

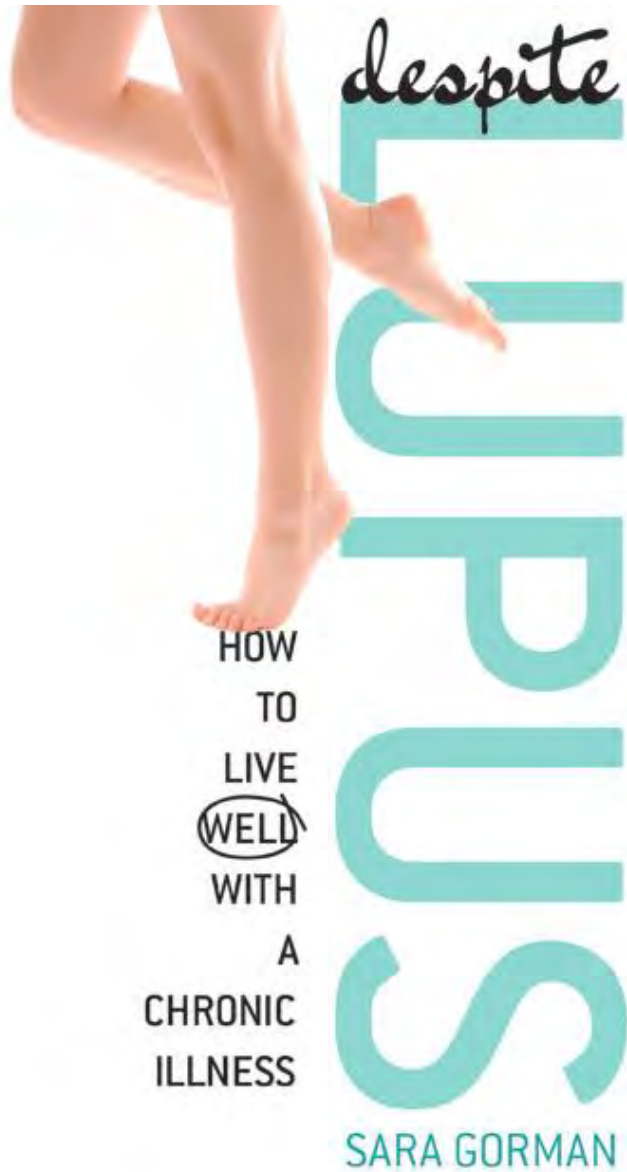


*despite*

# LUPUS

HOW  
TO  
LIVE  
WELL  
WITH  
A  
CHRONIC  
ILLNESS

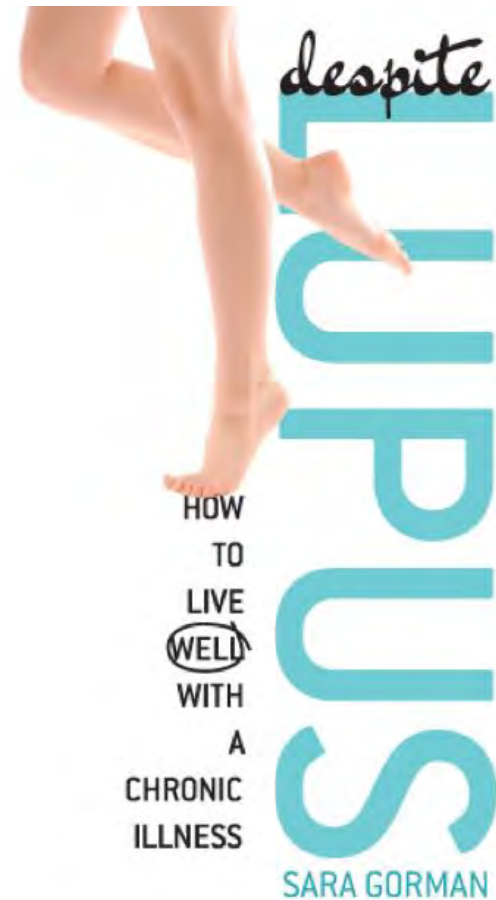
SARA GORMAN



Give Yourself  
Permission,  
Despite Lupus!

# Patient Snapshot

- Sara Gorman, author of “Despite Lupus: How to Live Well with a Chronic Illness” – [www.despitelupus.com](http://www.despitelupus.com)
- Lupus patient for almost 17 years
- Experienced the effects of lupus: at home and at work; emotional and physical



# Patient Snapshot

- Diagnosed at the age of 26
- Married just six weeks prior to diagnosis
- Thriving career in television production
  
- Chest pain in back & side - misdiagnosed. Developed joint pain, fever, swelling, sore throat, swollen glands

# Struggled to permit myself to...

- **Compromise** — To rest as needed; Leave work; Say “No”.
- **Let Go of my Guilt** — Commitments; Expectations
- **Take Action** — Start a medication; Make changes at work

# No Permission =

- No Flexibility
- No Allowances
- No Cheating
- All or Nothing

# No Permission =

- No Flexibility
- No Allowances
- No Cheating
- All or Nothing
- Emotional Toll  
Internal struggle
- Physical Effects  
Pushing beyond limitations
- Lifestyle: Work, Home  
Sacrifice/Cancellations

# Realization...

- Lupus was controlling the situation
- Lupus was determining when, where, and how
- I wanted options. I wanted a say.
- Stop trying to control lupus. Start *managing* it.



