

# How to cure lupus

# Okay if you ever read that headline on a title of an article or someone says this to you, then run away (except on this occasion!)

I will share why that is in this report, however the main reason for this report is that through my work as a speaker, coach, writer, etc I don't hide my Lupus, other auto immune diseases and Fibromyalgia and I aim to be a voice of "You can get through this" however a positive mindset is just not enough when it comes to these long term health issues, I know how truly tough they can be and I want to share what I've learnt. Originally this was going to be a blog article however I decided to create a downloadable PDF so you could keep it and read whenever you need it.

I've put this together in a way that it could be useful to;

- Anyone suffering from a long-term health issue.
- Anyone that cares for and loves someone with a long term condition.

The first thing I want to say is I'm not an expert, I'm not medical qualified, and I've no affiliation to anything I recommend or share that has helped me (except coaching.)

# Which leads me to our first top tip about what I've learnt is my headline "I can cure your lupus...."

Anyone that states they can cure your lupus is not doing you in any favours. I know there are a ton of people out there saying they *can* and they've had "great results with your illness" however that doesn't' mean it will work for you. And the reason I'm being so honest here (and at risk of alienating what some people think, but I take that risk because I care more about you who either has Lupus, a long term health issue or know and love someone that does) is because while there is firstly the ethical and trading standard angle to consider that what they are doing is against the law, on top of that trust me as someone who has tried a mountain of things, do you know how demoralizing and soul destroying it is when something that has *cured* someone else with



your illness it fails to work for you? I can tell you, I have felt stupid, and questioned why can't it work for me, "What's wrong with you Mandie?"

I'm not saying don't try these things just be cautious about the claims the business makes and the way they contact and engage with you, many are using illegal and unethical ways to engage with people like you and me who are quite frankly desperate to have a day without pain, exhaustion and feeling life our lives are over. And they are taking advantage of this even utilising NLP and other communication skills to engage powerfully with you and manipulate your response. I just don't want to see you get bullied into things.

# Fight, don't stop fighting and just when you think you can't fight another day, fight some more!

I should tell you that to get the diagnosis of Lupus; I had growing pains at 16 that got a lot worse and for a good few years they told me I had Ankylosis Spondylitis (easy for me to say!) and a curvature of the spine. Then as that got worse I changed many aspects of my life and coped fine (Okay if I pushed my luck I could end up with severe back ache but the right exercise, diet, massage, etc did help)

Then I got ill in 2011 and had to walk away from my business for 18 months unable to drive, work, even hold a phone. In the dark, in bed, (quite often trapped upstairs because I couldn't get down them) and at times rushed to hospital with what appeared to be a heart attack (turns out its pericarditis).

Jump forward 6 years after being told I had and then didn't have ME/CFS 5 times (and given the wrong medications accordingly 5 times!) I was then told by a fab guy (sorry I mean specialist) *"Mrs Holgate until you accept your life as it was is over there is very little we can do for you."* 

Gee thanks mate, 38 years old, children 8 and 10 years of age, living on my dream island or Mersea, running businesses I love, flying around the world and even on national TV and at the Home office for my work for women in business and it's all over.

"Hey Mandie go home and don't bother us" we felt like we'd been told. Me and my husband walked out the hospital that day and decided there was no



way we were accepting my life (and by design my families) lives were over. We fought, we made call after call, we ensured we got names, listed every phone call date and time (and duration) and basically felt like we were pestering.

It was soul destroying to spend your husbands' holiday on days in London (not having fun because you are too ill to do that) but slepping from one hospital to another even having specialists not turn up to appointments that we'd waited 6 months for! Yes that's right, meanwhile for 6 months I'd be at home in bed, feeling like I'd gone mad (because their tests were always clear) and that it was "all in my head".

Eventually as the amazing Doctor Lane at Addenbrookes told us 2 years ago "Basically I'm like House" (you know the TV show where "it's never Lupus"?) and she had found this rare antibody in my blood that pointed to Lupus and miraculously I was put on the right medication and so many symptoms were alleviated and some practically disappeared, genius!



