

10 Tips For Caregivers



Michelle Terrill Heath

10

Tips For Caregivers



❧ Michelle Terrill Heath ❧

“These are brilliant- I love the yoga, movement, breath-work stuff. I think the PMDA (PMD Alliance people would love these and the Parkinson foundation people too.)

~ **UCLA Administrator**

"Thanks so much, Michelle, for these words of wisdom! I will try to incorporate your tips into our daily routine and I appreciate how REAL they are. I especially like using happy memories to strengthen relationships with the "patient." It is so easy to get bogged down in the cares of the day that I forget all the wonderful years we have had."

~ **Kayla Stratton- Attorney and caregiver for transplant and aneurysm survivor**

“I was the caregiver for my late wife, Betsy, who lived with multiple sclerosis for 37 years. I wholeheartedly endorse this wonderful booklet full of excellent suggestions. I wish there had been something like this available for us as we began our caregiving journey.”

~ **Richard Baer, caregiver and retired hospice nurse**

Copyright © 2020 Michelle Terrill Heath

All rights reserved.

Design and Layout by:

Chelsea Travers

&

· | · **YOGI PRODUCTIONS** · | ·

michelleterrillheath@gmail.com

www.facebook.com/parkinsonslovestory

www.linkedin.com/in/michelle-heath-18613718/

PART ONE

I was a reluctant caregiver for my extremely disabled husband for almost seven years. Andy couldn't turn in bed, get up out of a chair or walk without help. He could not feed himself, brush his teeth, shave, cut his fingernails or toenails or brush his hair. The shaking he experienced from Parkinson's Disease was all pervasive and only stopped when he fell into a very deep sleep.

I was a reluctant caregiver because I didn't want us to be in this situation and I was angry about the loss of our life together before Parkinson's came into it. Much of the advice given to me during those hard years fell short of being helpful. Platitudes were plentiful but real help was in scarcer supply. After nine years with Parkinson's, Andy was fortunate to receive [DBS \(deep brain stimulation\)](#) surgery and to have most of his large and small motor muscle use restored and much of his independence returned.

My caregiver role shifted from what felt like a hurricane with massive flooding into a manageable rain storm. Parkinson's continued but we both got our lives back. Since this radical change for the better, I have taken time to reflect on advice I'd love to have received during those outrageously challenging years when I was responsible for both my husband's and my own well being. My failures have informed me as much as my successes. No advice will save anyone from that reality but perhaps my experiences and these ten suggestions can ease some of the difficulty and hardship.

First, I will suggest five strategies for you, the caregiver. These were the top five suggestions that helped me when I was fully immersed in my caregiver role, when my husband couldn't seemingly do much of anything anymore.

1

You Don't Have Whatever Diagnosis Your Loved One or Patient Has.

When a serious illness becomes part of your life, it's natural that life begins to revolve around the changes, challenges and reality of what that means. For Andy and me that meant absorbing the losses of what he could no longer do. We attempted to keep our life before Parkinson's going and that meant that I took up the slack and tried to do what he was no longer able to do. I fit being his caregiver into the extra busy life I was trying to embrace. One of the first forays into natural healing was with an organization in Santa Cruz, California called [Parkinson's Recovery Project](#).

In several of our healing sessions the practitioners turned the spotlight on me while they calmly treated Andy. "It's VERY important for you to understand and embrace the truth that you don't have Parkinson's Disease." They said. My first thought was, "Well yeah, I know." Each practitioner continued with a form of this message, "It's easy for a caregiver to take on the patient's issues and claim them as their own new purpose and reason for being. This just isn't true. You have your own path and Parkinson's isn't it. Let it be Andy's path and support him on it and never forget that you don't have Parkinson's."

I took that lesson to heart. I have different issues, challenges and my own life forward. It doesn't help Andy for me to let go of my life because of all the loss he was experiencing. Ultimately, we left the program in Santa Cruz behind as we moved towards other treatments for Andy's healing but not before I learned to keep my own life vital and to pay attention to my own path and future while being Andy's caregiver.

