

## Irene's Story

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**Note from Dr Stone: Irene has kindly provided her story which describes severely disabling functional neurological symptoms, so severe that she is bedbound. Whilst many functional symptoms are challenging to improve from, and fixed dystonia particularly so, please bear in mind that it is extremely unusual for functional symptoms to be this severe.**

I AM A 57YEAR OLD WOMAN WHO LIVES WITH A FUNCTIONAL DISORDER CHARACTERISED BY FIXED DYSTONIA OF LOWER LIMBS, PAIN AND CHRONIC FATIGUE. I HAVE BEEN LEFT SEVERELY DISABLED, AND HAVE BEEN BEDBOUND FOR SEVEN YEARS.

MY JOURNEY BEGAN IN 1987 WHEN I INJURED MY BACK WHILE NURSING AT A LOCAL HOSPITAL. I WAS WORKING IN A CONFINED SPACE AND SUSTAINED MY INJURY TRYING TO PREVENT AN ELDERLY PATIENT FROM FALLING ON TO THE FLOOR.

PRIOR TO THIS EPISODE I WAS A VERY ACTIVE MOTHER TO TWO YOUNG CHILDREN. MY HUSBAND AND I WERE ALWAYS VERY SPORTY AND LOVED TO PARTICIPATE IN MANY FORMS OF SPORT. LITTLE DID I KNOW THAT INJURING MY BACK THAT DAY WOULD LEAD TO SUCH LIFE CHANGING EVENTS.

I FIRST OF ALL ATTENDED MY G.P. WHO REFERRED ME TO THE LOCAL PHYSIO. SHE TRIED VARIOUS TREATMENTS, STRAPPED MY LOWER BACK AND GAVE ME A WALKING STICK TO TAKE THE PRESSURE OFF MY PAINFULL HIP AND LEG. WHEN THIS DID NOT HELP I WAS REFERRED TO THE HOSPITAL. THIS TIME I WAS TOLD THAT I HAD A SOFT TISSUE INJURY AND PROBABLY A PROBLEM WITH MY LUMBAR 4/5 DISCS, BUT THERE WAS NO POINT DOING XRAYS. I WAS TOLD TO REST FOR THREE MONTHS, BUT NOT BED REST. WHEN I RETURNED TO THE HOSPITAL I WAS STILL IN PAIN AND FEELING ILL, AND FRANKLY I WANTED SOMEONE TO HELP GET ME BACK TO WORK. I WAS TOLD THAT THE PAIN WAS CAUSING ME TO SUFFER FROM FATIGUE. I WAS ALSO TOLD NEVER TO LET ANYONE TELL ME I HAD CHRONIC FATIGUE AS THERE WAS NO SUCH THING.

TIME PASSED WITH NO CHANGE AND I WAS REFERRED TO AN ORTHOPAEDIC PROFESSOR, WHO MADE ME FOR THE FIRST TIME QUESTION MY FAITH IN THE MEDICAL PROFESSION. I WAS TOLD I WAS NOT TO ASK QUESTIONS, AND I WAS ONLY TO ANSWER THE PROFESSOR WHEN HE SPOKE TO ME. HE SENT ME FOR MORE PHYSIO, WHICH ONCE AGAIN MADE ME WORSE AND HAD TO BE DISCONTINUED. THE PHYSIO SAID THERE WAS MORE GOING ON BUT THE PROFESSOR WAS NOT A MAN WHO COULD BE QUESTIONED.

AT THIS POINT I TURNED TO ALTERNATIVE METHODS OF TREATMENT, IN AN EFFORT TO GET RELIEF. I WANTED TO LEAD A NORMAL LIFE WITH MY FAMILY AND TO GET BACK TO MY WORK. I TRIED ACCUPUNCTURE, MANIPULATIONS, HERBAL MEDICATIONS AND REMEDIAL MASSAGE. IN THE PROCESS I SPENT A LOT OF MONEY. I DID GET SOME RELIEF, BUT FOR ONLY A FEW DAYS AND I WAS BECOMING MORE DISABLED AND EXTREMELY FATIGUED. MY LOWER BACK WAS CONSTANTLY IN PAIN AS WAS MY LEG. MY LEG WOULD TIGHTEN AFTER A VERY SHORT WALK RESULTING IN ME HAVING SEVERAL FALLS. THE TIGHTENING IN MY LEG RESULTED IN ME DRAGGING MY LEG.