But wow, what a fight, so don't give up.



#### The right team.

To not give up you the need the right team. Medication is cruel and never says this;





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WARNING!!!

- This medication will;
- Make you feel sexy
- Give you luscious hair
- Give you strong nails and teeth
- Make you slim
- You will sleep like a princess

\_\_\_\_\_

- You will feel full of energy
- You will look amazing.

The point is when you end up with the horrific side effects you need the right people around you. You don't need someone saying that "It's your age that means you are putting on weight Mandie" Yes I had that!

One medication could make the weight fall of like I'd had a gastric band fitted and another

could make be balloon up like a overweight moon shaped hamster within a few weeks. No change in diet or activity, just medication. Therefore the last thing I needed was that level of negativity in my life.

Steer clear of those people. Choose your friends wisely and choose carefully what you listen to.

Which leads me on to....



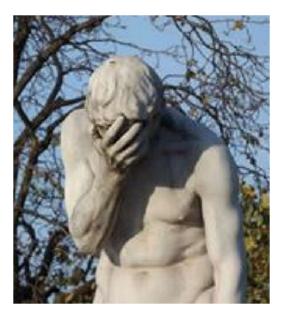
### ...People don't get it.

When someone says something like I shared above about my weight they didn't intend to be cruel they just don't get it and they are trying to be helpful oblivious to the damage they are doing to you.

I would hear;

- Have you tried regulating how much sleep you get, you must be getting too much during the day that is impacting on your sleep pattern.
- You need to watch what you eat.
- If you can just do some exercise I'm sure you will get better.
- That medication will make you a druggie you need to find a natural alternative.
- You're probably stressed and that's causing your health problems. Get your stress fixed and you will recover.

The list was long, arduous, sometimes offensive and so often very unhelpful as well as untrue. Accept what they have to say and then share your view and leave it there. I found that I realised it was their issue not mine. I was working hard to understand, research and gain wellness, literally searching the globes finest reports, books, studies, articles and ideas to find solutions, their comments were meant well and I'd leave it at that.



Ultimately their lack of understanding was their issue not mine. However, it doesn't make it any easier when people stop phoning or trying to get you to go out. People don't understand (and I personally now think I'm glad they can't) however it's still awful that you can't book a ticket to a concert next year, because you just don't know how ill or well you will be. They don't get that while you had every intention of being there this weekend, it turns out you need to hide in a dark room and go to bed at 6pm because you went to the shops two days ago or had the audacity to do a days work. I found that letting them go along with their opinions I could protect myself from a lot.



#### What I've tried;

While I said at the start I find some businesses methods of engaging with people with long term health issue at the very least inappropriate and at the worse like some wild west quack doctor in front of a throng of people outside the towns saloon and the man in the front stumbles forward barely able to speak or walk only to be miraculously cured with the quacks potion and the exclamation of "it's a miracle" I do think that many alternatives to medication can have their benefits. So here are some of the ones I've tried; (Just some!)

- Aloe vera
- Crystal therapy
- Reiki
- Ear massage (I think it was Taiwanese)
- Naturopath
- Nutritionist
- Aromatherapy
- Hydrotherapy
- Physiotherapy
- Occupational therapy
- Pacing
- Medication (too many to name!)
- Massage
- Reflexology
- Acupuncture
- Homeopathy
- Psychology
- Counselling
- CBT
- Eft
- Coaching
- Journaling
- Mediation
- Mindfulness
- The power of now
- Yoga
- Chinese medicine



- Indian head massage
- Argi 9
- Herbalife
- Cannabis oil
- Vitamins

I used to joke "That if sitting under a tree of crystal's, knitting yoghurt and humming Om would work, I'd do it!" I was desperate so I tried everything anyone suggested and kept an open mind to the possibilities.