It was a relief to understand. I don't have Parkinson's and you don't have



2. People Will Ask Awkward Questions.

I learned that part of being a caregiver was becoming the spokesperson for the patient. Of course, sometimes that made sense and flowed easily, but often being asked countless times to give updates about the one you are caring for by people on the phone, at the grocery store, while filling the car with gas, and going about one's day, was exhausting at best and often painful. One time, when at a workshop for Ayurvedic healing, all attendees sat on a lushly carpeted floor and there were blankets available for those who felt cold. Andy had visible tremors at the time and a woman who worked there came up to us and asked me, "Is he cold?"

My mom had shared a story about when she was my Nana's caregiver. Often, people would ask Mom questions that should have been directed to Nana. In a restaurant the server might ask Mom, "Does she want sour cream with her potato?" Mom learned that she could create a teaching moment for the server if instead of answering she looked at Nana until Nana answered for herself.

I looked at Andy until he said, "Thank you, I'm not cold. This shaking is part of the disease I have."

I know there are times when care giving includes speaking on behalf of the patient. One of those times happened while sitting in the ER, with a wildly shaking Andy, who was in a lot of pain because he had fallen and broken his scapula. As each health care professional came into the room where we sat, I'd say, "I know this looks bad but the shaking is not why we're here. It's caused by Parkinson's disease and Andy has fallen and hurt his back. He is in pain and he does not have dementia and can answer whatever you need to know."

As caregivers, we protect and advocate for our patients but we are not fodder for the random curiosity of people who know your situation but are not close enough to be in touch. I felt confusion when I was pulled out of my daily rhythm doing errands, not with a cheery, "Nice to see you, Michelle," but instead with a grip on my arm and a somber voice asking,

"How is Andy?" I'd be thrown into the heart of my pain. Andy wasn't well. Every day we struggled to do the best we could. Every day we faced losses. Every day there were disappointments and every day we somehow prevailed.

One of my dearest friends who had more experience than I with well meaning but nosy intrusive people taught me the only strategy that worked.

"He's fine." I'd answer.

"Really?" They'd say.

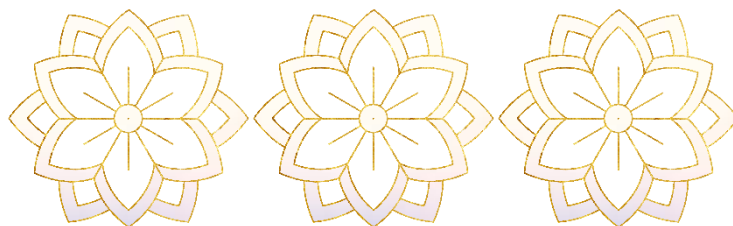
"Yes, he's fine." I'd repeat.

Once in awhile the person was overly persistent and would then say, "Is he better from the Parkinson's?"

I'd say again, "He's doing fine."

So, it is not your job to explain, entertain or engage in sharing intimate information, unless you feel it's appropriate, just because it is known that you are care giving someone who has Parkinson's or another disabling illness or condition.

As far as the world was concerned, I found the most powerful answer to awkward questions was always, "We are fine."



3.

Using Structure To Manage Time and Anger

When Andy's abilities were being challenged and compromised by his disease, I was there helping with everything as it came up. Unintentionally we became caught in a vicious circle where I had less and less time for myself and that turned into never having time that wasn't going to be potentially interrupted. It happened gradually.

Like many couples, our long marriage (thirty plus years at the time) had evolved into a nice flow of communication, jobs shared, tasks done and personal time realized. If one of us became sick, the other would step it up, pitch in more and take on the work necessary that the other couldn't do. It was a good solution for an acute problem.

Parkinson's was different as is any chronic incurable disease. As I'd step it up and take on more, Andy's illness didn't end and neither did the extra responsibilities. We found ourselves in a situation where Andy called me for any and every need he had as it came up. Sometimes it was really important and required immediate assistance and other times he could have waited. Andy was not a tyrant by nature but his illness made his continuous needs and requests of me feel tyrannical.

