

Introduction: Play This Song Backward; or How I Became the Singing Patient

I'm a performing songwriter. I write about everything from Klingons to Waffle House. Some say my songs are funny. Some just find them laughable. But for the past fifteen years I've managed to eke out a living with my wacky songs. When people ask me why in the world I turned out so strange, I trace it back to interactions with people like my grandmother.

I always enjoyed making my grandmother laugh, because then she'd quit asking me when I was going to get married. And because I could make her laugh, I got away with saying the most outrageous things. When she was trying to find something to wear to a wedding, I said, "Well, Gram, you know what they say: if you can't wear something nice, don't wear anything at all." People can't stay mad at you if you can make them laugh.

I spent the first two and a half decades of my life making people laugh, playing all kinds of musical instruments, flirting

with boys, and spending many beautiful South Carolina days on my bike, in a pool, or at the lake. I was so strong that even though I was barely five feet tall, I played the tuba in the marching band. (They called me “the tuba with legs.”) I was writing songs even back then, including a few funny ones, although I never shared them with anyone.

But when I got seriously ill at age twenty-five, I lost my sense of humor for a while. It took two years to get a diagnosis, and while I was waiting for that to happen, I kept getting sicker and sicker—my hair fell out, I had fevers spiking to 104°F every day, and the illness cost me my job and savings. At my literal lowest, I weighed eighty pounds, could not get out of a chair by myself, and hadn’t eaten an actual meal in probably two months. Turns out I was suffering from several autoimmune diseases, one of which was causing my kidneys to fail.

Autoimmune disease is what happens when your immune system starts attacking your healthy tissues; it can’t tell self from nonself. Of my several diagnosed disorders, lupus was the most life-threatening. Its symptoms range from mildly annoying (rashes) to devastating (kidney failure). Mainstream medicine has no idea what causes this process of self-destruction and offers no cure, instead attempting to control symptoms with powerful, sometimes toxic drugs. Progressive doctors and alternative medicine practitioners, I later learned, believe it is caused by multiple factors, and they offer a much sunnier prognosis—if you’re willing to work really hard at wellness.

Don't get me wrong: the path to wellness isn't straightforward, and fighting a chronic illness sometimes feels like "one step forward, two steps back." As my health improved, I started to pursue my dreams of teaching guitar, writing songs, and performing local gigs—I was reaping the rewards that come with regained health. Then I hit roadblocks, such as experiencing two strokes and facing kidney failure again. But I refused to believe that I would have anything less than a full recovery. Hope itself is powerful; so long as there's hope, there's hope. I completely recovered from the strokes, and eight years later, I still have my kidneys. They work just fine.

Illness can touch your life in unexpected ways. When I was in college, I had crippling stage fright. I wrote lots of songs, and I would sign up for open mikes and talent shows but run away before the emcees called my name. A funny thing happens when you face kidney failure and chronic disease and overcome them: you have a lot to sing about, and the stage isn't so scary anymore. And that's how I became the Singing Patient.

This book is the result of my years of searching for—and finding—better solutions than mainstream medicine had to offer by itself. I didn't abandon mainstream medicine, but I didn't end my search there, either. I didn't want to "manage" my disease with drugs for the rest of my life. I wanted to be healthy again. Today I don't have all the answers, but I do have my original kidneys, and I'm doing better than predicted and taking only one prescription (for high blood pressure).

My remissions did not happen by chance; I worked hard for them. I had to do some soul searching and take responsibility for what I ate, how I exercised, how I spent my time, and who I hung out with. I learned that having a sense of humor is essential to health. But I didn't do anything anyone else couldn't do, assuming they knew where to start.

There's an old joke: What do you get when you play a country song backward? You get your truck back, you get your wife back, you get your dog back. . . . Well, I wrote some songs about my medical journey, and even though they're not country and I've never played them backward, I got my hair back, I got my kidneys back, and I got my sense of humor back. If your health is not perfect, here's the good news: you can get better. Maybe just a little better. Maybe a lot better. Maybe completely better. Most of all, I hope you join me in finding laughter in both the good times and the tough—truly, how can we not laugh at a time like this?