I CHANGED TO ANOTHER HEALTH CENTRE AND IT WAS AT THIS POINT I WAS ADMITTED TO THE WESTERN GENERAL HOSPITAL, WHERE VARIOUS TESTS WERE CARRIED OUT. I WAS DISCHARGED WITH STILL NO RELIEF FROM PAIN, HOWEVER I WAS TOLD I HAD CHRONIC FATIGUE. SOMETHING THAT I WAS TOLD PREVIOUSLY DID NOT EXIST. I CONTINUED TO DETERIORATE AND I NOTICED THAT AS WELL AS DRAGGING MY LEG IT HAD A TENDENCY TO TURN INWARDS. I FOUND MYSELF GOING FROM A WALKING STICK TO USING TWO ELBOW CRUTCHES, AND EVENTUALLY I RELUCTANTLY HAD TO USE A WHEELCHAIR.

I THEN HAD A REHAB TEAM COME TO MY HOUSE. I WAS GIVEN CRANIAL SACRAL THEROPY, AND IT WAS DURING THIS TREATMENT THAT MY LEFT LEG ROTATED INTERNALLY AND MY LEFT FOOT TURNED A FULL 180 DEGREES. AS WELL AS BEING A FRIGHTENING EXPERIENCE IT WAS VERY PAINFUL. THE PHYSIO ALSO GOT A SHOCK AND TOOK OVER AN HOUR TRYING TO GET MY LEG AND FOOT BACK INTO A NORMAL POSITION. NEEDLESS TO SAY SHE ABANDONED FURTHER TREATMENT.

I WOKE ONE MORNING AND MY LEFT FOOT HAD DROPPED AND I WAS TOO ILL TO GET OUT OF BED AND

STAND. AT THIS POINT I HAD TO GET CARERS IN TO HELP WITH MY PERSONAL CARE AND TO ASSIST ME TO USE A COMMUNE. I BEGAN TO HAVE SEVERE MUSCLE SPASMS CONSTANTLY AND MY FATIGUE AND PAIN BEGAN TO MAKE IT HARD FOR ME TO DO ANYTHING FOR MYSELF.

I WAS ADMITTED TO THE LOCAL HOSPITAL FOR THREE WEEKS WHERE THEY TRIED TO FIND MEDICATION THAT WOULD HELP TO CONTROL MY SPASMS. I WAS ALSO GIVEN PHYSIO, BUT THE PHYSIO DID NOT TAKE INTO ACCOUNT THE LEVEL OF MY FATIGUE AND INSTEAD OF HELPING WITH MY CARE I BECAME WORSE AND THE PHYSIO HAD TO BE SUSPENDED. I WAS SENT HOME NO FURTHER FORWARD, EXCEPT FOR THE MEDICATION FOR PAIN AND MUSCLE SPASMS. I ALSO HAD MY CARE PACKAGE INCREASED.

I CONTINUED TO SEEK AN ANSWER TO MY CONDITION AND WAS VISITED AT HOME BY A NEUROLOGIST WHO SUSPECTED I HAD A NEUROLOGICAL FUNCTIONAL DISORDER, BUT I STILL DID NOT UNDERSTAND WHAT THIS WAS AND WHY IT HAD HAPPENED. I HAD TROUBLE WITH MY TRANSFERS ON TO THE COMMUNE AND AFTER SEVERAL FALLS AND INJURIES DURING SEVERE SPASMS I WAS ADMITTED TO HOSPITAL. DURING THIS ADMISSION I WAS SEEN BY A CONSULTANT NEUROLOGIST WHO CARRIED OUT VARIOUS TESTS INCLUDING AN M.R.I. SCAN, SEDATING ME IN THEATRE TO SEE IF MY CONTRACTED FOOT WOULD GO BACK INTO A NORMAL POSITION. SADLY MY FOOT DID NOT GO BACK INTO A NORMAL POSITION. I ALSO TRIED HYPNOTHERAPY, BUT AGAIN I DID NOT BENEFIT FROM THIS.