One morning, after every task I did for myself, from brushing my teeth to doing yoga and meditation was interrupted numerous times with Andy's needs. I fell apart and I was upset. How could I meet his needs and take care of myself at the same time? I didn't know the answer. Andy had been seeing a local counselor weekly, for a few months, to help him come to terms with the disease he had. [Ted](#) was a resource for our whole community because his depth and wisdom was extraordinary. I called and he agreed to see us together that afternoon. He squeezed us in because I said this felt like an emergency.

As wise as [Ted](#) was, he always offered practical and pragmatic solutions. He told us our previous easy flow of activities needed a structure to support our new circumstances. Since my 1.5 hour morning ritual of wash up, tea, yoga, meditation and journal writing was such an important part of my well being, that's where he helped us build the structure.

Our mornings became a routine that was no longer easy flowing and ever changeable and formed into something that worked. We'd get up at the same time and I'd attend to all Andy's urgent morning needs. This included helping him to the toilet, washing up, dressing, preparing breakfast and feeding him and settling him into a comfortable spot. It was usually around 8:00am by then. Then it was my turn. I had 1.5 hours that he'd agreed not to interrupt under any circumstances barring an all out emergency.

We kept to this schedule for a long time. My sanity was restored and my anger dissipated knowing I was able to have this much needed personal time almost every day.

Affection is another subject that falls in the same category of needing structure and routine where none was needed before. Parkinson's patients have "on" and "off" times when they are more or less able according to their medication. Many diseases have times of feeling more "well" or more "sick" or "lucid" or "confused" and on and on. We learned that five or ten minutes of lying in each other's arms and relaxing into a blissful hug of deep affection restored both of us. Taking that time every day was essential to our well being, even if we had to set an alarm for it at two am because that was when the patient was at his best.

We found that, when challenged with disease, small changes creating structure that allowed for self care triggered balance and contentment.



4. Flower Remedies

[The Bach Flower Remedies](#) must be one of the most powerful and least known medicines. The explanatory book, published by Wigmore Publications, states,

"These flower essences, like other forms of natural medicine, take effect by treating the individual, not the disease or the symptoms of the disease. They work specifically on the emotional condition of the person concerned. The effect of taking the essences is not to suppress negative attitudes but to transform them into positive ones, stimulating one's own potential for self healing and freeing the physical system to engage fully in fighting disease and stress."

This inexpensive, self care treatment has restored balance to Andy and I when we felt fatigue and negativity. I was first introduced to them, when I was 25, by a Doctor of Oriental Medicine who prescribed three essences. I responded immediately to the positive effects. There is a mixture of five essences available for emergencies, called Rescue Remedy. I have used this often for myself, Andy and our kids as they grew up.

I used Rescue Remedy for myself and Andy during the extreme times of his illness. I also looked in the book we owned to check out indications for the other 38 individual essences and used them according to our particular needs. This information is also online.

Although they sound and appear to be a New Age treatment, Bach Flower Essences are actually an old time remedy. Dr. Edward Bach lived from 1886-1936. He developed these medicines over his lifetime while also being recognized as a renowned doctor.



5. Movement, Yoga and Breathing.

I found being a caregiver to be hard work. The requirements on my body, mind, emotions and spirit were intense. In any one day I'd need to help Andy roll over in bed, get in and out of a chair, help him put on his socks and shoes and shave his prickly whiskers, all before feeding him breakfast. This was hard work for my body. That same day I might have spent a couple hours researching treatments for his condition and that engaged my mind. After he woke up from a nap, we'd probably talk over any new possibilities I'd found and that would make us face the reality that most doctors told us that likely he'd not get better, and our emotions would be tested. Our spirits, being the stream of life connecting our physical, mental and emotional, would be challenged.

Being sick is often an isolating experience. Being a caregiver means you are often with the sick person and isolated by association. When chronic disease hits, the limitations of life can become severe and yoga and breath work can be life savers. I say yoga and breathing in the same sentence because they naturally pair up. The yoga I'm speaking of is movement and when we move, we breathe.

