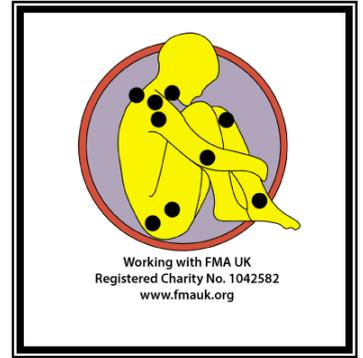


## Welcome to Our August 2015 Newsletter.

Note from the Editor Maxine: Hope you are all doing the best you can. After last month of the heat and feeling well, I've crashed because of the weather taking a turn downwards. I wonder how many of us are affected by the high and low weather pressure.



### Monthly focus.

We are a Registered Charity. Thank you to Caroline for all her hard work. Our charity number is 1161356.

No meeting at the wild life centre this month.

To lend especially for the holiday period the groups wheel chair or scooters for anyone that needs them, call Pam on 01204 793 846. To borrow the SmartCrutches, call Caroline on 01204 525 955.

### Dates For Your Diary:

#### Bolton Main Meetings at Wildlife Trust Centre, Bury Rd:

Our main meetings, often with guest speakers, are now held at The Wildlife Trust Centre, 499/511 Bury Rd, Bolton, BL2 6DH.

They occur on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). The building is past Morrisons/Home Bargains/Brightmet Health Centre on the right hand side as you go into town, very near the junction before you turn onto Crompton Way from Bury Rd.

Entrance is £1, carers are free. Tea, decaf coffee, water, biscuits, orange squash, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email [caroline@mesupportgroup.co.uk](mailto:caroline@mesupportgroup.co.uk).

### No meeting in August 2015

**Thursday 17th September 7:30pm.** Marie Oxtoby will be talking about the established Bolton Neuro Voices hydrotherapy project. As we are subscribing members of the organisation, members of our group can sign up to these sessions. They are five-week course for new users and there are continuation programmes for previous participants. It takes place at the Jason Kenny Leisure Centre (Bolton One) with professional support from Susan Pattison Therapy Services.

**Thursday 15th October 7:30pm:** Hannah Harrington, Bolton CCG's Engagement Officer

**Yoga Classes:** Are 3:15pm-4:15pm on Tuesdays at the Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Please contact our instructor Lisa Heaps Mobile: 0770 803 66 36 Email: lisayogatori1@gmail.com. **Our yoga classes are currently being funded by The Big Lottery Fund.**

Please note, there will be **no yoga on Tuesday 29th Sept 2015**, due to teacher training, sorry for any inconvenience.

**Prestwich Socials:** Our Prestwich socials are now at **The Church Inn, 40 Church Lane, Prestwich, M25 1AJ**. This has level access and free parking outside. We meet on the **second Wednesday** of the month at 2pm, the next meeting is **Wednesday 9<sup>th</sup> September 2015** The attendance at Prestwich has been doing better lately, but do please try not to turn up too late in case numbers are low.

If you are thinking of attending any of our socials, whether you are a new member or a member who hasn't been able to attend for a while, please remember that you can bring along your carer or a friend. We don't bite, but we understand that meeting new people or if you have been house bound for a while, it can be quite daunting going out by yourself and we look forward to seeing you.

**PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.**



**DISCLAIMER:** Anything expressed within this newsletter may not necessarily represent the views of the editor, the Trustees, nor the Bury & Bolton ME/CFS & Fibromyalgia Support Group (Registered Charity Number: 1161356). Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

### **Bury/Bolton ME/CFS & FM June 2015 meeting: talk by James Hall of the Wildlife Trust.**

James started by giving us a brief history of the wildlife trust and the site at Seven Acres, which used to be home to various industries including a bleach works, disused railway lines and aqueducts. These area are now being linked up with several others to form a "corridor", as far North as Turton, and south to Philips Park in Whitefield and on into Salford. There are mountain bike and walking trails. There is a rich variety of wildlife, including otters in the more secluded areas, and trout and even salmon are returning in some parts.

