

iFOG

NEWBIE PACKET

iFoG's Mission Statement

"We believe those who suffer the ravages of fibromyalgia DESERVE to never again feel hopeless or helpless. We fully understand the daily pain and despondency you experience because we have been there. Our entire purpose is to share our experiences and help you to regain a life filled with joy and improved health on a safe and highly successful protocol which has been used around the world for over four decades. Because our Hawaii members have improved so remarkably since 2001, iFoG is eager to pay it forward by offering you our assistance, guidance and support as you reverse the effects of fibromyalgia."

iFOG (informed Fibromyalgics On Guaifenesin) Membership Information:

Name: _____

Date: _____

Address: _____

Phone number: Home: _____

Cellular: _____

Work: _____

Email address: _____

How did you hear about iFoG? _____

Would you be willing to release your phone number and email address to others in the group if they request it? Yes _____ No _____

Age group: 15-20 _____ 21-25 _____ 26-30 _____ 31-40 _____ 41-50 _____ 51-55 _____
56-60 _____ 61-65 _____ above 65 _____

Think of yourself right now and the condition you are in. What do you picture yourself doing one year from now that would convince you that the guaifenesin protocol is working? _____

iFoG RELEASE FORM
(informed Fibromyalgics nn Guaifenesiri)

iFoG's mission: "We believe those who suffer the ravages of fibromyalgia DESERVE to never again feel hopeless or helpless. We fully understand the daily pain and despondency you experience because we have been there. Our entire purpose is to share our experiences and help you to regain a life filled with joy and improved health on a safe and highly successful protocol which has been used around the world for over four decades. Because our Hawaii members have improved so remarkably since 2001, iFoG is eager to pay it forward by offering you our assistance, guidance and support *as you reverse the effects of fibromyalgia.*"

I understand that my participation in iFoG is of my own choosing.

I have been diagnosed as having Fibromyalgia by a physician and am currently under a physician's care for any medical problems or other conditions I may encounter while on guaifenesin.

I am voluntarily choosing to follow the guaifenesin protocol by Dr. R. Paul St. Amand and am familiar with the contents of his book, "What Your Doctor May Not Tell You About Fibromyalgia" prior to starting the protocol.

I understand that information I receive at iFoG meetings may not be suitable for my individual condition and should be checked with my physician.

I understand results may vary from individual to individual and I do not expect nor does iFoG promise me a cure for the disease.

I understand that any personal information I may choose to share with members at iFoG meetings shall be at my discretion and with my full knowledge that it will become known to the group at large who are present at that meeting.

I agree to hold iFoG harmless and indemnify iFoG members from any liability or loss whether direct or indirect as a result of my association.

Signature: _____

Name (please print): _____

Date: _____

I KNOW THINGS ARE HARD RIGHT NOW.



YOU'RE GOING TO BE OKAY, BUT IT MIGHT
TAKE A WHILE. IT MIGHT BE SCARY, AND
YOU MIGHT WANT TO GIVE UP.

DON'T GIVE UP. YOU CAN DO THIS.
THINGS WON'T BE THIS WAY FOREVER.

ONE DAY, YOU'RE GOING TO BE
SO PROUD OF YOURSELF

Important points to remember when on the Guaifenesin Protocol (updated 6/1/20):

1. Read Dr. St. Amand's book "What Your Doctor May Not Tell You About Fibromyalgia" and commit to at least one year or not at all.
2. Stay salicylate free. Use i Fibro (facebook) for online group assistance. Doublecheck ingredients, use product list only as guideline. Save original containers/ingredient labels for recheck later. Buy a year's supply if able. To doublecheck ingredients, use Google search (type in product name followed by the word "ingredients") or go to <https://www.walgreens.com/> (type in product name and scroll to "ingredients"). Food is okay .
3. Get initial mapping before starting the guai & at least one month after you think you are on cycling dose (feeling tolerably worse or different) - left thigh should be clear after one month on correct dose. Recommend mapping 3 months later and whenever you suspect you are blocking. Contact information for mapping: Vicki Mauck: 371-2071 (cell) or email: vmauck@gmail.com
4. List all symptoms when starting out. Journal daily.
5. Begin one of the following guaifenesins as listed on the next page.
6. Remember that you will cycle symptoms, both physical and emotional (fatigue, pain, irritability, depression, etc.). Cycling may attack several different areas at one time. Remember that it is now hurting because the phosphates are coming out and going in the right direction. That is a good sign!
Important reminder: Not every symptom is related to cycling. If it persists, see your physician.
7. Do not get discouraged if you see no improvements immediately. Be patient. Trust your map and what it shows. Read the progress reports of others to encourage you during the rough times or whenever you are doubting the guai is working.
8. Follow the hypoglycemic diet if it applies to you.
9. Look for subtle improvements (check your initial symptom list).
10. When you start feeling better, do not overdo!!