## Of the above, the ones that have helped me and I'm still using;

- Magnesium spray if it tingles use it again the next day I spray it on my back and legs before bed. When it stops tingling I was advised I didn't need it for a few days, and weirdly (I don't know why this seems to be true.
- Vitamin D3 (under the tongue spray)
- Vitamin B12 (under the tongue spray)
- **Cannabis oil** (the smallest strength I use is 5%) Helps especially with sleep, muscle twinges and possibly the exhaustion and pain. But hey, sleep! (I only use the legal version at this time. Although I will be speaking to my specialist about the possibility of accessing this via them as the good ones are around £150 a small bottle!
- Journaling is useful to me however I've discovered that I can't do it too often. It can be depressing and tough reading about how bad you feel. So I tend to write it and forget about it. It does help me get my frustration, anger and disappointment out and dump it for a while.
- **Coaching**. Coaching is of massive benefit to me. It ensures I am focusing on the things I want in life. That I know the goals I want to achieve. And that I have the right actions to do that will enable me to get there while respecting my health needs too. It also helps me process my thoughts and feelings so that I can dump the negative emotions and feelings and get back to positive ones (I use reframing for this a lot) I've even just got myself a sick mentor so I have someone who I can say "it hurts so bad wail wail" without feeling guilt for sounding like I'm moaning. I hate boring my hubby with it all (even though he will happily listen, I don't want to just talk about my illness) so my sick mentor gives me the space



to purge as she gets to do with me. We have a warning system on Messenger;

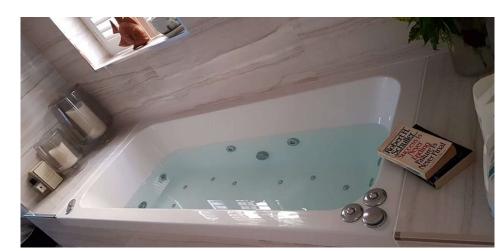
Green – I'm okay, are you?

**Orange** – I think I'm having a tough day, if you are about could we chat on messenger or the phone, don't worry if you are busy.

Red – I need you, can we please talk today.

I wouldn't have more than 2 of you in this relationship because it could get hard work. As a coach I know how to protect myself from other peoples negativity. It's called transference when you let other peoples stuff impact on you. However I appreciate that most people don't have those skills so I'd only work 1 2 1 on this.

- More aromatherapy oils than I can name and I don't go by the name as to if I use it that day I go by how it smells. I've noticed that at different times depending on what symptoms Im' experiencing, etc different smells appeal. For instance right now I can't stand oregano or citrus smells however I'm in love with Ylang Ylang, patchouli and bergamot.
- Epsom salt, Himalayan salt and II de re sea salt – in the bath with my aromatherapy oils.
- Hot tub and hydrotherapy bath. Help me



massively in more ways than there is time to say.

- Mediation and mindfulness. I'm hooked on being in the now and creating brain space with various tools and strategies some I've made up myself.
- **Dump the crap**. I don't hang on to crap, for instance I don't like confrontation therefore if it has to happen I say what I have to and then walk away. Life is (Literally too short to have these people in my life). See below for more on mindset.
- Anti malarial's definitely help with the rash and possibly the pain, however l've reduced the dose I take from time to time because they are now causing (after 5 years) some nasty floaters in my eyes that are

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getting worse. So I'm monitored for this with the Ophthalmologist and the optician. I have to watch which version I have because some brands can make me very ill. (Get your doctor to write on the prescription the exact one that works for you. Otherwise the pharmacy won't necessarily provide you with the brand you need.

