The Canadian Addison Society
La Société canadienne d'Addison

Offering support for those with Addison's disease
and other forms of Adrenal Insufficiency

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In this issue

Distribute to:

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PLEASE NOTE:
The content of this newsletter is intended for basic information only and not as personal medical advice. Please note that the Society does not endorse the information provided by guest speakers. Meeting minutes/notes are prepared by non-medical volunteers. Readers are advised to consult their own doctors before making changes to their Addison/Adrenal Insufficiency management program.

News and Announcements:

Have you ever heard of the Spoon Theory?

If not – check out www.butyoudontlooksick.com to read the full article written by Christine Miserandino (also attached).
It's her personal story of what it's like to live with a sickness or disability and tips on how to cope.

Great article and it can be applied to Adrenal Insufficiency as well.

Editors Comments

newsletter@addisonsociety.ca

Have you had an experience with Adrenal Insufficiency either as the patient, caregiver, family, friend, nurse, doctor or any other role? Please consider sharing your story for our **Personal Experiences** section, for the benefit of others. You may do so anonymously. Please forward to newsletter@addisonsociety.ca

President's Comments

president@addisonsociety.ca

Canadian Addison Society member Elizabeth Hill has been the Regional Representative for Saskatchewan for many years, along with her important role as a valued member of the Society's national Board of Directors.

Elizabeth has now handed over the Regional Representative responsibilities to Brenda Dinsdale. We are most appreciative of the many years that Elizabeth fulfilled dual roles for the Society. We are equally appreciative that she is continuing in her role as a valued national Director. It is this type of dedicated volunteer contribution of time and talent that make the Society work for all of us. On behalf of all Society members, thank you, Elizabeth!

We are therefore very pleased to introduce and welcome Brenda Dinsdale as the Regional Representative for Saskatchewan and wish her and all the Society's members in Saskatchewan good success. Please check the Meetings Schedule page on the website regularly for upcoming meeting details and updates.

http://www.addisonsociety.ca/support-group-meetings.html

Support Group Contact Information & Meeting Reports

B.C. - Vancouver Island Support Group

Meeting Minutes – February 17, 2018 1:00 to 3:00 PM

We had eleven Addisonians and their family members attend our most recent meeting. It was great to have such a large and active turnout.

We spent quite a bit of time discussing the pros and cons of Cortef (hydrocortisone-corticosteroid) and Prednisone (Corticosteroid). It was interesting to note that some of the members were taking both medications. While we spent a lot of time discussing medical levels we don't advocate any changes without speaking with your Endocrinologist.

As requested, here is the interesting story of the hydrocortisone pump for Addison's:

http://clearlyalive.blogspot.ca/2015/05/the-cortisol-pump_23.html

https://aiunited.org/cortisol-pump-continuous-subcutaneous-hydrocortisone-infusion-a-patient-experience/

We also spent some time discussing high level athletes with Addison's disease. In most cases these people take large amounts of corticosteroids during competition.

https://www.theglobeandmail.com/sports/olympics/addisons-disease-makes-gafuik-a-fighter/article4429100/

In the next few months I will be moving to the Nanaimo area and will hopefully be restarting the support group in that area. That of course, leaves the Victoria support group looking for someone to answer occasional emails and coordinate meetings. If you are interested in helping, please let me know.
Next meeting details TBA. In the meantime, stay heathy! -Derek

For further information on the Vancouver Island Support Group, please contact Derek Clarke at vancouverislandaddisons@gmail.com or (250) 857-4320.

Support Group Contact Information & Meeting Reports *continued*

BC - Lower Mainland Support Group

The next meeting is scheduled for April 14, 2018 at 1:00pm.

Coquitlam Public Library, Nancy Bennett Program Room, 575 Poirier St., Coquitlam BC.

Our guest speaker will be Mabel Tan RN MN, nurse clinician at Vancouver Children's Hospital.

For further information on this Support Group please contact Geoff Metcalfe at calfe579@telus.net or 604-533-0579.

Alberta - Edmonton Region Support Group

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or 780-454-3866 in Edmonton.

We are searching for a volunteer to take on the Regional Representative role in the **Edmonton** Region. If you are interested, please contact either Ginny Snaychuk at ginray@shaw.ca or Harold Smith at president@addisonsociety.ca.

Alberta - Calgary Region Support Group

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or 780-454-3866 in Edmonton.

We are searching for a volunteer to take on the Regional Representative role in the **Calgary** Region. If you are interested, please contact either Ginny Snaychuk at ginray@shaw.ca or Harold Smith at president@addisonsociety.ca.