"We all must suffer from one of two pains: the pain of discipline or the pain of regret. The difference is discipline weighs ounces while regret weighs tons"

Jim Rohn

Update on ordering Guaifenesin as of 6/1/20:

While there may be other options, iFoG's recommendations for purchasing guaifenesin::.

Go to www.Guai-Aid.com

Note for iFoG members only: **For 15% discount (no expiration date), go to "view cart" PRIOR to "checkout" and insert code "HAPPYGUAI". Free shipping for orders over \$75 in the United States.**

Order GuaiAid 300mg veggie CAPSULES which are medium acting and must be taken 3x/day (every 8 hours)

OR

(Recommended) Order GuaiAid 600mg CAPLETS which are longer acting and can be taken only 2x/day (every 12 hours)

Follow directions below depending on which guaiAid you are using:

If using CAPSULES:

- a) Start 300mg (1 capsule) every 8 hr for a week.
- b) If not tolerably worse or different, increase to 600mg (2 capsules) every 8 hr for a month.
Must be taken 8 hours apart! If you reach this dose, use up the 300mg capsules and you may then **order for subsequent use: GuaiAid 600mg capsules**
This will allow you to take 1 600mg capsule instead of 2 300mg capsules when you run out
- c) This is sufficient for 90% of patients. iFoG will work individually with you should your dose require a higher amount.
- d) DO NOT alter your dose from day to day. Doing this will make it extremely difficult to find your cycling dose.

If using CAPLETS:

- a) Start 300mg (1/2 caplet – it is scored) twice a day (every 12 hr) for a week.
- b) If not tolerably worse or different, increase to 600mg (1 caplet) twice a day for a month.
- c) This is sufficient for 90% of patients. iFoG will work individually with you should your dose require a higher amount.
- d) DO NOT alter your dose from day to day. Doing this will make it extremely difficult to find your cycling dose.

(Important: the above dosage guidelines differ from Dr. St. Amand's book because there has been a change in the manufacturing and availability of previous longacting over the counter guaifenesins)

Subj: Hi! My Name is Salicylate. Glad to Meet You!
Date: 4/8/03 12:31:16 PM Pacific Daylight Time
From: cherokey3@SOCAL.RR.COM
To: GUAIGROUP@PEACH.EASE.LSOFT.COM
Sent from the Internet (Details)

Hi my name is Salicylate. Glad to meet you.

I am very popular in your products. I love to block the action of your Guaifenesin. You see I am the only enemy that Guai has. Guaifenesin likes to take up all the *parking spaces* in the receptors of the proximal renal tubule of your kidney to make you purge those phosphates, but I can sneak in and park there too and stop the phosphates from leaving your body. How about that! I am a sneaky peat. I don't want you to get well using Guai.

Want to know my secret? I hide in your toothpaste, your dental floss, your facial tissues. Sometimes I am an Aloe. Other times I am a Mint. Other times I hide in your lipstick as Castor Oil. Bet you did not know I hide in your vitamins too as rose hips, bioflavonoids and quercetin. I can also hide in your massage oil..how about that! You say you smoke?....well I hide in your cigarettes as Menthol. I get real sneaky when I hide in your lip balm as camphor.

