**Workshop Diary by TW participant – Sue Gaskell**

**Week 1 of the M.E. Wellness Workshop February 26th 2016**

**ME BASICS – THE TREE**

I awoke feeling tired after a reasonable nights sleep. Today I am hoping that the effort it will take to go out today will be worthwhile and my hope that it will begin the changing of my life. I am hoping to gain new insights into my M.E. and Fybromyalgia.
My name is Sue Gaskell-Barlow and I was diagnosed with this condition, approximately 20 years ago at a time when not many people including doctors recognised this invisible and at times debilitating health problem.
Becoming your own health guru and energy monitor begins with simple steps after the diagnosis. For me years of reading, counsellors, doctors, extra nutrition and meditation amongst many other things had moved me forward. I was beginning to get through a day although gong out in the evening was a thing of the past for me. Then nursing (with love and compassion) my husband Steve who was diagnosed with Motor Nerone Disease at the age of 61 took its toll. With hospice help for two years, Steve had the best of care at home with just two respite weeks. On these two occasions he went into care and I rested, at home alone in my bed day and night for the first four days of the seven. I had crashed! The next three days I was able to recharge my batteries to a 5 out of 10 in energy. This was not very high however with help I managed to care for Steve and he died at home 7 months ago. This story is my journey since then and the opportunity to really nail this condition and learn to function and work by going on this amazing course.
I will not waste the time and am excited as I get into the car.
I am determined to be on time and so yawning most of the way, missing the turning completely and with brain fog, robbing me of the number of the centre, (even though I had been before) I stopped the car wondering if I was going to even get there! I felt very vulnerable and anxious. I had to do my breathing exercises and then go very slowly retracing my steps in the hope I would see something familiar. Nothing. By now it was ten minutes to the course starting and I had checked my address book and phone with no luck. Common sense and a straight road came to my rescue and I watched for any other car coming along. After a few minutes no luck and two drive ways later I had found  the driveway. With a huge sigh of relief I parked the car and looked around. Nothing was stirring it was beautiful the countryside astounding. Taking a deep breath I walked around into the allotted room and a very warm welcome. I sank into a beanbag and closed my eyes. I was here and it felt safe and I just knew I had been guided here by love.
When everyone was settled, Kira and Tina the course leaders introduced themselves and we were asked to say a few words about ourselves to each other. The scene was set and even though I kept closing my eyes I was relaxed an thrilled to know that everything was being given to us in handouts to take home. I could use my energy to focus on the amazing information that was being revealed to us. The relief, the feeling of not being alone was very real. I was understood. I was respected. I was accepted. Most of all I knew that at last I could begin to re-evaluate my life and even with this invisible illness I could structure my life so that a new normal would give me a truly rewarding rest of my life. I felt a sense of freedom and belonging. I felt the loving energy as though I could touch it. Here I was Susie, in my 70th year and feeling like a teenager in my spirit.
Time seemed to stand still for me and as the course unfolded, I knew the jigsaw puzzle, called my life was evolving. The pieces that I didn't know how to put together, were in the process of completion. I had come full circle I was coming home.
The tree of life and its branches which we were shown had answers to some of the reasons the body, mine had struggled over the years until in the end it had just stopped working properly.
Meltdown and frustration with little understanding had been my bedfellows for two decades. Now with patience and new insight and from the wonderful information given I was aglow. I have the best friend ever, MYSELF ,on my side cheering me on. I have an amazing support team who are here for me as I grow in awareness of how my precious miraculous body, will achieve wellness from illness. Take the I out of illness and add we. WELLNESS. Together we are a great team. I will close for now with gratitude and appreciation.