Saskatchewan Support Group

Our little Saskatchewan "Addy group" has now officially become part of the Canadian Addison's Society. We are quite pleased by this change! We have been meeting about every month for coffee and a snack, with lots of talk about how we are feeling, changes in health or care, and we provide each other support and compassion. We all find it a necessary part of self-care, disease acceptance and responsible management.

Our January meeting saw six (6) Addisonian's in attendance (all but one being primary adrenal insufficient) and revolved around discussion about the bustle of the holidays and a great deal of decompression from the stress - whether it is good or bad, it always comes at a cost to us. It is always a "congratulations, we made it" kind of moment, with lots of laughs and sometimes some tears.

In February, we opened our meeting to family members as well, and had a formal practice session on emergency injections. We always make it a point to direct each Addisonian to keep their emergency kits up to date, but the practice sessions are a crucial component for those who rarely, if ever, inject. Eleven people attended, ranging in age 26-80 years old, and all our practice vials were utilized. We also played a game of hearts. On Valentine's Cards I wrote out scenarios that could be cause for stress dosing, injecting, or doing nothing. Each person was to read their card and provide the beginning of discussion for each. It became comical, informative and personal at times, but definitely provided insight into how quickly things can go badly. About 90% of our group states they have at one time or another or are currently fighting steroid guilt, feeling it hinders their decision to take extra steroids when they need to. Most of our Addisonian's take low daily maintenance doses. Also, several in our group struggle with side effects of Florinef, and have trouble maintaining a good Renin balance because Florinef is so hard on them. We expressed a wish for a gentler mineral corticoid. We also discussed getting information and brochures into Endocrinologist's offices and doctor's offices to generate awareness of our meetings and stronger protocols for emergency treatment.

Regina and Prince Albert Addisonian's have a long way to travel to our monthly meetings, so we are going to begin coffee groups there, and do the same kind of agenda. The plan is to meet once a year with the entire province and begin regional coffee groups, depending on interest. We would all love to meet each other, giving a personal touch to our interactions on social media. We are in the brainstorming mode to determine guest speakers, and I would appreciate any suggestions from other groups. I can be reached by email at: bren2@sasktel.net
Stay safe and healthy, fellow Addisonian's and Family, and have a wonderful new year! ~ Brenda Dinsdale

For information on the Saskatchewan Support Group, contact Brenda Dinsdale bren2@sasktel.net or 306-466-2244

Ontario - South/Central Support Group

The next meeting is scheduled for April 28, 2018 from 1:00pm to 4:30pm. Registration opens at 12:30pm. The meeting will be held at Erin Mill United Church, Lower Hall. 3010 The Collegeway, Mississauga, ON L5L 4X9

For further information on the activities or meetings of the South/Central Ontario Support Group, please contact Becky Sparks in Sarnia at rebeccalouisepacker@gmail.com, 519-402-2833.

Ontario - Eastern Support Group

We are searching for a volunteer to take on the Regional Representative role in the **Ottawa** Region. If you are interested, please contact.

For more information on Eastern Ontario Support Group activities or meetings, please contact Harold Smith at president@addisonsociety.ca. *Those located in Quebec, near Ottawa, would be most welcome at our meetings.*

Quebec - Montreal Region Support Group

Our semi-annual meeting took place on February 17, 2018 at PF Chang's restaurant in Montreal. The largest attendance to date with 12 people including members, family members and one service dog. Our meeting was an informal opportunity for everyone to share their experiences and knowledge of Addison's.

New and recently diagnosed members were able to learn from veterans living with Addison's for many years. We had a demonstration on how to administer the solu-cortef injection and discussed the importance of carrying the injection in the event of an emergency. Some members were never prescribed an emergency vial of solu-cortef or carried a medical letter from their doctor stating they had Addison's and what to do in the event of a crisis. It was strongly recommended they get the appropriate documents.

Quebec - Montreal Region Support Group continued

It was a nice afternoon where we were all able to meet and share. I would like to thank everyone for making the effort to attend and will be planning another meeting in the summer.
Those located in Ottawa/Gatineau area would be most welcome at our meetings.

For information on Montreal Region Support Group activities or meetings, please contact Shelley Saklatvala, email shell326@hotmail.com or telephone 514-991-0294.

Quebec - Québec City Region Support Group

We are searching for a volunteer to become our Regional Representative for a Quebec City Region Support Group. If you can assist in this volunteer role please contact Harold Smith, president@addisonsociety.ca.

In the interim, if you are trying to connect with the Society for support please call our Montreal Area Regional Representative, Shelley Saklatvala at 514-991-0294 or you may also call the Society via our Toll Free number 1-888-550-5582 or email info@addisonsociety.ca or president@addisonsociety.ca.

Atlantic Canada Support Group

For information on the Atlantic Canada Support Group activities or meetings, please contact, Holly Mclean at hquilter@nb.sympatico.ca or telephone 506-546-1687. Holly lives in northern New Brunswick.