I'll really get you with you mouthwashes, deodorants, chewing gums, nasal sprays, your breath mints, razors and your shaving cream. I'll hide in your shaving cream too. I can hide in all of these products as camphor, castor oil, mint, spearmint, peppermint or wintergreen oils. You say you have a cough and use cough drops. Well then I hide there too as eucalyptus oil. Oil is a neat way for me to hide. Sometimes I hide as an extract. Wow. Bet you didn't know that.

You say your breath is bad and you are using mouthwash. Oh my...I'll get you there too. I hide as salicylic acid or methy salicylate. In toothpaste I hide as salicylic acid or methyl salicylate in addition to Mint. I got a lot of people with the toothpaste. You know why? Folks ran to their store and just bought up any old brand. They did not check that Salicylate Free Products Link on the Fibromyalgia Website. <http://www.fibromyalgiatreatment.com/EasyQuickLinks.htm>

You say you like to walk barefoot on your grass. I'll get you there too. My favorite hiding place is in the leaves of the grass...especially when they are wet because I am even more potent. How about when you do your dishes by hand every day. Do you have cuts on your hands and fingers? If so..I'll get you! I hide in your dish soap as Aloe Vera, Lavender, yland-yland, Patchouli, green tea extract and other neat plant names.

How about your sunscreen. I am hiding there too as oxyl-salicylate, homosalate and aloe. One of my favorite names is witch hazel. I hide there in your toner. Sneaky yes? One of my favorite tricks is to hide in your facial tissues and toilet paper as Aloe.

My biggest fear is that I will become exposed by folks continuing to go to the Fibromyalgia Website and reading all the Salicylate Links. They may even find out about my hiding places by checking dictionaries or using a Google Search Engine to identify me. They may buy the Book "What Your Doctor May Not Tell You About Fibromyalgia" by R. Paul St. Amand, M.D. and Claudia Craig Marek. Wow...then I will really be exposed! Folks will then learn just how I work to hinder the Guaifenesin Protocol. If you find me then I am doomed and you will get well by using Guaifenesin without me.

Written by Char Melson
GUAIGROUP Admin Team Mem

Common Salicylates to look for in products

All of the following may contain salicylates so check them carefully: Acne products, dandruff shampoos, bubble baths, cosmetics, gums, shampoos, conditioners, sprays, lipsticks, lotions, lozenges, muscle pain creams, razors with aloe strips, skin cleansers or exfoliants. Herbal medications such as ginseng, St. John's wort, ginkgo biloba, saw palmetto, blue-green algae, Echinacea, or nonni juice.

Make sure products don't contain plants, herbs, extracts.

No words or syllables with "sal" in them.

Check for aloe, menthol, extracts, castor oil.

In deodorant - check for castor oil.

In lotions - look for aloe, other herbals.

In hair products - look for chamomile, lavender, herbals, aloe.

Toothpaste and dental floss - make sure it doesn't have mint.

In makeup - look for castor oil, other plants.

Shaving cream - check for plant derivatives such as aloe, mint or mentholatum.

Sunscreen - check for oxy-salicylate, homosalate, aloe, meradimate, ecamsule/mexoryl sx

No medicated creams, like Ben-Gay, Noxzema, Blistex, balms and lotions such as Myoflex, Zostrix (Capsaicin or capsicum)

If it feels cool or if it burns, it probably contains menthol.

No mint candies or chewing gum.

If it is a chemical it is okay unless it has "sal" in it.

No lipsticks with aloe, camphor or castor oils.

Be suspicious of anything that says "natural" and read carefully for any mention of flowers, plants, etc.

In Toners, no witch hazel.

Vitamins such as C or E that are derived from Rose Hips or contain bioflavonoids, added herbs such as alfalfa, parsley.

Toilet paper and Kleenex may have aloe.

No Pain products labeled salicylate or salicylic acid such as aspirin, Salsalate, Disalcid, Anacin, Excedrin.

No Medications such as Alka Seltzer or Urised.

Use waterproof gloves when gardening. Use gloves for chores utilizing Pinesol, Lemon Oil, Etc.

No Bubble baths and lotions with essential oils or plant parts such as aloe, cucumber, lavender; almond or grape seed oils etc.