As a caregiver, my time for long personal walks, going to the gym or any type of committed exercise routine was dependent on how my patient was doing. Often, getting away for exercise wasn't going to happen. Deep breathing and yoga was the one exercise I could do anywhere and anytime and the benefits happened to coincide with my biggest needs.

Physically, yoga stretched out my muscles in a way that nourished my need for movement while turning up my awareness of how I was feeling. The slow holding of stretches allowed me to literally untie the knots in my body.

[Breathing rhythmically](#) calmed my mind and the attention I put on those deep breaths made space for my emotions to rest and my spirit to be recognized. My body/mind felt connection and harmony. Yoga is easy to learn, at least enough to have a self practice that can accomplish the much needed movement and peace of mind for caregivers.

I suggest Brett Larkin Yoga and her free 100% beginners' [online class](#).

Part Two

This next section includes five more strategies that address ways of working with your patient.



6. Don't be the Only One Who Does Everything.

Every care giving situation is unique and the notion that one person can do all the care probably most often comes up when the caregiver is the spouse of the patient. This happened to me. As life partners Andy and I were used to taking care of each other. It felt natural and good until it became overwhelming. If the patient has been diagnosed with a progressive condition, meaning over time it will likely get worse, then it isn't really a surprise that the caregiver role will also progress. What can be difficult is if the caregiver does it all until they can't and the patient has gotten used to receiving care from only one person and might not want anyone else to help. I took care of all of Andy's needs for as long as I could. We couldn't easily afford other help and many of the things I did for him were intimate and personal.

Learn from my experience and don't wait to find other people willing and able to do some of what you do for your patient. In our case limited financial resources was at first a reason that I was Andy's only caregiver. Our situation evolved until financial considerations became what finally pushed us to hire help. I needed to work and we needed the money I could earn.

Andy was not thrilled at the prospect of neighbor friends coming over to feed him meals and do small household tasks while I worked. I was not thrilled to ask people if they'd be willing to come over and feed Andy bite by bite with a spoon. When we got over our inherent shyness and uncomfortable feeling of dependence, these other people in our lives became an essential blessing. They were essential because the pressure from me being the only caregiver was released. Our husband and wife relationship came back into a better balance. For both of us.

I had time engaging in work and life when I was not solely defined as the person whose husband had Parkinson's Disease. Andy got to socialize with neighbors and be mentally stimulated by conversing and being up to date with other people and friends.

This all lasted from 2007-2013. There were periods of months when one or another of our kids interrupted their own lives and lived with us in order to help with their dad's care. At first I thought this was sad and wrong because we wanted our kids to be free of the burden of needy parents. In actuality, it was a blessing for everybody. Our kids kept active relationships with their dad, witnessed his courage and strength in hard circumstances and expressed their love through the care they offered.

Because our situation was somewhat unusual, in that Andy got better after brain surgery, I can look back and say my only regret is not reaching out and asking for help sooner. Depending on personal circumstances, some refused payment. Money was an issue for us, but no matter your financial reality, reach out and ask for help. There are sometimes community organizations that offer help without payment and there are often Good Samaritan type people who will offer to help when a need arises and they are told about it. This is never an easy step to take, and even knowing that, I encourage you to do it anyway. Your patient will get used to others helping them and you will not define yourself as much by your loved one's illness.

I have come to realize that taking the risk of asking for help was similar to other life situations that I had resisted. I was the child not wanting to take the medicine that would help me get better.

I was the young woman perched on the edge of the cliff before jumping into the sea. I was the pregnant new mom wanting labor to begin and wishing it didn't have to. I was the mother smiling as my son went off to college and saving my tears for later. I was the granddaughter staying with my nana in the hospital when she was dying. I was the daughter flying in the wee hours to the Mayo Clinic for my father's lung transplant. Now I was the wife of my beloved and sick husband and I needed to find some help.

Do it.

Be brave.