- **Sunglasses** they reduce the light and protect my eyes, reducing migraines and head aches.
- **Big hats and sun factor 50** (I use Clarins 50spf because it is made to blend with my makeup so I can wear it all year round) and I'm allergic to UV which causes the Lupus rash.
- Pacing (but not how the NHS teach it!) I had to do a pacing course which was ironically and literally painfully funny. Because there I was too ill to work and yet somehow I had to drive myself to a pacing course for 6 weeks so that they would continue to investigate what was wrong! They don't share practical solutions or do anything around mindset. So here is my version of pacing;
- Listen to your body if you are getting the warning signs, (for me they include sneezing, feeling cold, muscle twinges and a slight headache) don't power through, stop. If you power through now you will crash for longer later. So stop.
- 2. **Rest** means not playing on your phone (that is making your brain work which needs the rest just as much as your body) and you need to hold your phone which means you are using muscles.
- 3. Only read if the book can be propped up and you don't hold it.
- 4. **Don't answer the phone** it takes energy to think about what you say, holding the phone, hearing sound, etc. If necessary leave it another room and add a message saying you are out.
- 5. For me sound and movement can make me feel overstimulated and so I know that pacing includes a **calm view and a quiet space**. I also benefit from seeing and being in nature so I will wrap up warm get some blankets and cushions so I'm properly supported and will sit in the garden.
- 6. **Change your attitude** to things that are now outside your control. For me it was house work. I'm a clean freak but now I can't clean like I used to. I'm reliant on 2 teens and a hubby to clean the house. And they just don't do it like I would! I used to get really stressed by the cobweb they'd missed or the feather on the floor, far less does it impact on me

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now, because I know that stress definitely makes my illnesses worse, so while my house is not perfect I am looking after my body and mind. Look at the things that you love to do and can't or like a certain way and you now can't achieve and change what you expect. Adjusting your expectations and what you assume what needs doing will help.

- 7. **The right clothes**. When I'm really struggling with the pain and sensitivity I even wear different clothes, that are very comfortable and lose to give my body a break.
- 8. Build up your ability to walk if you can only walk 4 steps and have to turn back (as I did at the start and occasionally during a flare may experience) then that is your limit. Aim to build it up every few days, even it is just one more step, but don't push yourself. Pushing yourself and thinking you are some marathon runner that must do it, will ruin your pacing. Monitor how you are developing, even if you aren't developing now when the weather changes or you get on different medications you might.
- 9. Your diary. When you've been ill for a while you may start to notice patterns to your illness. Things that cause a flare or aggravate symptoms. I know that January and February for me are tough so in my diary for the next 2 years it says on every day for January and February in 2019 and 2020 "Mandie do not overbook this is the time of year you are most likely to experience a flare!"

I also use my diary so that if I book something in I book the day after as a rest day and I allow nothing to go in there. Its' your choice if you over do it and end up needing 4 days off instead of 1 or 2 because you didn't listen to your body.

### 10.Sometimes but this is rare, ditch the pacing!

Because long-term illness can be very isolating and that can lead to additional problems like mental health issues like anxiety and depression. So once in a while ditch the pacing and go to the concert, or go the theatre, or go shopping with your mates. Yes you will pay for it, yes you will be floored for a few days, and yes you are going to pay in pain and exhaustion, however you will have given yourself a mental boost. We need to do this once in a while so that we can stock up emotional positive feelings, just be sensible about how often you ditch the pacing. I would ditch the pacing possibly once a month depending on how active my illnesses are.



#### **Placebo effect**

I read a book called "You are your placebo – making your mind matter" by Dr Joe Dispenza which looks at the power of a placebo effect. With this in mind I only read my prescriptions instructions and not the symptoms. I ensure I ask the doctor lots of questions about why I'm on the medication, what side effects am I at risk of, but then I choose to not read them on the pack. I don't want to plant the seed of an idea about what I may end up suffering with. (This is just my personal choice) Ultimately, I will soon get to find out what side effects I'm experiencing!

The point is that as this book explains our minds are very powerful and we can learn tools and techniques to help reduce our symptoms. For instance I use a visualisation that my pain is a bright black light across my body and I move the light up my body towards my little finger on both sides and as I do this I ensure I'm in a very relaxed position and concentrating on calm deep breathing with no distractions. Then as the "pain light" gets to my little fingers I visualise the pain being shot out of my fingers and



turning into a white light and going away. I can make my brain reduce in severity for a few hours. It is not a permanent solutions however it gives me some space from it. If you practice this and adjust it to make it powerful to you, see what works for you.