No Lozenges with menthol, mint, peppermint or spearmint

No Wart or callus removers (sal-acid plasters)

SAL 101 Class - Quick Reference / Salicylate Guide / Screening Test

All plants make salicylates. When eaten in foods, the amounts are tiny (the vegetables are not concentrated enough to do us harm). The liver gets the tiny amounts and processes it to salicylate tagged with glycine, which apparently renders the offender less blocking. When applied to skin, lips, mouth membranes however, the salicylates are rapidly absorbed and get to the kidneys without benefit of first passing through the liver.

BASIC SAL SCREENING GUIDELINES

These are the main no-no's to watch out for when buying a product. Check both active and inactive ingredients on the label.

If you find just one of the following, you cannot use the product.

1. Don't use if there is the word "oil", "gel", or "extract" with a plant name (easily identified by TWO latin words) in front of it
The exceptions: Anything that comes from the **grain or seed** of these plants: Corn, Rice, Rye, Oats, Wheat, or Soy (C.R.O.W.S.) are **okay**
2. Don't use if there is aspirin (acetylsalicylic acid) or the word "salicylate" or the syllable "sal"
3. Don't use if there is mint, menthol, or camphor; or the syllables "menth" or "cam"
4. Don't use if you see the following in vitamins and supplements:
Bioflavanoid, Rutin, Quercitin, Hesperidin
5. Don't use if you see Octisalate, Homosalate, Mexoryl or Meridimate in sunscreens
6. Don't use butters such as shea, cocoa or mango butter in skin products

Other precautions:

1. Avoid drinking tea, smoothies or juicing
2. Avoid any over the counter toothpaste
3. Avoid products with blue, violet or green dye

- * Don't use it if you can't check the original fine-print label.
- * If it has salicylates in it at all, you shouldn't put it on your outside.
- * If it has enough salicylates in it to make a difference in your mood or how your body works, you shouldn't put it on your inside.
- * Anything that promises to lubricate or moisturize or anything that feels cool should be suspected immediately.

First glance at a label just to see if you immediately recognize any definite "Nos". Because if there is even one, you can't use it, so don't bother with the rest. If unable to determine if it is a plant, use "Google" search.

Details of above Screening Guidelines:

1. **Don't use if there is the word "oil", "gel", or "extract" with a plant name (easily identified by TWO latin words) in front of it**

Certain plants seem to be more "trendy" or "common" to include than others. So once you know that aloe vera, ginseng, ginkgo biloba and castor oil are all plants and off limits, you can quickly eliminate a lot of the products you pick up without having to read the full label if the first time you read you look for what you *know* you can't have. If unable to identify easily, some helpful hints to look for:

Scientific names for plants are based on latin...and there are *two* words in each name. A lot of them have a similar "ring" to them... The endings "us", "sia", "ii" and "sis" above are very common in scientific names for plants, for example:

Sunflower (Helianthus annuus) seed oil	Cinnamon (Cinnamomum Cassia)
Jjoba (Simmondsia chinensis) oil	Aloe vera (Aloe barbadensis) extract

The other tip-off that these are plants is that two are called oils and one is an extract. As well as the fact that there is both a "plain English" name together *with* a scientific name

Memorize **CROWS** - The oils, gels and extracts from the **grains** of these plants are salicylate free. These are the only exceptions:

Corn

Rice or Rye

Oat

Wheat

Soy

Foods have been tested many times because of patients with allergies. The grains actually do not contain salicylates, though the plant parts they grow on--do. So wheat germ is fine, but wheat grass would contain salicylates.

ALSO

any oil, gel or extract that does not have a plant name is fine. For example: fish oil, placenta extract or vitamin E gel are fine to use too...

2) Don't use if there is aspirin (salicylic acid) or the word "salicylate" or the syllable "sal".
salicylic acid, octylsalicylate, homosalate

3) Don't use if there is mint, menthol, or camphor; or the syllables "menth" or "cam".

Note: You may be confused between menthol, menthyl, mentha and methyl.

Here's the way to remember it. If you see an "N" in it -- it's a salicylate. Remember "N" stands for "**NO**" - These words are all from the latin word for MINT.