Medical Q & A's

Question 1

I've been diagnosed with Addison's Disease since 2003. I am 55-year-old Female. I take 20mg of Cortef per day, 10mg in the AM, 5mg at Noon and 5mg at Supper and 0.05 of Florinef daily. The big problem I've been facing with no one to give me answers to is I am always shaking. Always! I do have other medical problems such as Diabetes, Potassium Deficiency, Hypotension (though for years and years it was low normal) Tachycardia, Trigeminal Neuralgia, Diabetic Neuralgia, Narcolepsy, Cataplexy, Hypothyroidism, and some others. My GP checked a few things to see if any of those would be causing me to be so shaky however he couldn't. I also see two neurologists and after tests I was told it was not of a Neurological matter. So, may I ask you, could my Addison's Disease be playing a role here? I feel as though I'm receiving inadequate amount of Cortisol. However, after speaking to my Endocrinologist and he wasn't blaming it on Addison's, I was told it had no relation at all. Puzzled. I left however, puzzled seems to be the underlying word in my vocabulary since 2003. Thank You for any light you may be able to shed.

Response 1

I would be surprised if your Addison's problem is responsible for the shaking. The list of problems that you have outlined is formidable and there may be a list of medications you are on to deal with them. This is too complex a situation for me tackle. I agree with your endocrinologist that shaking is not a symptom that is normally associated with Addison's disease.

Question 2

Can you recommend a diet plan for a person with Addison's Disease? Foods that are best, food that are worst, foods to never have, etc? There's so much confusing information out there. As well as Addison’s, I am also hypothyroid and take Synthroid, Cortisol, and Florinef. Thank you!

Response 2

I hope I have some good news for you about the ideal Addison's diet. There really is no special diet for individuals with Addison's disease or hypothyroidism. A well-balanced diet is important in both cases. With Addison's disease, the diet should have an adequate amount of salt and you should avoid liquorice because it can affect the control of sodium and potassium. It is important to get the correct Cortisol and Florinef replacement.

The thyroid medication should be taken at least an hour after food and wait at least an hour before eating, particularly foods or pills containing calcium or iron. Some individuals with Addison's disease can develop a form of Colitis due to gluten sensitivity and these individuals have to avoid foods containing gluten such as bread and pasta.

Except in special situations, individuals with Addison's disease can eat a regular diet.

Question 3

I have been living with Addison's disease for 36 years, and have had only one crisis requiring medical intervention, so I think I know what I'm doing. My problem is that no matter how careful I am (sleep, food, exercise are all excellent) I simply cannot get my strength and stamina up enough to be able to get through a normal day's activities without having periods of exhaustion, perspiration, weakness, and/or rapid heart beat. I started asking my GP about this about 4 years ago. She doesn't know much about Addison's, so she sent me to an Internist, who prescribed boosting my daily Cortef intake to 37.5 mg. I refused to take that much, as I thought it might be damaging, but I did start to take 35 mg. It made no difference to the bouts of exhaustion. Then, last March, I caught a nasty virus, mostly respiratory, but with some diarrhea also. The respiratory problem cleared up, but my stools remained loose, sometimes explosive, watery, and mucusy, and all tests came back negative. This carried on until finally on December 13 I got in to see our local Internist. He was horrified at the high dose of Cortef I was taking and told me to cut it down to 20 mg, immediately.

He also put me on a gluten free diet, in case that was causing my diarrhea. I agree I needed to cut my Cortef down, and I started cutting 5mg per week, until I got down to 20 mg per day, and found this was not working well, so I am back up to 25 mg. I have been faithful to the diet, and I have cut back my Cortef. My stools are better, but still not normal, so I don't know what to think. I see that in the U.K. DHEA is used for stamina, which is my main problem. Is there any chance I can get a prescription for DHEA in Canada, just to try it? Maybe then I can get on a normal dose of Cortef and still function.

Response 3

There are several aspects to your question, but I think the main thing you wanted to know had to do with DHEA. This material is not legally sold in Canada, but it can be obtained from some compounding pharmacists. These are pharmacies that mix some of there own preparations. The literature on DHEA is that most studies have not shown any beneficial effects on general well being. One study suggested it was helpful for sexual interest and anecdotal reports suggest beneficial effects in non-placebo-controlled trials. From your description, I do not think that DHEA would solve your problem. You could find a compounding pharmacy that could provide you with this material and give it a try.

Response 3 continued

Your description of your cortisol (Cortef) dose is interesting. It seems you did well on a dose of cortisol which was around 25 mg a day. Presumably your weight was stable and your blood pressure satisfactory. You did not mention Florinef which is required for control of sodium, but most people are on 0.05 to 0.1 mg daily.

