 593248** www.disabledpf.org.uk

Bradford Resource Centre (BRC)

17-21 Chapel Street, Bradford, BD1 5DT Tel: **01274 779003**

Bradford Law Centre

31 Manor Row, Bradford BD1 4PS Tel: **01274 306617**

VoicePower

Tel: **01423 870476** <http://voicepower.co.uk/> info@voicepower.co.uk

Manchester Hazards (RSI Support)

Windrush Millennium Centre, 70 Alexandra Road, Moss Side, M16 7WD Tel: **0161 636 7557**

RSIAction...

PO Box 173, Royston, Herts, SG8 0WT www.RSIAction.org.uk – info@RSIAction.org.uk

Disabled Living Foundation

380-384 Harrow Road, London, W9 2HU Tel: **020 7289 611**

Access To Work Tel: **0113 2142355**

Job Centre Plus www.jobcentreplus.gov.uk

Health and Safety Executive Regional Office

Marshalls Mill, Marshall Street, Leeds, LS11 9YJ Tel: **0113 283 4200**

HSE Information Line Tel: **08701 545500**

The Ergonomics Society

Devonshire House, Devonshire Square, Loughborough, Leics LE11 3DW Tel: **01509 234904**

Pristine Conditions www.pristinecondition.com

Acupuncture Yoshiko Urquhart Tel: **01423 561428**

Bio-mechanics Peter Jamshidi Tel: **07949 903160**

Louise L Hay www.louisehay.com