*What seems nasty, painful, evil can become a source of beauty,
joy, and strength, if faced with an open mind.*

—Henry Miller



Top Ten Annoying Things to Say to Someone Who's Just Been Diagnosed

Hate and fear can poison the body as well as toxic chemicals.

—Joseph Krinsky, MD

Nobody plans to walk into someone's hospital room and blurt out insensitive, inappropriate comments. And yet it happens all the time. If Hallmark had a section for "This is going to hurt you more than it hurts me," the following phrases would possibly be the top ten best sellers. (And in case you are caught unprepared, I'm including my responses—feel free to steal them or improvise your own!)

Inappropriate comments: when silence isn't awkward enough.

10. *"I knew someone who had that. She died."*

(Thanks for the boost of confidence!)

9. *"I know someone who has that; he's in perfect health."*

(You can't be in perfect health when you've been diagnosed with a serious illness.)

8. *"Is that a form of cancer?"*
(Ask a doctor, or look it up on the Internet. The appropriate response is not curiosity but compassion.)
7. *"Is that a form of AIDS?"*
(See comment 8, above.)
6. *"God is punishing you because you have a hidden sin in your life." Or: "The devil is attacking you because you are doing God's work."*
(Mr. Wizard, Don Knotts, the founder of the Peace Corps, and two serial killers were all diagnosed with cancer. Disease is not doled out on a "who deserves this most?" basis.)
5. *"I'm sure it's nothing. You'll be fine."*
(Great! I'll cancel all my doctor appointments.)
4. *"Is it genetic?"*
(If you're not my twin, why does that matter right now?)
3. *"Have you tried [insert any form of alternative medicine you can think of here]?"*
(There's time for problem solving later. Be a friend first.)
2. *"You don't look sick."*
(You don't look insensitive. I guess appearances can be deceiving.)

And the number-one annoying reaction to a diagnosis of serious illness:

1. *"Is it CONTAGIOUS?!"*
(Yes! And you can't leave until I LICK YOUR FACE!)

When I've been the visitor, I'm sure I said something less than perfect. I truly understand now why police are instructed to always say to the victim's family, "I'm sorry for your loss." Better to sound like a prerecorded message than to blurt out something idiotic.

Here's what I wish folks would say:

- "You don't have to be brave."
- "I've been thinking of you."
- "I'm sorry."
- "Can I bring you something?" (Some of my favorite gifts when I'm in the hospital: a tabletop fan, a pillow, my favorite stuffed animal, something to read, my iPod, food that doesn't taste like cardboard, a funny movie, meditational CDs, a notebook to draw or write in. Thoughtful gifts for someone with lupus, Raynaud's, or fibromyalgia who is out of the hospital: a heating pad, a Pampered Chef jar opener, a paraffin wax hand bath, hand and foot warmers, a Back-nobber self-massager.)
- "I don't know what to say."
- "I am praying for you. We are all praying for you."
- "What can I do for you?"
- "How can I help?"
- "Let's do something fun as soon as you're feeling better."
- "I'm here for you."

- “Don’t worry about answering all those phone calls and e-mails. People understand you’re not up to it right now.”
- “I’m checking in on your house and your cat twice a day.”
- “I have a cold so I stayed home rather than risking infecting you.” (Thank you!)

Even as we deal with much pain, fear, anxiety, and uncertainty as patients, those around us are also dealing with a lot of emotions. It’s a shock to see someone you care about weak and helpless. Our friends and family feel helpless, too, and afraid. People want to help—they just don’t know what to do. If we give people something to do or say, they won’t feel so helpless, and we won’t feel so neglected. It won’t stop everyone from saying stupid things, but maybe it’ll be a little less annoying if I’m holding my favorite stuffed animal, reading *Calvin and Hobbes*, and eating some chocolate.



Lessons from the Nudist Festival: How Much to Reveal

One of the venues on the acoustic-music circuit is a nudist festival in West Virginia. I've played there several times and always enjoy it. Clothing is optional, and, yes, I always take the clothing option.