MENTHOL--is an alcohol from mint oil (C10 H18)

MENTHYL- is compound radical that is the base of menthol (C10 H20 O). So

MENTHYL anything is a salicylate. It signifies a compound made from menthol.

MENTHA - is the prefix meaning Mint. (Latin, like most plant names) So

Mentha Arvensis, Mentha Piperita, Mentha Viridis are just species of mint plants.

The above are all salicylates and cannot be in products you use.

METHYL (**note, there is no "N" in this word**) signifies a chemical derived from METHANE (by the removal of one hydrogen atom). So these chemicals are NOT salicylates, **except for METHYL SALICYLATE** which is obvious because you see the word "salicylate." Methyl salicylate is oil of wintergreen, or a mint oil.

MEN--watch out for salicylates = NO

MET== OKAY unless it is methyl **salicylate**

Camphor definition: A fragrant compound from an Asian Evergreen tree that is used in skin care products because it feels soothing to the skin.

Chemicals are okay. If ingredient names are long and hard to pronounce words that you would not use in normal conversation or may even have numbers in them, these are probably chemicals and chemicals are OKAY to use. e.g.:

caprylic/capric triglyceride cetareth-20	C 12-15 Alkyl benzoate dimethicone	glyceryl stearate panthenol	cetyl alcohol
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What do chemical names sound like? Things ending in "ol" are alcohols (propylene glycol) and alcohols are chemicals.

Other common "sounds" in chemical names are:

"ate" (retinyl palmitate)

"yl" (methyl... propyl...)

"meth" (dimethicone)

Some chemicals have initials as part of their names (dmdm hydantoin, tetrasodium edta).

glycerin is ok...and there are other chemicals in here that have "glycer" as part of them, so their names sound "chemically" (caprylic/capric triglyceride, glyceryl stearate)

4. Don't use if you see the following in vitamins and supplement:

Bioflavanoid, Rutin, Quercetin, Hesperidin

Definition of Bioflavanoid: Plant derivative with antioxidant and anti-inflammatory properties;

Compounds found in fruits such as lemons, grapefruit, cherries, blackcurrants and buckwheat.

Examples of bioflavonoids are hesperidin, rutin, and quercetin.

5. Don't use if you see Octisalate, Homosalate, Ecamsule/Mexoryl sx (camphor), Meridimate (Menthyl anthranilate) in sunscreens --these are salicylates that are not obvious

6. Don't use butters such as shea, cocoa or mango butter in skin products

Other precautions:

1. Avoid drinking tea, smoothies or juicing

2. Avoid any over the counter toothpaste

Toothpaste is brushed into the gums and we suspect that the salicylates would get into the blood stream via the abrasions this would cause, thus avoiding processing by the liver.

* IFoG highly recommends for toothpastes, that you stick to only baking soda, order the toothpastes from Andrea Rose (www.andrearose.com), or Squigle Toothbuilder Sensitive Toothpaste

3. Avoid products with blue, violet or green dye as it may slow down energy production and stall clearing

Miscellaneous info:

Regarding teas, supplements, vitamins:

Do not use any herbal medicines or plant concentrates as supplements or if in vitamins. When they are taken by mouth, there are often larger salicylate bursts to overwhelm the liver's capacity to glycinate (adds glycine or glucuronide to the salicylate which renders the compound even less potent) and delivers it directly to the kidneys.

Dish Washing, Laundry & All Cleaning Products

Avoid any citrus extracts/natural plant ingredients and blue, violet or green color in dishwashing soap

Avoid cleaning products such as Orange Glo (has concentrated orange oil) or cleaning products with lemon oil, etc. Wear gloves

Avoid laundry soaps that are blue, violet or green (e.g. Tide liquid or Tide Pods which are blue)

Fragrance

In Perfumes and Colognes, fragrances are okay as long as it doesn't list any essential oils. To be safe, we recommend misting on clothes and avoiding skin contact.

In other products listing fragrance, it is normally not an issue unless plants are actually listed. Occasionally, it might contain a small amount of salicylates that may not be obvious but would only affect those very salicylate sensitive.