Dig deep and embrace this too, and once you do, so much more becomes possible.



7. Get A Really Comfy Chair.

When an illness happens and a disease is being lived with, a lot of what one has come to expect in life changes and a lot of comforts go out the window. In our case, Andy's constant shaking made most activities very difficult for him. We had lived for many years in our housetruck. It was a 240 square foot custom home that Andy had built and was our "dream" home as we raised our kids, cooked delicious meals, and had parties and gatherings. We'd say to friends, "Living in our housetruck gives us the freedom to travel and ski. Sure, it's small but we live outside, mostly. It's perfect for cooking, sleeping and reading. It's big enough to do yoga and homeschool. We love it."

And we did.

After Andy got sick, it became confining, difficult and we felt stuck. As Parkinson's progressed, our living situation caused more care giving work and necessitated more confinement for Andy. It was dangerous for him to maneuver in and out of our small sized door, down the front steps and across uneven ground for 100 yards to get to the outhouse. It was dangerous for him to boil water on the stove and pour it into our wash tub with his shaking hands. Our home was too small for chairs and Andy was left with the reality of being uncomfortable as he tried to find a way to sit on the floor cushions we'd always enjoyed before Parkinson's.

In every illness, different challenges come into being according to the living situations that exist. My father has a lung disease and before his transplant he had to drag a large oxygen canister around with him everywhere he went. At home he was tethered to it and had to organize his life to fit into the distance the electric cord would allow. My mother has a circulation illness and had to find a way to get her feet above her heart for long periods of time. My grandfather had severe dementia and needed a spot he could recognize as his own and where he could relax and be safe.

In every case, a patient's life can be enhanced with the right chair. In our case we went to the [La-Z Boy](#) store and tried out many chairs before we found the perfect one for

Andy. It fit in our housetruck with less than an inch to spare. We set it up by one of our doors that had an oval window providing natural light. Andy could easily open the door a crack if he wanted some fresh air. A friend commented that it looked like a first-class airplane seat. The chair we chose was a plush power recliner with built in back support. We set up a small TV (Our entire home was 240 square feet) and finally he was able to be as comfortable as possible when he was home. My dad ended up using a large rocking chair every day and my mom bought a zero gravity chair at The Relax Your Back store and my grandpa spent many hours in a restored deck chair from The Queen Mary ship that was set up for him on a screened in porch. As a caregiver it is comforting to know your patient has a home base to relax in. As a patient having a place where you belong is a relief and fills a basic need.

We were able to finance our La-Z Boy chair at zero percent and paid less than \$100.00 per month for a year. We had the sales people load it in two parts in our Subaru Outback car to avoid an expensive delivery charge. Find the best chair for your patient, get it and discover all the benefits as soon as possible.



8. Foster Independence.

Being a caregiver to someone means that person will be dependent on you. This is part of the job and requires a lot of giving. There is a natural imbalance that happens between the caregiver and patient that is unlike other adult relationships. I sometimes felt like I was caring for Andy like I'd cared for our children when they were small. If you are a parent it is likely that this will come up. I had to remind myself that this wasn't an equivalent comparison. Though I was helping him do many things I'd helped our children with, dressing, bathing, eating, remembering stuff, and getting around, he was not my child and he did not want to be dependent on me for these things. The best antidote to this awkward situation was to be as creative as possible finding ways Andy could keep his independence.

Andy could no longer feed himself most foods or drink from a cup without spilling. When making ourselves focus on what he could do we found ways he was able to access some degree of self care and independence. He could hold on to a large chunk of cheese and he could get crackers into his mouth from a large bowl. He could suck from a straw, placed directly into a glass jar of juice or water that sat on a counter, as long as the cap had been loosened. In this way, during Andy's most disabled years, he was able to be safe in our housetruck, feed himself lunch consisting of cheese and crackers and drink when he was thirsty, using a straw and not touching the jar of liquid. His chair gave him a safe and pleasant spot to sit and read, using beanbags a friend had made for him to hold his book steady, or watch TV or nap. I could leave him for some time and work or do errands and he was able to be independent of me. If the phone rang, he'd knock it off the cradle, put it on speaker selection and shout to be heard. There was no way he'd hold the receiver to his ear as he'd be banging himself in the head. It wasn't ideal but he could answer the phone.