The first time I played there, I marveled at the courageous men grilling hot dogs and using staple guns in the nude. Then I had to get used to being onstage, looking out and seeing an audience of naked people. Suddenly, that nerve-calming strategy of imagining the audience in their underwear gained new meaning. And urgency.

Then I sat down and had dinner with some of the folks. Now, the “offending parts” were all below table level, and I realized that these nudists were intelligent, interesting people. It was *my* hang-ups about nudity that made me uncomfortable; the issue was mine, not theirs.

I'd chosen to enter the sanctuary of their inner circle, and I knew going in that they would be naked. I had no grounds for being offended by their choices (they were just nude—they

weren't having sex in the open). They didn't demand that I remove my clothes, and I didn't demand that they put theirs on.

When these folks leave the colony, they put on clothes. They don't try to make the nudity thing work everywhere they go. They blend with the norms of society when they are out in it. It's not worth the punishment to try to make the rest of the world understand their point of view.

What could this possibly have to do with having a serious illness? More than meets the naked eye.

The nudist colony, a safe place where everyone is a nudist, is like a support group where everyone is struggling with an illness. In the safety of the support group we can "let it all hang out," be ourselves, and not worry about being judged. If someone comes to the meeting and isn't sick, he would be really out of line to shout, "Hey! Can't we talk about something besides illness and feelings? How 'bout those Giants?"

When we leave the safety of the support group, we have a choice: we can remain "nude," wearing our feelings and problems on our sleeve and talking constantly about our illness, or we can choose to "put on clothes" and try to blend in with the rest of society.

"It's not fair!" you shout. "I have a right to talk about my illness. It's bad enough I'm sick, and now I have to worry about other people not being able to handle it?"

You can talk about your illness as nakedly as you want, as long as you are willing to accept the consequences. Just like nudity, some folks are going to have issues with your being sick,

not necessarily because of your own hang-ups about being sick, but because of *their* hang-ups about being *around* someone who is sick. It forces them to think about mortality, their own vulnerability, or the fairness of the universe, when they'd much rather be out on the beach building a sand castle and believing illness and death could never happen to them. It's going to stir up fear, and that's going to make some people say and do hurtful things. This includes family, who have their own very strong emotions about their loved one being ill.

Decide how much of yourself you want to expose. The "clothing" is not really to protect others, it's to protect you. Rather than try to turn the rest of the world into the compassionate people you wish they were, realize their limitations, stop trying to get blood from a stone, and divulge the gory details only to those who can handle it. Choose your listeners wisely.

Having a devastating illness comes with lots of powerful emotions that need to go somewhere, however. Find yourself a "nudist colony" of safe people where you can be honest about your illness and feelings without getting punished for it. This can be in the form of a healthy support group, where feelings are handled in a compassionate manner. If you can't find a good one nearby, start one or join one online. And you always have the sacred secret space of your diary or journal, where you can say anything and everything you need to express.

Then, you can put your clothes back on and join the rest of the world, where you can talk about something besides your illness and forget your troubles for a bit. At some point it's going

to be a welcome relief to hear “How ’bout those Giants?” instead of “How are your kidneys?”

How much should you reveal to the world? That’s up to you. A thong? A burka? Something in between? Totally nude? It is your choice, at all times, to choose when and to whom you reveal your illness and the details about it.

Here’s how I handle it. When I’m among other patients, or performing at a health conference, or in other safe environments, I speak about my illness openly. No one in these settings is bothered by such talk, and we have helpful, meaningful conversations. But I’m well aware that out in public—at dinner parties or hanging with friends—folks don’t want to hear about that sort of thing for the most part. So I don’t impose it on them, and I don’t open myself up to being hurt by their fears or ignorance.

If someone asks me how I’m doing, I give a short summary. I’m not dishonest about my symptoms or my well-being, but I don’t usually tell people my diagnosis. Sometimes I just answer, “Good, thanks for asking,” or “Been a little tired, but I’m doing okay,” or sometimes I’ll put in a good word for acupuncture or whatever else I’m doing that’s working for me.

If I know the person a lot better, I give a bit more detail, but I don’t feel the need to go on for long in a social gathering, because I have other, safer outlets for my emotions, and I don’t want “unsafe” people to overhear too much and start asking invasive questions. There’s a time and a place to be naked.



