



# DLM Spring

## *From the Desktop*

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### Special points of interest:

- Subscribe to the Dystonia Living Podcast or listen online!  
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- Add your voice to the next issue of DLM! Tell your story, share event information, art, resource or recruit volunteers.  
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Ah, Spring!  
Is there anything as lovely as the freshness the turning of the planet towards the sun produces? The days have steadily offered more sunlight since late December, but it isn't until the late Spring afternoons that I begin to really notice the difference.

Life can be like that. Sometimes there is a positive change waiting in the wings that has been slowly gaining strength

for some time, but we are unable to see it until it seems the whole world must shift on its axis or we'll explode.

*Ah, Spring!*  
This is the time when we partner with Mother Earth to revitalize our lawns, lay out our gardens or just shed our winter clothes. Spring is a time of promise and reward -- After all, we've made it through the toughest of all seasons!



*Caption describing picture or graphic.*

As you enjoy the newness this year, we at Dystonia Living wish you all the best. May you discover new shades, paths and flowers to thrill and com-

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## *Dear Diary...*

*Dear Diary: Is This Brain Disorder Affecting My Brain?*

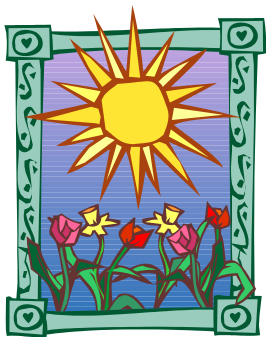
I'm going to be perfectly frank right now and say that I am fed up.

In the past 9 months that

I have been disabled by my Dystonia I have met many wonderful people with Dystonia. By 'meet' I don't mean the number of people who stumbled on this blog or follow me

on twitter, I mean people that I have actually held a conversation with, or read or listened to what they had to say. Some have become good friends, others have just become

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*Spring: a time for renewal*

## *From the Desktop (cont.)*

fort you. May you rake away all the withered, useless, suffocating blades, pluck out brand new weeds and bury the seeds that will be most beneficial to your soul when they are prepared, nourished, and given time to grow.

## *Suite!*

### ***Is it time for you to upgrade your diet?***

Difficulties with chewing, swallowing, cooking or even getting food into one's mouth can precipitate an abandonment of healthy eating. It becomes easier to just 'grab something'. If you are the head of household the problem can be even worse, as you may prepare the familiar, healthier foods for the family and ultimately be unable to eat them.

Often diet modification is not medically indicated, but no less helpful and necessary for an increased quality of life. Those who are treated on a basic level may never have change suggested to them, as some medical professionals might miss the subtle changes in lifestyle caused by swallowing difficulties or creeping disability.

#### **Try this!**

**Eat softer.** Cook less often. Easy recipe stews, homemade vegetable soups, casseroles and pasta can be prepared, stored in air tight containers and reheated quickly. For a warm summer, a cool choice like gazpacho can be prepared for consumption and frozen, are easy to serve and to swallow. All of these types of foods can be adjusted for the desired consistency (for chewing & swallowing) without losing their appeal.



*Eat Softer. Cook less often.*

The podcast this issue is all about living with Generalized Dystonia. Often times, this very debilitating form of the disorder goes without proper support, understanding or care. Here at Dystonia Living Magazine we want to do our part in improv-

ing the education of and palliative care choices for those living with GD, while reducing the isolation that so easily overcomes us.

Accept our best wishes for an excellent year.

— Rebekah

**Use supplements.** For some of us it is hard enough to eat a sufficient amount and on a regular schedule without having to worry about variety, color, freshness and balance. Choosing a high quality supplement like USANA can help. Not only are vitamins essential to the modern menu, but they can actually improve energy use and vision, as well as the way we think and feel.

**Broach the subject.** Are you ever too tired to eat? Do you choke on your own saliva, foods, juices or water? If this is happening once or twice a week it might be time to talk to your doctor about seeing a speech-language pathologist. You may also benefit from the use



of thickening products, such as Nestlé's Thicken-Up!, however, it is really best to take advantage of the information an evaluation of your particular situation can offer.

#### **Bon Appétit!**

Food is an essential part of life. It is interwoven into culture, relationships and memory. Upgrade your life today by implementing these or your own ideas, then let us know how it's working for you!

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## Dear Diary (cont.)

new additions to my vocabulary, but nonetheless they have shaped my experiences.