The Wildlife Trust building has nest boxes for birds and bats, and the pond supports a moorhen who produces up to 3 broods per year, Canada geese, kingfishers, a heron, fish and many other forms of wildlife. There are a whole variety of projects run at the centre,

from the Men in Sheds to school projects and many volunteer groups, too. You can visit the centre, or simply the country park behind (we saw a couple of dog walkers).

Quite a few people took up James's offer to accompany him on a short walk, to gain a flavour of the area. The ducks and moorhen kept a low profile, but came out again after we had all gone back inside, so those who stayed in didn't miss too much. The Wildlife Trust is always grateful for any support or volunteer help.

## **The Warm Home Discount Scheme**

For winter 2015 to 2016, you could get £140 off your electricity bill through the Warm Home Discount Scheme.

The money isn't paid to you - it's a one-off discount on your electricity bill, usually between September and March.

The discount won't affect your Cold Weather Payment or Winter Fuel Payment.

The following suppliers are part of the scheme:

- Atlantic
- British Gas
- Co-operative energy
- EDF Energy
- E.ON
- Equipower (Ebico)
- Equigas (Ebico)
- First Utility
- Manweb - see [ScottishPower](#)
- M&S Energy
- npower
- OVO
- Sainsbury's Energy - see British Gas
- Scottish Gas - see British Gas
- Scottish Hydro
- ScottishPower
- Southern Electric
- SSE
- SWALEC
- Utilita
- Utility Warehouse

## **The Spoon Theory by Christine Miserandino**

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*You may have heard people with chronic illnesses like ME/CFS, FM, Lupus, Addison's and many other conditions refer to themselves as "Spoones". This is because in an effort to explain how exhausting it was living with Lupus, in 2010 she came up with "The Spoon*

*Theory". It's a very good way of explaining limited energy reserves and payback to people who don't understand your condition.*

*There are a lot of things you can buy to raise awareness of your "Spoonie Status", like bracelets, necklaces or keyrings with tiny spoons on! T-shirts and magnets too. I've met one or two people with these on and struck up conversation, so it's a great way to raise awareness and understanding. These items are very often made by people with chronic conditions, so you are supporting them, or a charity they may be raising funds for by making them.*

Christine explains **The Spoon Theory**:

My best friend and I were in the diner, talking. As usual, it was very late and we were eating French fries with gravy. Like normal girls our age, we spent a lot of time in the diner while in college, and most of the time we spent talking about boys, music or trivial things, that seemed very important at the time. We never got serious about anything in particular and spent most of our time laughing.

As I went to take some of my medicine with a snack as I usually did, she watched me with an awkward kind of stare, instead of continuing the conversation. She then asked me out of the blue what it felt like to have Lupus and be sick. I was shocked not only because she asked the random question, but also because I assumed she knew all there was to know about Lupus. She came to doctors with me, she saw me walk with a cane, and throw up in the bathroom. She had seen me cry in pain, what else was there to know?

I started to ramble on about pills, and aches and pains, but she kept pursuing, and didn't seem satisfied with my answers. I was a little surprised as being my roommate in college and friend for years; I thought she already knew the medical definition of Lupus. Then she looked at me with a face every sick person knows well, the face of pure curiosity about something no one healthy can truly understand. She asked what it felt like, not physically, but what it felt like to be me, to be sick.

As I tried to gain my composure, I glanced around the table for help or guidance, or at least stall for time to think. I was trying to find the right words. How do I answer a question I never was able to answer for myself? How do I explain every detail of every day being effected, and give the emotions a sick person goes through with clarity. I could have given up, cracked a joke like I usually do, and changed the subject, but I remember thinking if I don't try to explain this, how could I ever expect her to understand. If I can't explain this to my best friend, how could I explain my world to anyone else? I had to at least try.

At that moment, the spoon theory was born. I quickly grabbed every spoon on the table; hell I grabbed spoons off of the other tables. I looked at her in the eyes and said "Here you go, you have Lupus". She looked at me slightly confused, as anyone would when they are being handed a bouquet of spoons. The cold metal spoons clanked in my hands, as I grouped them together and shoved them into her hands.