**Week 2 of the M.E. Wellness Workshop March 11th 2016**

**SYSTEMS OF THE BODY AND PHASES OF THE ILLNESS**

I awoke after a reasonable sleep although I was conscious of needing to wake up in good time to get everything ready. I was going straight from the workshop onto Waihi to spend the weekend with my nephew and his many wonderful friends.
I prepared my picnic and flask of decaffeinated coffee and packed my clothes and gluten free food and drinks that I was taking. Ready to go I would give myself a 6 out of 10 tiredness wise. My enthusiasm to learn more skills and insights into managing my M.E. and Fybromyalgia was high and in my excitement I passed the turnoff and went a few minutes out of my way before realising I needed to turn back.
I arrived at the group on time and exchanged greetings and enjoyed the information given to us as the talks began, with handouts from Kara.
Realisations are wonderful things and the biggest for me this morning was being able to say how I felt with regard to trusting others with my story. I had been very badly misunderstood and often so disrespected in the past 20 years when everyone including most doctors thought 'it was all in my head' Grr.
The workshop felt a safe place to be honest and once again Kira and Tina created a very safe environment. I also have understood and accepted that I was there for myself. I have always cared about others. Other people and their feelings and needs were paramount to me and I have gone out of my way in helping others, to the detriment of my own health.
Today's workload gave insight into the different systems of the body and how having  M.E. affects us, with lots of references to glean more information from which could be found on the Internet. We had a video explaining how there were stages in recovery with M.E. and this again gives me hope as I grasp a deeper understanding of the magnitude of what tasks I had expected from my very hard done by body. Thank you for hanging in there! The meeting came to a close and after saying our thanks we all went our separate ways. I began my journey to my weekend holiday feeling more aware of what my role was in my recovery. I would continue being the best detective possible as I observed my body and its needs, knowing I intend to pass this hurdle with flying colours.

**Easter Break Share**

My aim this Easter is to enjoy each moment. The idea Tina shared with us at the 3rd meeting has really made me rethink my energy pacing. The idea being that each task I do represents a marble and to show how much energy I use each day is inspiring me at the moment.
I have a large glass dish full of pretty coloured marbles which I call " My memories bowl. I love marbles. I love their happiness. I used to be the marble queen as a girl. I played happily at this game in the school playground and had a huge collection of them which unfortunately got lost. I grieved the lost a decade or so ago and decided to buy some more because I deserved them. Steve my late husband added to them so the marbles are precious in many ways. They now have a new meaning my life's energy monitoring, I am quietly hopeful. This is a skill I can adopt in a happy way to be an even better detective on myself? After the meeting on the way home I went to Kmart and bought (costing $1) a pretty little white bucket which is ready for my project activity today. I am excited.
Each marble I put in the small bucket is from my energy levels used from today's energy tank. I will then and 'see' how many marbles I use each day( I am not losing my marbles😀 )
When I have a low day, I will recognise that today, I need to reserve some energy,along with resting and being aware of what type of pacing is required to get myself back onto an even Keel. My aim that day will be to 'save' some energy and the marbles will be a visual reminder of where I use my energy and how I can do this.
All the while the marbles are a joy for me to use and enjoy the happy memories associated with them. A win win Situation.
Writing this is very enjoyable as it represents growth from the amazing workshop I am attending. I wish you each an amazing Easter as you reflect on how things are going to be this time next year with your new found friends in the M.E. group and the most important BEST-FRIEND YOURSELF 😀

**Week 3 of the M.E. Wellness Workshop March 24th 2016**

**PACING**

I awoke and realised that this morning was our 3rd session and I was picking my granddaughter Millie up from the airport before the meeting. It was going to be tight time wise and the weather was very windy. I hope things all go according to plan or I would be late for my very important meeting for the M.E. Workshop 3.
If I was late I knew I would be welcome anyway by Tina and Kira. I like to be on time when I can out of respect.
The drive to the airport was stress free and even though the plane from Wellington was 20 minutes late and it was now 10 minutes to the meeting I remained stress free. I greeted my granddaughter and she went to the car as I went to pay the meter. The pay station was out of order, my ticket came back out automatically as there was no evidence that the machine wasn't working, when I put my ticket in. A queue was forming I put my ticket back in to the advice of the machine saying try again. Again the ticket flew out this time the wind took it and I played chase for a while. Retrieving my ticket I went over to the car and Millie.
Chatting as I then took her to meet her mum who was at work and would give Millie the key to her car,  I felt valued and helpful. Two of my main functions in life that of needing to achieve and help others were being satisfied and my energy was enhanced. I have a very hungry achiever!
At our destination I was given a lovely hug and smile from my granddaughter and off she went. I felt very content as I went on to my group and was indeed about 20 minutes late. I quietly went in, sat down, nodded acknowledgement to Tina and Kira as the speakers in progress. No stress. I really am excited as I become more aware of the triggers that set off my anxiety if I am not mindful. I knew that if I had missed anything in that first 20 minutes that the whole meeting would be presented on our Facebook page ( private) by Kira. How amazing yet again this meeting was and these two very dedicated ladies are. Thank you both and the members in the group.