Recently, I was an exhibiting artist at a small art show in Colorado. I was alone at my booth when two women walked up wearing shirts that said, "Alzheimer's" across the front. They approached me and one of them said, "I have Alzheimer's and I'm part of a group promoting better public awareness of this disease. We are here today as volunteers and will watch your booth if you need a short break." I was surprised and said, "That is very kind of you but my daughter and sister are both here helping me and I don't need a break."

She was well spoken but I was hesitant and realized I didn't know nearly enough about the situation to be able to entrust my booth to a person actively informing me they had Alzheimer's. I admired her courage in approaching me. Then, her companion spoke, "I do not have Alzheimer's and I am a caregiver promoting public awareness through [our organization](#). We are experimenting with ways our Alzheimer's patients can be more visible, out in the world and serving their communities." I told them that I support their mission and it would have helped to have been given a little background and a head's up about the idea.

Long story short, independence is essential for human beings and as caregivers it is our job to find ways to promote that in our patients.

My mom was my grandmother's caregiver. Nana suffered from arthritis and found it hard to move, especially quickly. Once, Nana was sitting with Mom and a group of friends on someone's front porch, when Nana's cane slid down from where it had been leaning against her chair and fell on the floor. The group watched Nana struggle to pick it up and someone chastised Mom and said, "Pick up your mother's cane for her." Mom calmly answered, "She's doing it herself and if she wants my help she will ask." It would have been easy for my mom to pick up the cane and it also would have been one more thing Nana depended on someone else for. If there's a chance for a person who has a caregiver to be independent, take it. It will only help.



9. Use Memories Often.

We all have countless memories in our memory banks. Everyone has a mixture of positive, negative and insignificant memories waiting for retrieval. Some illnesses cause memories to be mixed up, confused and lost and I'm not addressing that. Whatever state your patient's memories are in, they can be mined and used to keep the person inside the sick body alive.

When Andy was at his most disabled, I found and shared photographs with him from other times of our life together. This is easy if you are giving care to a relative and a strategy to explore if not. I found it helpful to "post" photos around our home, on the refrigerator and in places where Andy would see them. If photo albums are available they can be taken out and used as memory triggers or evidence of a life lived before the disease.

The point is not to show the patient that they used to have such a wonderful life and now it's over. NO, NO, NO... My grandmother, the same one who dropped her cane, complained to me,

"I don't understand why people treat me as if I'm only 85 years old. Yes, I'm 85 but I'm also all the other ages up to 85. I'm 14 and 22 and 38 and 57. All those ages are still part of who I am but the world seems to forget that and I'm often treated like a diminished person who's only 85, instead of celebrated with acknowledgment of ALL my years."

She makes a great point and memories are one way to access and celebrate that whole person. Being a patient and being a caregiver are both opportunities to shift from an outdated paradigm to a more useful concept of illness, exploring what illness means and what it doesn't mean. My own experience has shown me that even in the most severe cases of dementia there is still a person inside that sick body/mind longing to be recognized. In Andy's case dementia was not an issue but being overlooked and lost inside a frail shaking body was an issue.

There can be a balance between staying in the present and living with what is happening in the moment. Taking time to consciously remember the joys and adventures of a lifetime can help maintain contact with the whole person who is presently experiencing illness. I don't suggest living in the past. I know present moment conscious use of memory can enhance the reality of your patient's life. This also reminds the caregiver who it is you are really caring for.

When Andy was stuck in his frail shaking body and we'd remember training for the Ironman Triathlon while living in Hawaii, much healing would occur. Our remembrances served to remind him of the physical strength he had once cultivated and he'd be inspired by his own self. We laughed at our younger selves, during that same period, being audacious enough to purchase a Hobie Cat sailboat on a trailer, but not having enough money for a vehicle to pull it. We remembered hitchhiking with our boat and the characters who'd pick us up and tow our boat to the launching place. We cracked up and our laughter from that memory triggered all sorts of endorphins and inner peace in the present moment. Memories are a treasure trove in every life that can be used to open us up to a new improved model of living that supports the worth of a person living with an illness.