# Alter my strategy:

Open – To Ideas; To Change

Honest - What worked; What didn't

Flexible

Self-Aware - Take notice

Self-Respect – For myself; Also my family

Dignity – Deserve to feel better

Responsible – Be a Better Patient

# Why is this our job?

- We know our disease best.
- We're living it. We should be the ones to manage it.
- We should create the boundaries. Write the script. Not lupus.

# Give Yourself Permission to:

- Compromise
- Let Go of Guilt
- Take Action

# Compromise

Why are we unwilling to  
**compromise**  
for the sake of our health?

# My Difficulty:

\*Sign of Weakness

\*Scared – is it forever?

\*Frustrated - Lupus has already taken so much

\*Driven to do it all.

\*Liked Control

\*Pre-Conceived Notions

\*Pride – what will “they” say

\*Worried

\*Embarrassed

\*Overwhelmed

# Compromise

- Giving In is *NOT* Giving Up.
- Working toward a solution, rather than away from one.
- Creating ***workarounds*** = Sign of genius  
Def: “Method for overcoming problem or limitation”

# Seeking Compromise

- Retrain your brain
  - Proactive, Creative, Responsive, Preemptive, Healthy
  - “Always another way.”
- Move past excuses
  - We can all say no. Who’s going to say yes?
  - Whose excuse is it?
- Share the Burden
  - Show people how to help. Kids, Rest, Work, Dinner.

Ex: My Daily Nap

# Tools for Compromise

**Tracking Systems** – Health Tracker Apps, Chronic Control Sheet

**Support Groups, Online Sources** - Confirmation

**Practice** — Developing skills & tactics. More strategic.

**Ex. Napping during Renovation** – Fan; Headphones;  
2<sup>nd</sup> bedroom; Changed houses; Changed Schedule.





“Concentrate on areas where you can affect change. Doing so will bring you the satisfaction, feeling of influence, and inner strength you’ve been craving.”

*--Despite Lupus: How to Live Well with a Chronic Illness*

# Time to Practice

Name two areas of your life where compromise would be helpful.

What is standing in your way?

Intentionally Left Blank

# Letting Go of Guilt

Why do we feel guilty  
about taking care of  
ourselves?

# My difficulty:

\*Commitments

\*Hard to say no

\*Don't want to disappoint

\*Uncomfortable

\*Requires explanation

\*Causes Conflict

\*Invites criticism

\*Feels Selfish

# Letting Go of Guilt

Def: *Having the knowledge that you're doing something **wrong***

- Doing something RIGHT!
- Creating Positive Result
- Whose Guilt? – Yours? Theirs?  
Ex. Nap vs. Christmas Decorations; Sewing new skirt for Elf

# Being Guilt Free

- Consider the Consequences
  - Cause and Effect; Pros and Cons
  - Weigh the Options. Experience the Results.
- Strive for Consistency
  - Do the right thing. Every time.
  - Creates Expectation: Still a challenge. Not a surprise.
- Ignore the Pressure
  - What do we tell our kids?

Ex. Trip to Charlottesville



# Tools for Deflecting Guilt:

- **Write it down** — Journal, etc. Track it.
- **Choose to move beyond** — aka “Ignore”.
- **Educate** — Demonstrate, then move on.

Ex: Pool with Kids

“The harder I push, the sicker I get. The sicker I get, the less I resemble myself. The less I resemble myself, the harder I push to regain some semblance of who I used to be.”

*--Despite Lupus: How to Live Well with a Chronic Illness*

# Time to Practice

Name two things you feel guilty about doing for the sake of your health.

Source of guilt?

How can you move beyond it?

Intentionally Left Blank

# Taking Action

Why is it so hard  
to take action – for the sake of  
your health?

# My difficulty:

\*Feel selfish      \*Hard to make big Decisions

\*Turn my life upside down      \*Not in my plan

\*Unexpected      \*Worry about outcome

\*Hard to admit – Forces acknowledgement

# Taking Action

- **Change is Hard**
  - The familiar is always easier.
- **Unknown is...unknown**
  - Will only know if you try.
- **Action is forward motion**
  - By taking action, embracing disease; first step toward rebuilding, with lupus in tow.

# Taking Action

- **Most Decisions aren't Forever Decisions**
  - Try it on for size
  - Ex. Part Time Work
  
- **Prioritize Your Health**
  - Choosing "You"
  - Talk to employer; Set up the carpool; Rest so you can function.
  
- **Set Yourself up to Succeed**
  - Put on this earth to make an impact. To contribute. To make a difference. We can't miss our chance.

**Ex. Cellcept** — Nothing else was working



# Tools for Taking Action:

**Do your research** – Use your doctor, consult others

**Practice** – Making good decisions gets easier. Build on momentum! Ex. Hair, Job, Cellcept

**Consider the Long Game** – Write down where you want to be, with lupus in tow. Take baby steps to get there.

“Assertiveness is about diplomatically displaying a self-confidence that cannot be ignored.”

*--Despite Lupus: How to Live Well with a Chronic Illness*

# Time to Practice

Name two areas where you're struggling to take action.

Write down the first baby step toward taking action for each

Intentionally Left Blank

*“Despite Lupus: How to Live Well  
with a Chronic Illness”*

Sara Gorman

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