Before you dismiss this as "mumbo jumbo" in the second world war Dr Joe Dispenza talks about surgeons having to remove arms and legs and carry out urgent operations on the battle field with no morphine because they'd run out. And the doctors would fill a IV with a saline solution and the soldiers didn't suffer any pain because they believed they were getting morphine. A lot of research is being done on the power of the placebo and our ability to have power over our body with our mind, so trial some techniques out for yourself, And if you find some good ones, let me know about them!



#### Don't over think about getting cured

I used to do to over think and I'd daydream that the doctor would say "Mandie we've found a cure, here's your life back!" but eventually it became depressing. And negativity can cause stress which can make your symptoms worse. To be honest I wouldn't over think anything anymore. It makes for a busy mind and that is not good for you or your health either.

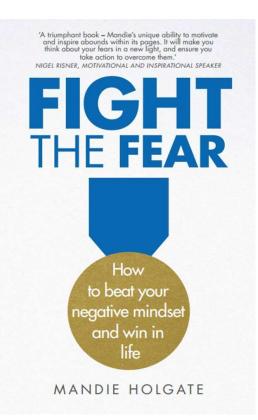
#### Keep the faith

While I don't agree with holding on the idea that I will be getting a cure. I do have faith that whatever this disease does to me I will be able to find solutions that will help. Find ways to have that faith too. (You are reading a report that is packed with ideas to try!)

#### Learn to say no

This is one of the hardest lessons I ever learnt. As the eldest of 3 children I have always done more than my fair share. Hosted Christmas, sourced the holidays, hosted all the parties and barbecues, organised the big presents, etc, etc.

Not any more. I can't so while my extended family don't like me very much, tough. I was literally putting myself in hospital saying yes to everyone and everything. For me the fear of saying no is connected to my fear of what people think. So, I sorted that out too. There are a ton of resources, tools and techniques in my book "Fight the fear" on how to deal with both of these fears – the fear of saying no and the fear or what people think. <u>You can learn more</u> and buy here.





#### Gratitude

This is not always easy, however every night I create a list in my head before I go to sleep of 10 things I'm grateful for. They don't have to be big. When I was at my worse health it may say "Thank you for giving me enough energy to cut the carrots for tea" hardly running a marathon or baking a cake, but acknowledge even the little things you can do. And studies are now showing that this practice can actually change the chemicals in your brain that can alter our ability to deal with pain as well as many other positive benefits too.

### Reframe the sh\*t out of everything.

I reframe everything. Therefore, if I'm in the middle of an awful flare and I can't leave the house or even have a shower because I'm so weak and likely to fall over. I will say to myself things like "think of all the fuel I'm saving" or "I'm not going anywhere, and no one is going to see me so think of the energy I've saved by not showering."

Or when I look in the mirror and feel really fat and ugly (I've been tempted to get a T-shirt printed that says "I'm not fat because I eat too much, it's because I'm on horrific medication and it don't just make me fat like Hammy the Hamster!") But since that is not a good idea, I would look in the mirror, do my hair and make up and then say "Well Mandie, you've done the best you can, ultimately you haven't got to look at this, they have!"

It would make me laugh (which again is a positive) and I remind myself that my true beauty is the person I am not the size of my body. Real friends and family do not care about your physical appearance, they care about how you make them feel and what you can do for them.



#### It could be worse

Michael J Fox, reportedly said that if a room full of sick people were in a room together and we could all put our illnesses in the middle of the room and swap our illnesses for someone else's in the room, we would all choose to have our own illness back.

Try it – not literally!

I discovered that this is true and it reminds me it could be worse. As a Caucasian woman in her 40's I'm less likely to experience the serious symptoms related to Lupus. They tend to impact on African American, Hispanic/Latino, Asian, and American Indian women far more. Do not concentrate on how it could be worse, just acknowledge that it could be worse.

#### Protect your mindset

I created a tool kit of things that look after my mindset. Our mindset needs to be positive because it is essential to cope with long term health issues. My doctors have often said that they feel I would be a lot worse if I didn't have such a positive face even in the face of adversity. I've created a toolkit for my mental health to help me stay mentally well and to look after my mindset you can <u>click here to see mine</u>.