THE TURNING POINT FOR ME WAS FINDING A CONSULTANT WHO SPENT A LOT OF TIME TALKING TO ME AND GIVING ME AN EXPLANATION FOR MY CONDITION. I WAS PREPARED TO HAVE MY LEG AMPUTATED BUT WAS ADVISED AGAINST THIS AS EXPERIENCE IN OTHER PATIENTS WITH THIS CONDITION SUGGEST THAT DYSTONIA TENDS TO GET WORSE IN THE OTHER LIMB WHEN YOU AMPUTATE.

THE WAY I NOW UNDERSTAND MY CONDITION IS WHEN I FIRST INJURED MY BACK THE PROLONGED PAIN MADE MY BRAIN SEND WRONG SIGNALS TO MY BODY, A BIT LIKE WHEN THE SOFTWARE IN A COMPUTER GOES WRONG. I WENT HOME AFTER TWO WEEKS IN HOSPITAL EXHAUSTED WITH THE HOSPITAL ENVIRONMENT, BUT UNDERSTANDING MY CONDITION.

MY MAIN AIM WAS TO TRY AND HAVE SAFE TRANSFERS AND TO TRY AND SIT IN MY ADAPTED WHEELCHAIR WHICH WAS MADE FOR ME BY MY HUSBAND. SADLY I SUFFERED MANY INJURIES INCLUDING BROKEN BONES. EACH INJURY MADE MY CONDITION WORSE AND MY DISABLEMENT HAS INCREASED, I HAVE FIXED DYSTONIA IN BOTH LEGS. MY LEFT HIP IS SEVERELY INTERNALLY ROTATED AND MY FOOT IS PLANTARFLEXED AND INVERTED. MY LEFT LEG NOW STICKS OUT AT NINETY DEGREES AT MY KNEE. I SUFFER SEVERE PAIN AND EXTREME FATIGUE. THE CONSULTANT STILL KEEPS IN TOUCH WITH ME AND I AM FREE TO CONTACT HIM AT ANY TIME.

I HAVE TRAVELLED A LONG WAY. I HAVE HAD MANY BAD EXPERIENCES ALONG THE WAY COPING WITH PAIN, FATIGUE AND SEVERE DISABLEMENT AND NOT BEING BELIEVED BY MANY MEDICAL PROFESSIONALS WHOM YEARS AGO I HAD HELD IN HIGH ESTEEM HAS BEEN DIFFICULT. NOW I HAVE A CONSULTANT WHO BELIEVES ME AND KNOWING WHAT IS WRONG MAKES IT EASIER TO FACE,

I AM LUCKY, I HAD A GREAT CHILDHOOD, WAS A VERY ACTIVE SPORTY PERSON. I WORKED AS A NURSE, A JOB THAT I LOVED AND FOUND REWARDING. I HAVE A LOVING HUSBAND AND TWO DAUGHTERS WHO CARE FOR ME AND WHOM I LOVE DEARLY, AS WELL AS FAMILY AND FRIENDS WHO CARE ABOUT ME. I WAS BLESSED WITH A HAPPY NATURE AND ALTHOUGH I SUFFER PHYSICALLY I TRY HARD TO STAY POSITIVE AND TO MAINTAIN A SENSE OF HUMOUR. I ALSO ENJOY THE INTERACTION WITH MY CARERS AND STILL CARE ABOUT OTHERS.

SADLY NOT EVERYONE WITH A FUNCTIONAL DISORDER FINDS TREATMENTS WHICH BENEFIT THEM, SO IF YOU ARE LIKE ME DON'T BEAT YOURSELF UP WHEN YOU READ STORIES FROM OTHERS WHO HAVE RECOVERED. IF YOU HAVE TRIED TREATMENTS WHICH HAVE FAILED THEN YOU HAVE TO ACCEPT YOUR CONDITION AND ADJUST YOUR LIFE AND LEARN TO LIVE WITH IT. YOU WILL HAVE DAYS WHEN YOU WILL FEEL LOW, SO YOU HAVE TO LEARN TO TELL YOUR FAMILY HOW YOU ARE FEELING. HOPEFULLY YOU WILL FIND A DOCTOR WHO CAN GIVE YOU SUPPORT AND BELIEVE IN YOU. REMEMBER YOU ARE NOT ALONE.