

Shadows by D. H. Lawrence

*And if tonight my soul may find her peace
in sleep, and sink in good oblivion,
and in the morning wake like a new-opened flower
then I have been dipped again in God, and new-created.*

*And if, as weeks go round, in the dark of the moon
my spirit darkens and goes out, and soft strange gloom
pervades my movements and my thoughts and words
then I shall know that I am walking still
with God, we are close together now the moon's in shadow.*

*And if, as autumn deepens and darkens
I feel the pain of falling leaves, and stems that break in storms
and trouble and dissolution and distress
and then the softness of deep shadows folding,
folding around my soul and spirit, around my lips
so sweet, like a swoon, or more like the drowse of a low, sad song
singing darker than the nightingale, on, on to the solstice
and the silence of short days, the silence of the year, the shadow,
then I shall know that my life is moving still
with the dark earth, and drenched
with the deep oblivion of earth's lapse and renewal.*

*And if, in the changing phases of man's life
I fall in sickness and in misery
my wrists seem broken and my heart seems dead
and strength is gone, and my life
is only the leavings of a life:*

*and still, among it all, snatches of lovely oblivion, and snatches
of renewal
odd, wintry flowers upon the withered stem, yet new, strange flowers
such as my life has not brought forth before, new blossoms of me*

*then I must know that still
I am in the hands of the unknown God,
he is breaking me down to his own oblivion
to send me forth on a new morning, a new man.*



*Reflections of Sunlight and Shadow — Cross River, BWC-A
Dawn, August 15, 2007*

Photo by Earl J. S. Rook

December 2007

Dear Friends —

The older I get, the more introspective I become. ALS has exacerbated this tendency in me, and the insidious progress of the disease — and the ravages it works on my body and spirit — makes a review of 2007 bittersweet. Perhaps more bitter than sweet this year, although that changes day by day — and (as has always been the case with me) can even change by the hour.

My strongest impression of the year as a whole is that it was a never-ending swirl of light and shadow, good times mixed with bad, progress and erosion. All years are like that, but 2007 contained some elements that made the contrast more noticeable than usual — or maybe I was just paying more attention.

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More than Enough Health Drama

In February, Earl was told he had lymphoma. Bad words were said; to quote him, “Yet another *#@%ing opportunity for personal growth.” It turned out to be Stage 1A, non-Hodgkins, and indolent (their word, not ours). It’s never good news to be diagnosed with cancer, but this was about the best we could hope for. He had a mass removed from his neck and underwent a course of 17 radiation treatments in April. His beard barely survived (it got pretty thin for a while) but is now back, thick, full and more handsome than ever. The radiation really sapped his strength and, even though his August CT scan showed no active cancer sites, he is just now feeling like he’s back to full vigor. He’ll continue to have scans every six months; they treat lymphoma of his sort as a chronic disease – one that requires continual checking, but which (with luck) may never return

Retirement

ALS has forced me into an early retirement – not just from work, but also from a wide range of activities that I have long held dear.

My last day in the office was April 30, 2007. Always an oddity among job-hopping baby boomers, I had worked there since January 18, 1978 – so leaving was heart-wrenching for me. But by April, fatigue and weakness prevented me from being at the office more than 20 hours a week, and I felt that it would be better to retire than to continue to ask the office to limp along with me as a part-time director in a job that had always required much more than a full-time commitment.