What could yours include? I've always said it is a good idea to know on a good day how to deal with a bad day.

#### Listen to your body

It really is no good fighting your body. If you consider the things I've learnt above and shared in this report hopefully you can see that.

Don't learn the hard way as I used to and end up in A and E at 2 in the morning struggling to breathe with severe chest pain. It's not worth it.



#### Medication is not a crime

I know the side effects are horrible and I even get the joy of injecting myself once a week with a small dose of chemo, so I get the joys of weak bones, teeth, hair and nails too. However, those 12.5mg of Methotrexate are the reason I can drive a car, run a business and have a lot less pain and exhaustion.

Yes, the lack of sleep caused by it is horrendous (about 40 minutes a night without a sleeping table, which I won't take if I'm driving a car.) However, my medication has given me a lot of life back.

So, don't hate your medication. I used to get to the end of a pack of medicine and think "Yippee finished them!" as if it was a course of antibiotics, crazy right?

Because medications like Folic acid and anti malarials I will be on for the rest of my life if I keep taking the Methotrexate. So, get your head in the game, and don't be ashamed of your medication. My size fluctuates between a 10/12 to a

16/18. I used to get so upset about it, but now I reframe and look for the good. I have jackets ranging from a size 10 up to a size 18! And apparently no one has ever noticed! (I think they are just being too polite! Check out the



hamster look and lack of hair I had a few years ago. I used to spray the underneath and back comb my hair to make it look like I had some!)

I'd say learn to dress well regardless of your size and those that matter won't care and those that care really won't matter!



#### And lastly...

I hope me sharing my own journey, ideas, strategies, tools, medicines and alternative therapies that I use help you too.

I'm more than happy to have a chat.

I do have **boundaries** though and I'd like to leave you with those....

I have days that are rest days and I don't answer the phone or the emails. I tell people to give me a call and people often say "I don't like to disturb you, I know you need your rest" I always reply with "If I'm not well enough to answer then I won't, will I?" For me phone calls are easier than getting involved in email ping pong so I'm very savvy with my time too.

Ultimately people don't know if you are not answering your phone because you are too ill to or because you are out partying, working or walking the dog. Therefore, create boundaries too and ensure you let people know they exist.

If you aren't going to answer work messages at the weekend, have the confidence to tell people that and stick to it. If people want more out of you and you work for yourself, charge them for it. (I started charging for coaching reports separately when I came back to work and everyone wanted them even though they can take me an hour and a half to type up, so I increased my hourly rate to reflect the cost, and I've not lost any clients, if anything most clients pay me the day they get their invoice, so it shows I've attracted the right, respectful clients that are awesome to work with!

Everything you do has consequences that you will feel far more than a healthy and well person, so prioritise what you need and don't feel bullied or pressured into doing things that will damage your health.

Ultimately good time management and the above things mean I can run 2 businesses, I can cook meals when I want to, I can go on holiday and I can have some life, okay not as much as I'd like but I'm not laying in bed shaking like Elvis on Morphine like I was 6 years ago!

Heal well, and keep in touch.

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www.mandieholgate.co.uk 2018



### **Enjoyed this?**

This report on how to look after yourself was free and it took me a lot of time to create, so a review on Google, my Facebook page or on LinkedIn could be your way of saying thank you without having to spend any money and I'd be very grateful.

I also have online courses that you can do that are £7 to £25 around building confidence, communication skills, and business.

They all include tools and techniques I use to enable me to grow my business, look after my clients, gain lots of new ones and new opportunities and still do all that when I'm sat on a beach (with my phone turned off) so they are great tools for those who really need to have a good work life balance as we do.

They are in small lesson sizes so you can do a lot or a little every time you visit the course and work as fast or as slowly as you like and you will have access to the course for as long as you want.

Considering what we have talked about in this report I would recommend;

Rocketing your confidence

Powerful public speaking - to help with your communication skills

And if you are in business – Mandie's marketing production line and my 6 week kick butt course for busy business women.

#### Learn more and order yours here

# If you can think of other ways I may assist you, please do not hesitate to contact me.