So, You Come Here Often?

Ever stop and think about how bizarre the doctor-patient relationship is? Within five minutes of meeting you, the doctor knows your age, weight, and any embarrassing ailments in your or your family's history. And you're in your underwear. And you don't even know his first name.

Imagine being in any other setting and being asked these questions by a total stranger. If you were on a blind date, he wouldn't make it past the server bringing the ice water.

"Hi, nice to meet you. Let's see, now . . . how old are you?" (*slap!*) "What do you weigh?" (*slap!*) "Any pregnancies?" (*slap!*) "When was your last period?" (*slap! slap!*) "Are you sexually active?" (*punch!*)

But there you are in the doctor's office, and while you're talking the doc jots down various things on his clipboard: white female, 120 pounds, age twenty-nine (okay, I'm lying a little bit), nonsmoker, nondrinker, scar on left side. Sounds like a personal ad. (Well, until the scar part. Then it sounds like you're describing someone who just robbed a liquor store.)

If you were describing yourself to someone you were actually trying to get to know, you'd mention something about your personality and beliefs, maybe even your religious preference. If a doctor ever asks me my religious preference, I know it's not because he's trying to get to know me as a person—it's because he's about to do something to me that increases my chances of meeting Jesus face-to-face. Soon.

It's too bad doctors have to rush through appointments and don't have a chance to get to know their patients as people, because taking time can give some insight into what may have brought on their ailment. Plus getting to know folks can be a real treat. I love sharing conversation with new acquaintances: finding common ground, hearing about their hobbies, learning where they're from. Doctors don't have time for all that; they have to cut to the chase. They typically only have eight minutes per patient. (Most of my dates lasted at least twice that long.)

So, I wondered, how can we make the most of these eight minutes? I had an opportunity to sit across a table and converse with Dr. Patch Adams, so I asked him, "How do I get my doctor to treat me more like a human being?" This is what he said:

There is plenty of pain to go around. Not only are the patients suffering, the doctors, nurses, and administrators are all suffering from an abusive, oppressive system that sucks the meaning and joy out of their life's calling. The health care providers are just as frustrated as the patients are.

Instead of assuming everyone is a jerk until proven otherwise, it is just as accurate but more constructive (and compassionate) to assume everyone is lonely and hurting until proven otherwise.

To reach through the cloud of insanity and build a relationship with the doctor: do something silly to grab their attention, hug them, ask them how they're doing, bring them cookies, compliment them, or do whatever you would do in order to get anyone to like you, white lab coat or not.

In other words, act sort of like you are on a date.



Chapter 5

Rubber Chicken Soup:
Keeping a
Sense of Humor



How Can You Not Laugh at a Time Like This?

Through humor, you can soften some of the worst blows that life delivers. And once you find laughter, no matter how painful your situation might be, you can survive it.

—Bill Cosby

You can feel so powerless at the doctor's office. You can't get anyone to listen. You can't get them to see you on time. You can't even get them to validate your parking. Illness can steal our energy and our health. Health care can take our time and money. But I'll be darned if they're going to take away my sense of humor.

I was in the hospital at one point and—for some reason—not enjoying myself. Maybe it was the needles. Maybe it was the rubber gloves. Maybe it was the rubber food. All I know is, there's a reason the windows don't open. How else do they keep you from escaping?

About day three of my incarceration, a ray of hope: Saralyn—my bubbliest, silliest friend—called to cheer me up. She jumped from topic to topic, then got to griping about maxipads. I chimed

in, complaining about how they stick to everything except what they're supposed to! Next thing you know, I'm writing lyrics about maxipads on a napkin (a dinner napkin, that is). I felt like me again, not just patient 2946065 in bed 31A with diagnosis x, y, and z. I'll always be grateful to Saralyn for that phone call. She not only cheered me up—she brought back my sense of humor.

Spurred on by our marvelous maxipad song creation, I started writing ridiculous songs about everything. The more humiliating, the better. After all, comedy equals pain plus distance, so the more painful it was, the more potentially funny. By falling apart physically, I had haplessly stumbled into a well of comedy gold.