What I have learned and experienced is an overwhelming negativity associated with many of the people I have met, watched or read. It has gotten to a point where it actually hurts my heart. For the last couple of months I have been struggling to understand why this is in both my Dystonia comrades and myself.

I try not to make this blog too technical, because I am not a health practitioner, but let me break down the definition of Dystonia. Dystonia is a disorder of the basal gan-

glia. It affects movement. It by current definition does not affect personality or cognition. Yet, If you were to lock yourself in a room with 100 people with Dystonia the majority of them will either be angry, depressed, or self conscious.

### Why is this?

The Dystonia medical research foundation states that chronic illness frequently affects psychological health.

Is that why we are in love with Michael J Fox and Lance Armstrong.. because they are immune to the chronic illness blues?

I am not so quick to write off stress as a reason for the sour grapes many

seemed to have ingested.

Could the neurons be attacking other brain cells like they attack cognition in Parkinson's? Could some forms of Dystonia just naturally make you mean?

I know one thing: Dystonia has made me more outspoken, more aware of the day to day, and more likely to take a siesta or two. When I find myself sucking on the Dystonia sour grapes.. well I do like I do with my daughter..

I give my brain a time out.

—**Jennifer McKnight** is a model, mother and advocate for Dystonia awareness.



*Dystonia has made me more outspoken, more aware...*

### Do you Tweet?

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## Candid Perspectives

The Garden, in my family, is something that has taken on a life of its own. For as long as I can remember, early spring meant spending entire days out in the yard, digging, raking, plowing, planting the wonderful little seeds and baby plants that would nourish our tummies and souls all

summer long.

We took baskets to our neighbors and smiled when others helped themselves.

Well, I have discovered that I can still participate in the whole gardening experience. It's a great thing, because I love being able to work on

something so real and have the privilege of seeing a tangible reward.

So what if I spend the majority of my limited time outside mostly prostrate on the ground, sometimes trying to make sense of what I see and manipulating my lower limbs so that I can have



*I can still participate...*

*Candid Perspectives (cont.)*

*“I have had to adapt...”*

functioning access to my hands? It's a great experience.

One of these days I will have an elevated garden on paths that are wheelchair accessible. I am sure that I will enjoy planning the space, supervising and scattering seeds. I know I will enjoy the unmistakable smell of the wet dirt,

fresh tomatoes and other plants that have been such an important part of my personal traditions.

I have had to adapt quite a bit and some things I can only just remember doing, but the tradition -- the anchor-- and the benefit continues.

I don't ever want to give

up a pleasure, skill or duty when all I really need to do is adapt. I want to make the change before change 'makes' me.

So there it is, tapped out with dirty fingernails. There is the whole of the matter.

— Candid Writer

*Fiction: Rhododendron*

Carson slipped the plastic sheath over the flat bed floor and hoisted the heavy black pot over the wall. It wasn't the best looking one in the shop, but it was

the right color. Rhododendron: sturdy deep green leaves holding delicate purple petals. Bunches so perfectly arranged they looked like bridal bouquets, bounced happily against the still crisp spring air as he put the truck into gear and gunned it over the gravelly lot.

“Slow down, honey. I don't want it to fall.” He eyed her, annoyed.

“Listen, Mina, I've been driving for a good many years and I don't need you giving me guidance.” He slammed the breaks just in time to miss the tail end of the shabby old hound Jim's Potted Pleasures was known for letting roam the premises. The dog was an icon.

“Carson, my goodness...” She tried not to say too much and took deep breaths. *I hate this truck. It's such a bumpy ride I can barely stand it. I hope I can still get something done today.*

By the time they pulled into the lane leading up to their private driveway, the deep muscles in Mina's neck and shoulders were engaged in an all-out battle. She'd taken

her time release pain medication, so she could handle the increased activity. At any rate, she was determined to get that plant in the ground.

Carson maintained his annoyance, glancing sideways at her. He hated gardening, especially now that she was less able to pull it off alone and he was forced to court her in the sometimes blazing heat. At least, that is what his conscience told him. Carson also hated his conscience.

Mina opened the heavy door of the 150 slowly and cautiously placed her feet on the step trying to appear fluid and carefree. Far from convinced Carson blew and rolled his eyes, “Mina... Dangit...”

He could barely contain himself. “Are you seriously going to dig that hole tonight?” He jumped from the cab and slammed the door, dragging his feet around the back of the truck. He gazed into the faded blue sky watching a passing plane leave its trail. “Sun'll be down in less than two hours.”