I explained that the difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn't have to. The healthy have the luxury of a life without choices, a gift most people take for granted.

Most people start the day with unlimited amount of possibilities, and energy to do whatever they desire, especially young people. For the most part, they do not need to worry about the effects of their actions. So for my explanation, I used spoons to convey this point. I wanted something for her to actually hold, for me to then take away, since most people

who get sick feel a “loss” of a life they once knew. If I was in control of taking away the spoons, then she would know what it feels like to have someone or something else, in this case Lupus, being in control.

She grabbed the spoons with excitement. She didn't understand what I was doing, but she is always up for a good time, so I guess she thought I was cracking a joke of some kind like I usually do when talking about touchy topics. Little did she know how serious I would become?

I asked her to count her spoons. She asked why, and I explained that when you are healthy you expect to have a never-ending supply of “spoons”. But when you have to now plan your day, you need to know exactly how many “spoons” you are starting with. It doesn't guarantee that you might not lose some along the way, but at least it helps to know where you are starting. She counted out 12 spoons. She laughed and said she wanted more. I said no, and I knew right away that this little game would work, when she looked disappointed, and we hadn't even started yet. I've wanted more “spoons” for years and haven't found a way yet to get more, why should she? I also told her to always be conscious of how many she had, and not to drop them because she can never forget she has Lupus.

I asked her to list off the tasks of her day, including the most simple. As, she rattled off daily chores, or just fun things to do; I explained how each one would cost her a spoon. When she jumped right into getting ready for work as her first task of the morning, I cut her off and took away a spoon. I practically jumped down her throat. I said ” No! You don't just get up. You have to crack open your eyes, and then realize you are late. You didn't sleep well the night before. You have to crawl out of bed, and then you have to make your self something to eat before you can do anything else, because if you don't, you can't take your medicine, and if you don't take your medicine you might as well give up all your spoons for today and tomorrow too.” I quickly took away a spoon and she realized she hasn't even gotten dressed yet. Showering cost her spoon, just for washing her hair and shaving her legs. Reaching high and low that early in the morning could actually cost more than one spoon, but I figured I would give her a break; I didn't want to scare her right away. Getting dressed was worth another spoon. I stopped her and broke down every task to show her how every little detail needs to be thought about. You cannot simply just throw clothes on when you are sick. I explained that I have to see what clothes I can physically put on, if my hands hurt that day buttons are out of the question. If I have bruises that day, I need to wear long sleeves, and if I have a fever I need a sweater to stay warm and so on. If my hair is falling out I need to spend more time to look presentable, and then you need to factor in another 5 minutes for feeling badly that it took you 2 hours to do all this.

I think she was starting to understand when she theoretically didn't even get to work, and she was left with 6 spoons. I then explained to her that she needed to choose the rest of her day wisely, since when your “spoons” are gone, they are gone. Sometimes you can borrow against tomorrow's “spoons”, but just think how hard tomorrow will be with less “spoons”. I also needed to explain that a person who is sick always lives with the looming thought that tomorrow may be the day that a cold comes, or an infection, or any number of things that could be very dangerous. So you do not want to run low on “spoons”, because you never know when you truly will need them. I didn't want to depress her, but I needed to be realistic, and unfortunately being prepared for the worst is part of a real day for me.

We went through the rest of the day, and she slowly learned that skipping lunch would cost her a spoon, as well as standing on a train, or even typing at her computer too long. She was forced to make choices and think about things differently. Hypothetically, she had to choose not to run errands, so that she could eat dinner that night.

When we got to the end of her pretend day, she said she was hungry. I summarized that she had to eat dinner but she only had one spoon left. If she cooked, she wouldn't have enough energy to clean the pots. If she went out for dinner, she might be too tired to drive home safely. Then I also explained, that I didn't even bother to add into this game, that she was so nauseous, that cooking was probably out of the question anyway. So she decided to make soup, it was easy. I then said it is only 7pm, you have the rest of the night but maybe end up with one spoon, so you can do something fun, or clean your apartment, or do chores, but you can't do it all.