Gums, Candies & Breath Fresheners - Avoid breath fresheners/breath mints, candies/lollies, chewing gums, lozenges, etc. with any natural mint, peppermint, piperitone (artificial mint), natural or artificial wintergreen. Avoid natural flavors, and use artificial flavors instead

Hair Products - Colorants can be used without concern as they are not being applied very often.

Washing your hands while visiting a rest room away from home normally isn't a concern because soap is on your hands only a few seconds, and your hands don't absorb much. But it can be a possible blocker IF you wash your hands often. Suggestion - taking along plain Purell instead

Castor oil – do not use in ANY form even if it says “PEG40 hydrogenated castor oil”

Flaxseed – you may use up to a teaspoon of flax seed daily but do not grind them up or use flax seed oil

Stevia – do not use

Lutein, BHT, inulin and hydrogenated cocoglycerides – use with caution as iFoG members have been suspected of blocking from these (these have not been confirmed with Dr. St. Amand, but as a precautionary measure, iFoG recommends staying away from these, sometimes found in eye medications, cosmetics and supplements)

All blue, violet and green dyes- avoid mainly in medications (such as Nexium) and supplements and avoid in products used daily such as dishwashing soap, blue laundry detergents and shampoos. It has been suspected of affecting the production of energy in our cells and interfering with clearing although they are not salicylates. They may hinder progress in some.

Personal Basics by Andrea Rose, Salicylate Free Skin Care Products is the original online company that has produced salicylate free products for people on the guaifenesin protocol for over 20 years. This is the only company we fully trust. You do not need to read ingredient labels should you decide to go this route.

To order, visit the website at www.andrearose.com or call (310) 470-0691. Please note this website has all the makeup products. For her skin care, hair care and dental products, go to www.DrJonDC.com (this link is at her site also).

Instructions for journalling

G = GOOD
MG = MEDIUM GOOD
M = MEDIUM
MB = MEDIUM BAD
B = BAD

Jot briefly how you feel that day (e.g. when waking up, afternoon, night) on calendar "big" square each day