“I can do it. I want to get it in before the next rain.” She unlatched the short back door of the cab and felt blindly for the clasp to which her folded walker was attached. When she found it, she released the Velcro and tried to drag the frame towards her, hoping she wouldn't lose her balance. Her eyes were facing

*Fiction (cont.)*

down, but she felt like she couldn't see anything. Her walker wouldn't move.

"Carson..."

Quickly beside her, his strong hand landed on her forearm. "Move." He pushed a little, but she couldn't make her feet agree. He ended up having to catch her as quickly as he'd suggested she give him more room. He softened, "Here, just take my arm for now. I'll bring your walker out when I get you settled."

"Carson, I'm not settling yet. I'm putting in that bush," she protested.

"Look, honey, just help me get moving forward a

little and I'll be fine. I already took out the little spade."

Carson bit his tongue and locked his jaw. He knew when there was no point in pressing the issue. He grabbed the plant and stalked off through the yard.

Around the little paved path and down a little ways, Mina's eyes fell on her most treasured gift. Carson had surprised her, late last summer, with the barrier-free gazebo. All winter long she had been waiting for the first hint of spring to emerge, so she could get into it. She smiled and relaxed a bit



*She carefully maneuvered her walker ...*

when she considered all the memories to be made there.

The rhododendron would go just in the center, where Carson had asked the contractor to leave a circular spot of earth. *His heart is right*, she thought forcefully. *He planned that spot for just this type of day.*

She watched him drop the plant beside the round and turn towards her, solidly miffed. As he passed

her, he grumbled, "Let me know when you're ready to put it in."

She crossed the last few feet to the round and carefully maneuvered her walker behind her. Locking the brakes, she plopped into the seat. A few daring articulations of her foot and upper core and she had the spade by the handle. After silently reviewing the instructions the man at the greenhouse had given her, she began to move the soil. Thankfully, the contractors had laid some new dirt and it was devoid of the hateful clay found throughout the rest of her property.

Tiny scoop here... larger scoop there... dropped spade... Carefully standing, leaning bodyweight on metal and wood... Divide the lump. Lift and remove. Drag it out—every option was put into play. She rested after nearly every movement, forcibly, and soon the burning ball of gold she'd prayed would slow its progression, sat regrettably on the horizon. She was decidedly a tad more than chilly.

"Ow, ow, ow..." She complained, sliding onto the ground where she'd decided she could get more accomplished. She lifted and pulled herself over to the attached bench to her right and grabbed the hand rake she'd asked Carson to lay out. A couple additional trips and she had moved the liquid fertilizer and the bag of mulch nearer to working position.

After mixing the dirt and mulch, she turned to the house. Every light

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*Oh, the Irony!*



**Carson had fallen asleep over his alma mater's latest missive or some military journal.**

*Fiction (cont.)*

extinguished, she assumed Carson had fallen asleep over his alma mater's latest missive or some military journal. A breeze passed her, sending a shiver up her front and tripping her into a set of more aggressive

movements.

*I'm getting this in the ground tonight. I'm going to do this thing.* She took as deep a pull of air as she could manage and allowed her body to tumble sideways onto the remaining mulch. The sack had held much more than this small spot required and she was able to rest on it, feeling the wrenching muscles in her scalp, neck, shoulders and core release.

Her breath came steady, but created little smoky puffs above her nose. Staying out much longer would make her a fool. Her lungs couldn't handle too much of this. Resting is necessary, but there are times when you just have to make due. *In a minute*, she thought, *I'm going to get up and finish the job.* She checked the sky for stars and noticed that there were one or two. She pushed away thoughts of disgust and self-pity, which threatened to weaken her. Her mind flashed with images of how to do each movement – now and back then. *To get that bush out, I'm going to have to get up.*

*Now.* She told herself and shifted until she could hold the base of the bush with both hands. Bravely, she tipped it to its side and used the well established branches to gauge her position as she sat up. "Sorry, little bush. But you and I are in this thing together."

As she could manage, she placed her hands beneath her lazy lower limbs, placing them against the stiff temporary pot. Wiggling it, a bit, she loosened the soil and then, slowly, but firmly, separated it from its plastic home.

She smiled and laughed out loud, no longer concerned about the cold. It was only a matter of minutes before the beautiful little bush was settled in the earth with her scraping the displaced soil around its sides.