The dose of cortisol required varies from patient to patient. Some people do well on 15-20 mg a day and others require 25-30 mg. The decision regarding the dose depends on how you feel and what effect it is having on your weight. There are reasons why different people require different doses of cortisol, but the minimum dose that makes you feel well and keeps your weight stable is the best for you. How the cortisol is taken can also affect how you feel. It is best to take it 3 to 4 times a day, eg. 10,5,5 or 15,5,5, or10,10,5 or 10,5,5,2.5. You can discuss this with your doctor.

The problem with your stools is likely a different problem. It could be the result of the virus infection that you had and if so should gradually improve. It could be a gluten problem as suggested by your internist and should respond to your diet provided you are adhering to it carefully. It could also be a form of colitis that can occur in patients with Addison's disease. This can be tested by a blood test measuring serum transglutaminase.

I hope things work out for you, but you should see an endocrinologist if your problem persists. I do not think that DHEA is the answer.

Medical Questions and Answers

Dr. Donald Killinger, MD, PhD, FRCPC
Medical Advisor to The Canadian Addison Society

Dr. Killinger will answer your questions about Addison's/Adrenal Insufficiency. Send your question to Dr. Killinger directly from the webpage or this link http://www.addisonsociety.ca/index.php/education/faqs/ask-a-question

By emailing info@addisonsociety.ca or by Canada Post to The Canadian Addison Society, 2 Palace Arch Drive, Etobicoke, ON M9A 2S1
Questions and answers that may be of interest to everyone may be published in the Newsletter and on the website.

Personal Experiences

To the Newsletter Editor,

I was diagnosed with primary Addison's over 30 years ago by Dr. Guy Emery, while I was a "dying" patient at the Toronto General Hospital. It was December 1987.

It was roughly two months after giving birth to my first son. David's birth actually saved my life because it precipitated my unexplained "crisis", which required immediate hospitalization shortly after he was born. I was kept isolated at first, for fear of some unknown infectious bacteria, and tested for absolutely everything, with no definitive answers in site. I was so thin, so weak. I couldn't hold my own head up. I was unable to respond to most of what was going on. I didn't even remember giving birth, or that I had a newborn.

I was such an "interesting case", that all the residents at this teaching hospital, crowded around my bed on a daily basis to learn about and figure out what was wrong with me, but with no luck. My siblings cried every time they entered my room, because I was so tired of being poked and prodded, and I just wanted them to let me die in peace. After 8 weeks of interventions, my body was finally shutting down. My family began lighting candles and praying.

In all this time no one had questioned my extremely dark brown skin, (which should have been olive due to my Portuguese heritage). And no one had ever looked in my mouth long enough to notice the black patches on my tongue, or the fact that my gums were black rather than pink. I could barely speak, let alone open my mouth wide enough, but I remember a doctor asking my mother what country I had vacationed in because I had such a beautiful tan. I had responded that for as long as I could remember I always vomited throughout most of my summers, and that I always seemed to "tan in the shade". Well, it was enough to peak his curiosity. When I mentioned that my tongue and gums also "tanned", he quickly looked into my mouth and had a "eureka" moment as he ran out of my room telling my mother he thought he knew what I had.

What happened after, was relayed to me by my family. Well, a special "machine" had to be brought to the hospital from northern Ontario where it was presently being used. There was only one of these available in all of Ontario, at that time, that could positively confirm his diagnosis of Addison's Disease. It was such a rare illness, that there was very little literature on it. Apparently, there was lots written about dogs with Addison's, but not so much about humans because only 1 in a million people had it (that's what he quoted in 1987. There had only been one other case in Toronto, that he knew of.)

Addison's Disease was indeed confirmed! I was put on huge amounts of steroids and other medications. Within 2 days after taking the hydrocortisone and fludrocortisone that my body so desperately needed, I was discharged.... with incredible energy, a very clear head, with quite an appetite, and making jokes because I couldn't understand why my family members were all crying uncontrollably, while hugging and thanking the doctor that had saved my life. I went from rag-doll to cheerleader in 2 days. It was like night and day! It was a miraculous recovery!

On December 20, 1987, weighing less than 89 pounds, I was discharged from the hospital. I went home to spend my first Christmas with my 10-week-old baby boy!

That's my story......

P.S. I subsequently had another son in 1998 (at the age of 37), a daughter in 2000 (at the age of 39), and another daughter in 2004 (just shy of my 44th birthday). Sadly, I also suffered 3 miscarriages between the births of my two daughters.

But You Don't Look Sick?
the stories behind the smiles

The Spoon Theory

by Christine Miserandino
www.butyoudontlooksick.com

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 then others; some days I have more spoons then 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".