I rarely see her emotional, so when I saw her upset I knew maybe I was getting through to her. I didn't want my friend to be upset, but at the same time I was happy to think finally maybe someone understood me a little bit. She had tears in her eyes and asked quietly "Christine, How do you do it? Do you really do this everyday?" I explained that some days were worse than others; some days I have more spoons than most. But I can never make it go away and I can't forget about it, I always have to think about it. I handed her a spoon I had been holding in reserve. I said simply, "I have learned to live life with an extra spoon in my pocket, in reserve. You need to always be prepared."

Its hard, the hardest thing I ever had to learn is to slow down, and not do everything. I fight this to this day. I hate feeling left out, having to choose to stay home, or to not get things done that I want to. I wanted her to feel that frustration. I wanted her to understand, that everything everyone else does comes so easy, but for me it is one hundred little jobs in one. I need to think about the weather, my temperature that day, and the whole day's plans before I can attack any one given thing. When other people can simply do things, I have to attack it and make a plan like I am strategizing a war. It is in that lifestyle, the difference between being sick and healthy. It is the beautiful ability to not think and just do. I miss that freedom. I miss never having to count "spoons".

After we were emotional and talked about this for a little while longer, I sensed she was sad. Maybe she finally understood. Maybe she realized that she never could truly and honestly say she understands. But at least now she might not complain so much when I can't go out for dinner some nights, or when I never seem to make it to her house and she always has to drive to mine. I gave her a hug when we walked out of the diner. I had the one spoon in my hand and I said "Don't worry. I see this as a blessing. I have been forced to think about everything I do. Do you know how many spoons people waste everyday? I don't have room for wasted time, or wasted "spoons" and I chose to spend this time with you."

Ever since this night, I have used the spoon theory to explain my life to many people. In fact, my family and friends refer to spoons all the time. It has been a code word for what I can and cannot do. Once people understand the spoon theory they seem to understand me better, but I also think they live their life a little differently too. I think it isn't just good for understanding Lupus, but anyone dealing with any disability or illness. Hopefully, they don't take so much for granted or their life in general. I give a piece of myself, in every sense of the word when I do anything. It has become an inside joke. I have become famous for saying to people jokingly that they should feel special when I spend time with them, because they have one of my "spoons".

## **Recycling Old Spectacles**

Do you have a small pile of glasses and cases in a drawer? VisionAid Overseas can recycle these. I took in 14 pairs! 12 of these were my Nanna's going back to the 80's and she'd decided to finally part ways! - Caroline

Vision Aid Overseas runs a nationwide spectacle collection scheme which operates to raise money for Vision Aid Overseas and ensure spectacles are recycled in an environmentally-friendly way. They do not take the cases though.

Optical practices all over the UK and Ireland can collect spectacles for Vision Aid Overseas and send them free of charge. I took mine to Boots Opicians (just dropped them in, wasn't going in for a test), as all Boots Opticians seem to participate in the scheme (but check first).

The Vision Aid Overseas website has details of their work, and you can search for details of participating national and independent opticians local to you.

As they will not take glasses cases, if you have some spare, you can do all sorts of useful things with them! We've put drill bits in one so they're easy to find in the tool box. They also make great sewing kit cases, for concealing personal hygiene products, keeping small delicate items safe in your luggage, makeshift manicure set, kids jewellery case (you can decorate the case with things from the craft shops), saving used postal stamps to pass on to us, and storing pill packets and the like for a day out.

To reduce waste in the first place, if your case is still ok, keep using that and decline the new one you get with new glasses. Not many people seem to have realised that yet!

<http://www.visionaidoverseas.org/recycle>

01293 535 016 (9am-5pm Monday to Friday)

## **Pet key ring Alerts**



From Facebook by Caroline.

I bought these off a charity facebook page in case something happens to me outside. It alerts someone to the fact I have pets, with my name, pets names and a contact number.

I have one for each scooter key (most likely to see scooter key first if I am out and have a problem) and one for the house keys.

Thought they were a good idea, as if anything happens to us, could be a while until someone realises and sees to the cats.

If anyone wants to know where to get them, contact Caroline. They have 3 designs to choose from.