Memories can help us acquaint with the whole person and not only the part that presents as sick. Doing this work as caregivers can be a model for the world as the outmoded paradigm shifts to something better.



10.

Movement.

Movement is crucial for life. When we get sick it's natural to have bed rest and peace and quiet as we recover. Movement becomes secondary to rest. We all grew up being told, "Get back into bed or you won't get better." No wonder it feels counterintuitive for a caregiver to encourage their patient to get up and exercise. We know in our heads that chronic illness has different parameters than an acute case of the flu or bronchitis, when rest is a big part of the remedy. Even so, when someone isn't well, the last thing that comes to mind to prioritize can be exercise. I like to broaden the meaning of exercise, which can conjure images of knocking out pushups, 4:00 am military style runs or training for some grueling race. Let's define exercise as the simple idea of movement. To move is to be alive and doesn't always require traditional exercise.

I don't mean to demonize the word exercise. I, personally, love working out and training in many ways, but I am sensitive that someone with an illness may not feel like exercising while they may be open to movement that feels good.

Andy's dad had colon cancer and shortly after his surgery he was up and walking the hospital corridors. A nurse questioned his rationale and he told her, "I've never heard of a patient dropping dead while walking but I know lots die in their beds."

My mom has heart failure and COPD as someone who has never smoked. She is 86 years old and at age 82 we thought she might be in her last year of life because she was terribly weak and fatigued every day. With trepidation and initial resistance she entered a cardiac rehab program for a few weeks. Now, years later, three times a week she moves her body using a machine called the [NuStep](#) and then walks on a treadmill. Regular movement allows her to be strong enough to go to the grocery store by herself, to attend church, to participate in her book club and go on visits with friends and family that would have been impossible a few years ago. Every doctor will recommend that every patient finds a way to exercise. We all understand that this is imperative.

There is a reason this is my last recommended strategy and that is because it is known by all and followed by few. I tried everything I could think of with Andy-----biking on a trainer at home, gentle swimming, walking with hiking poles, easy yoga, a dance routine at his support group meeting-----nothing lasted. Andy had been an athlete all his life and I think ex athletes might be the hardest cases of all. Finally, I gave up and I felt like a failure as a caregiver. My patient wasn't moving much. His breathing was shallow, he was too thin and his muscles were atrophying. He suffered from lack of movement.

I comforted myself with the first strategy in this booklet. I reminded myself, "I don't have Parkinson's." I made time for yoga every morning and several times a week I'd hike or run or ski with a friend, while Andy was cared for by someone else. I loved Andy as he was and enjoyed our expressions of affection. I took my flower remedies and gave them to Andy. I felt happy seeing him sit in his comfy chair and we shared positive memories often and with joy. In short, I followed all the other strategies and took responsibility only for my own choices. I let go of the investment I'd made in wanting Andy to move using exercise and deferred to his independence in making his choice not to.

Only after I let go completely did he begin doing some movement at home on his own. I came home unexpectedly one day and found Andy on the floor doing some stretches and trying out some push ups. This led to him experimenting with some gym workouts and later he started attending an exercise class for people with Parkinson's that was offered by [two enormously talented and kind individuals.](#)

Sometimes caregivers have to stop caring so much and allow the life of the patient to unfold in the patient's own way.



That's the last piece.

Do care.

But don't care so much that you try to have control.

Surrender, and trust that every life has its own path.



About The Author



My journey has never gone in a straight line, followed a conventional path, or been predictable and because of that I've had to dig more deeply to find creative ways to move forward at every step. The creativity I've discovered inside myself is both my source of great joy and my connection to a higher power.





Author of
Your Wildest Dreams: A Parkinson's Love Story