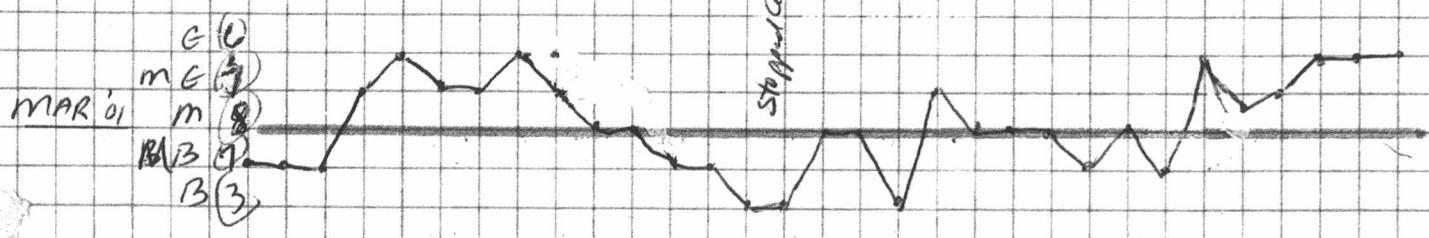
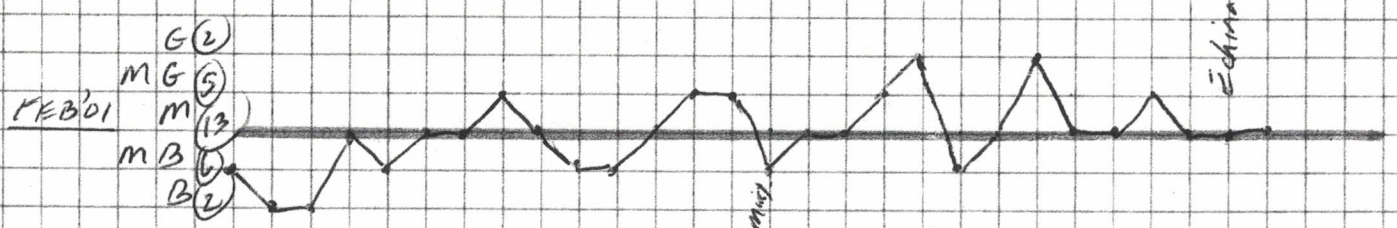
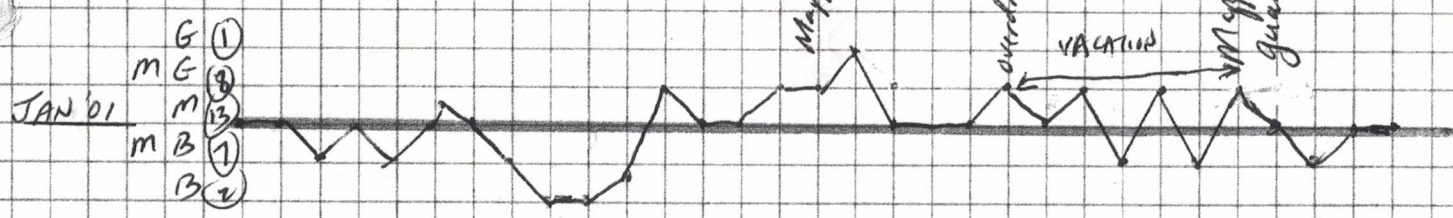
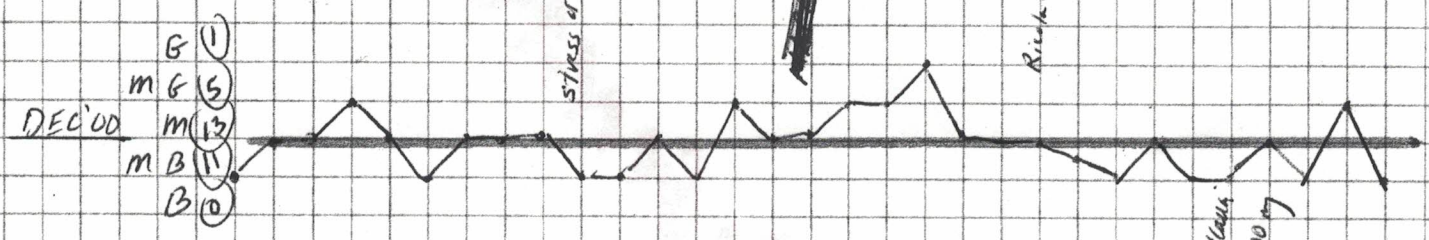
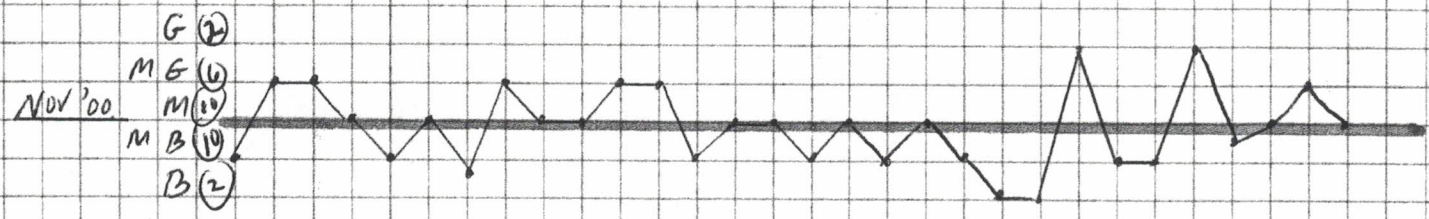
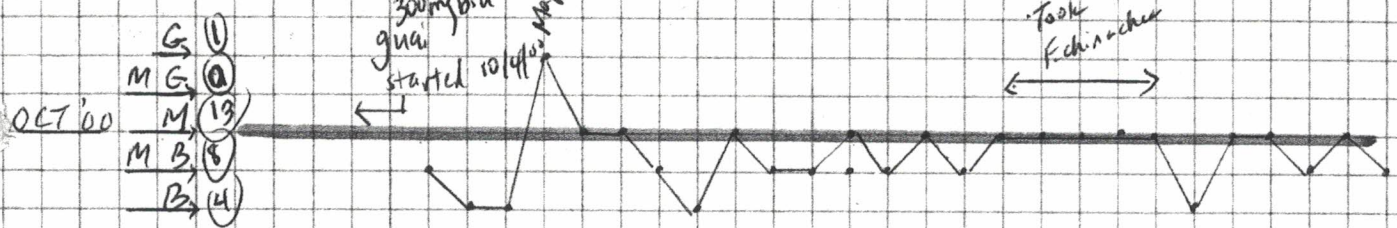
Rate your overall day from key above and insert letter (G, MG, M, MB or B) into small square of calendar