For hours every day, I wrote. I wrote about drug side effects, racing to the bathroom, and even being patient 2946065 in the indigent ward. If it was humiliating or painful, I tried to find the humor in it.

Laughter provides pain relief, lowers blood pressure, boosts the immune system, and even works as exercise—perhaps the only exercise you can get when you're hobbling around with a cane. Just as importantly, it gave me my power back. If you've ever been to a comedy club, you know the funny person in the room is the one with all the power. She can speak the truth, and she can make people listen to her. It also changed the way I looked at and felt about what was happening to me. I started seeing the world through laugh-colored lenses. Once I stepped back and saw the absurdity of my situation, I really had to say, "How can you *not* laugh at a time like this?"

"The Maxipad Song"

(Sing to the tune of "My Favorite Things")

I'm cranky and crampy, my jeans are too tight

I'm looking for comfort, not for a flight

I just want the confidence maxis will bring

The kind that do not have those stupid old wings

When the curse strikes

When the flow comes

When I'm feeling bad

I don't want those wings sticking to everything

I just want a plain old pad



How to Get and Stay Sick: A "To-Don't" List

Want to get sick and stay that way? Want to see if it's as fun as it looks? Follow these excellent suggestions, and you'll end up with something regrettable eventually.

- Eat crap and die (it's not just a pithy schoolyard comeback!). Not sure what crap is? Processed foods, preservatives, artificial colors and sweeteners, loads of sugar, and plenty of salt. You can find crap in every aisle of the grocery store, minus the produce section. Speaking of which: avoid all fruits and vegetables. They will screw up the eating-crap-and-dying process. Bonus: If you eat all that sugar, you can start a yeast farm on your tongue.
- Get six-pack abs: Pop open a can of soda for breakfast and enjoy the blood sugar roller coaster all day. Any kind will work. The aspartame in diet soda is damaging to your nervous system, and the high fructose corn syrup in regular soda can lead to diabetes. Also, drinking cola regularly may contribute to kidney problems. Now start doing those sixteen-ounce curls!

- Allergic to a food? Chow down on it! A little hair of the dog, that's what you need!
- Ask your dentist for plutonium fillings in your teeth. Can't get plutonium? Well, many dentists still make amalgam fillings with other toxic metals, including mercury, tin, and nickel.
- Don't brush or floss. Ever. If God had meant for us to brush our teeth, we would have plastic bristles on the ends of our hands, right? Let that bacteria build up in your gums so it can get into your bloodstream and go after your heart. Then blame your heart condition on bad luck.
- Drink lots of alcohol. Haven't you heard? Wine is good for you. So lots of wine must be *really* good for you, right? If you can't find wine with nitrates, then drink a twelve-pack of light beer a day. It's loaded with chemicals. More great news: alcohol depletes you of vitamins and minerals. So does caffeine, so chase your beer with a frappuccino.
- Take prescription drugs for fun. Everybody's doing it! If you're ever in pain, you'll need double the dose for it to work, but that's such a small price to pay for being able to numb yourself from all emotions. As a bonus, you'll probably be constipated.
- Take antibiotics for everything. This may eventually lead to getting an antibiotic-resistant infection. Think big!
- Move next door to a pesticide plant, or into an old house with lead pipes, lead paint, and asbestos. Drink the tap water from those rusty pipes without filtering or distilling

it—that ruins the taste. If you can, find a place that also has a high-voltage power plant across the street and lots of overhead plane traffic. Add a crack house next door for excitement. Location, location, location!

- Sit around and do nothing. It's very Zen, you know. Be ultra-Zen: no fresh air, sunshine, other people, or exercise.
- Not good at doing nothing? Try martyrdom. Work all the time and put everyone else's needs and demands above your own. Others get sick from being lazy and irresponsible—you get to feel self-righteous.
- Don't do anything about that stress. Meditating is for weirdos.
- Hang out with the drama queens. Balanced people are so boring.
- Hang on to grudges and nurse them. Mmm, justifiable anger!
- Focus on everything that sucks. Stuck for ideas? Turn on the news.
- No laughing! This is serious! Do not have fun.