"Yes, we are in this together." She fell back into the mulch and sighed, resting a second before she tamped the earth. She reached for her phone. Without looking she pressed the dial key, surprised to hear Carson's phone ringing in the yard. The surprise left her body frozen in position, so she called out to him.

"Carson. Honey, is that you?"

All was quiet and for a second she felt her heart pounding inside her chest as she imagined a thousand awful things.

"Carson!" she called, unable to change positions. She recognized the sound of his footsteps on the path.

"Mina, you really are something!" He said, falling to

his knees beside her. His eyes glistened in the first

light from the full moon rising. He kissed her on her forehead as she relaxed, happier than she had been in a long time.

"You're going to have to

help me up, honey. I'm all in!" She laughed, making a move to rise. Carson supported her in his way, so that her flexed feet barely touched the ground. She laughed again, this time upright, which always caused her to bend double. This time the movement while he held her made her laugh even more, but Carson didn't mind.

"Baby, you're going to have to stop laughing or you're going to fall off the walker. I was bringing out your chair when I saw you on the ground. Let me get it." He ran down the path, returning quickly with her inexpensive transport wheelchair and helped her into it, carefully lifting her feet onto the rests. He kissed her again. "I thought you

were hurt, but then I saw what you were doing... I'm sorry I didn't help, but I was just so amazed... I don't know how long I was watching."

"Carson. It looks wonderful in that spot, doesn't it?"

He nodded.

"It will grow to be five feet tall, five feet wide." She squeezed his hand.



*Fiction (cont.)*

“That’s almost my natural height, do you remember?” She smiled, wishing she could get another look at her accomplish-

ment, but unable to force her body to turn. “It is a sturdy little bush.”

Carson, rubbed his arms against a passing light wind and rose to push the chair up the path.

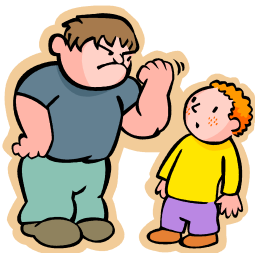
“It’s sturdy. It can endure rough weather. It can survive change.”

**Rebekah Willis** lives with early on-set generalized Dystonia. She started this magazine to be useful to all those living with Dystonia and to lend her efforts towards meeting a perceived need for practical living support within the community.

## *With a Body Like This, Who Needs Enemies?*

Worry, anxiety, confusion, grief, uncertainty, anger, physical and emotional fatigue-- These are only some of the new and persistent challenges brought into the emotional playlist of one living with Dystonia. Depending on the severity of symptoms, the impact of daily living is a heavy burden to bear, endurance of which is doubtless one of the most transformative experiences available to mankind.

In light of all the personal growth, personal stress and personal management we deal with, who needs enemies? Unfortunately, ‘brawling behavior’ is not so rare an occurrence around the Dystonia watering holes. Emotional



flare-ups are only part of the problem, since it seems that some are simply hard of heart, finding fault with others within the community at every turn.

Some examples of poisonous behavior include: gossip, slander, vitriolic diatribes, condescending attitudes/language (verbal abuse), threats, divisive movements, pervasive paranoia, etc...

The bad news is, when these types of negative influences are allowed to flourish in a community such as ours, they only prevent advancement of the cause and stifle the wholeness and relief of the individual.

The good news? We don’t have to fall prey to the bullying whims of others. If we train ourselves to

find some way to empathize with the person (or persons) involved, we can keep our own heart joyful and avoid validating useless negativity.

First, ask yourself (as we all must do if we want to live honestly), “What could I have done differently?” and “Am I the problem, or a part of the problem?” If you answer ‘yes’ to one of these questions, take some time with yourself, with a counselor or close friend to discover and work through some of the things that charge your emotional flashpoints, such as stress, anger, frustration, hurt or control.

If your honest answer is ‘no’, learn as much as you can about deflecting negative behaviors. Perhaps, your kindness and/or stern, but patient response will be just the right amount of Love the often unwitting aggressor needs.

Stay active, even when your body overrules itself. If you have the proper support, mobility and accessibility equipment, you can stay active. It is vitally important to participate in local community life and personal development activities. It helps to keep us balanced.

So, blow off steam. Explore religious faith and attend communal events. Enrich your emotional experience in the museums and open areas. Volunteer, practice optimism, take a deep breath.... and then.... just be kind!

**Find more conflict resolution resources online @ <http://dystonialiving.com>**





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