On graph, put a dot that corresponds to that day's rating. The horizontal numbers correspond to the days of the month (1-31). The vertical corresponds to the key above. Connect the dots daily.

At the end of the month, total the number of days corresponding to each letter rating and insert next to letter. Circle each total. Note the "number" above the middle line (Medium) increase and the "number" below the line decrease as you go further into the protocol.

Sun	Mon	Tue	Wed	Thu	Fri	Sat
1	2	3	4 Guai started	5	6 Little sore am. MB Walked more normal as day passed. Fingers joints achy. Feet toes occasionally numb. Overall achy. Rt inner heel sore, Lt breast bone sore, bitchy	7 Slept till 8:15. Bad Lower back / hip pain. Achy. pimples
8 Lower back B sore, eased after 1/2 hr. Bad sinuses, slight headache. Long nap - achy in afternoon. Feet itchy	9 Woke up pretty good. Edge of jawline very itchy. Fine rash. Slight heel pain. No backache. Feet itchy. Eye - NO PAIN! Tennis 3 sets. Rt toe numb, heel hurt after 10:30 am	10 Legs achy M again, heel sore. Face dry, itchy, rashy. Used Lozoid. Fatigue improved. Aches present but diminished	11 Pain in heel M present. Overall aches. Tolerable. Mapping done.	12 Heel pain MB bad, achy. Knees, worst. Shoulders achy, neck getting sore	13 Woke up sore. B especially shoulder, neck, rt heel sore. Midmorning pain really bad while body. Couldn't push cribs without hurting. Advil. Wheezing in eve	14 Pretty good M am. Slight hip pain. Rt outer heel slightly tender. More sore in eve.
15 Woke up MB sore, nose running all day in airplane. Vegas	16 Woke up sore MB. Legs achy all day. Heel inner part got worst throughout day. Nose running all morning	17 Walked strip. Mainly achy, heel pain off & on	18 Woke up MB. Beaky am. Knee - severe cramps, achy legs, neck, shoulder in eve. Knee cramps again	19 Pain mostly in knees	20 Hip pain MB in am. Yucky urine? Legs achy. Headache all day. Lots of fatigue	21 Fighting off M cold. Took echinacea + vitamin C w/ rose hips. Heel sore
22 Stuffy nose M. Achy. Tired in church. Sleepy. Legs tired. Heel pain in late pm, early eve.	23 Woke up M. Little achy. Feet not bad. Cold, but not bad. Shoulders hurt more in eve. Achy at tennis	24 M	25 Left leg cramp M. This am. Neck sore, foot hurts. In eve burst of energy + cleaned house. STOPPED Echinacea	26 Sore this B am. Legs, rt midback, bottom of feet. Very fatigued. Slept 1200-1630. Whole body really achy in eve. Hard to even bend to fold clothes	27 Achy, M. Headache in afternoon	28 Fair day. M. Achy. Stomachache in eve. Fatigued at church
29 Achy on MB walking. Shoulders, feet tender. Played 2 sets tennis. Very achy upper shoulders, heel pain, neckache in eve. Elbow, arm bad	30 Very stiff M. This am. Vulvar pain now. Fatigue not bad. Pain in wrist joint when pressed. Itchy stomach in eve	31 Woke up MB both legs achy + both heels very sore. Very stiff. Right lower butt hurts. Right middle finger, sub. sprained. Sides burning - worst in eve. All fingers sore				

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31



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 this time, with a 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 choice, 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 a 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".