I wish I could say that, by retiring in the spring, I was able to spend all summer puttering in my garden. I was able to enjoy the sunny days and the lovely flowers my friends had planted, but my hand strength and mobility were so poor that I couldn’t do much more than dead-head the flowers and pick the blueberries I could reach from my chair. It was something – certainly better than not being able to spend any time in our beloved gardens – and on most days, it was enough.

eroded away, it is clear that the essence of me is not my body. I bitterly miss making pies, wrapping gifts, and cooking (all things that I can no longer do because ALS melted those muscles), and I am highly frustrated by not being able to pick up anything or speak clearly and loudly. Yet, when I sit still, I find I feel as alive as ever – what’s up with that? Shedding the aspects of myself that I thought defined me, made me lovable, gave me something to offer the world is hard, unpleasant work. It’s work each of us must do at some point

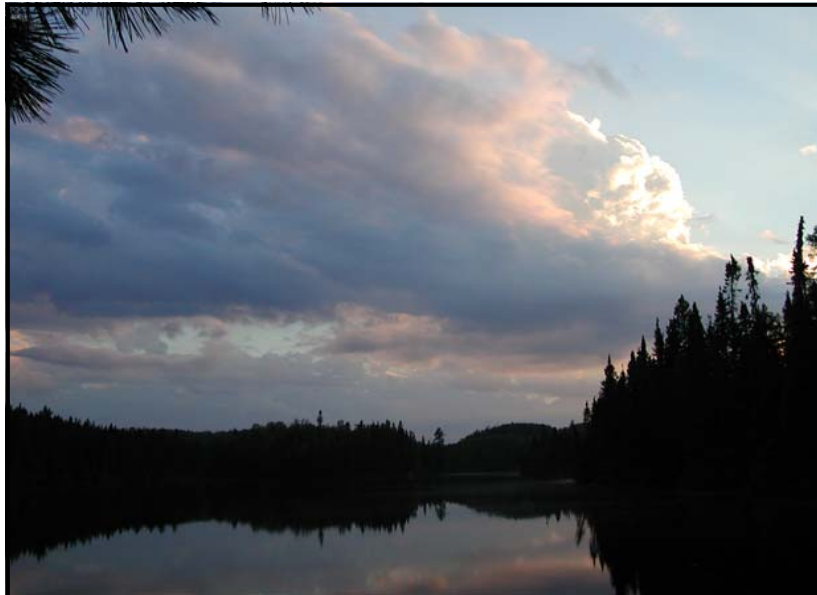
I could – and do – dwell in the dark shadow of all that now seems impossible for me – morning walks, photography, travel, playing piano, gardening, rolling over in bed, and a long list of other things that no one would want to read. But I also try to bask in the light of what I can still enjoy – reading a book, gazing at the sky, communicating with friends (via email and/or slow, slurred speech), watching my beloved nieces and nephews blossom into dazzling individuals.

Even the increasingly-labored breathing ALS has produced in me serves as a reminder to focus on each moment, each breath, each sparkling second of this embodied existence. I don’t pretend that I’m able to do that all the time – but I have found that the more I do, the more content I am. The past provides too harsh a reminder of what I used to be able to do, and worrying about the future (particularly the messy physical decline it certainly will bring) makes me miss this moment when I am as physically capable as I will ever be.

I wouldn’t wish ALS on anyone, and I would give a lot to not be going through it myself. And yet, I would not trade for better health if it meant I had to forgo the past 30 years with Earl, not know the love of my family and friends, never see the beauty of a sunrise, never smell garden soil in the spring, or never rest in the peace of a moonlit night.

I hope 2007 has given you much to be thankful for – and I hope that 2008 brings you delight, contentment, and love.





*Storm Clouds Enhance the Sunset — Gordon Lake, BWCA
Dusk, August 15, 2007*

Photo by Earl J. S. Rook

needs.

Over my birthday in September, we drove to the North Shore with our friends Barb and Keith. Our first road trip with the power wheelchair and our van, it worked well. Of course there were places that were not accessible to me – but the four of us had fun, ate well, and were able to marvel at the immensity of Lake Superior.

We spent Thanksgiving in Sioux Falls, where my brother and some of my nephews live. We stayed at a hotel and brought a hydraulic lift to raise me from sitting to standing (necessary for getting out of bed in the morning and climbing into bed at night – and every up-from-the-wheelchair event in between). Being with my whole family on Thanksgiving was a very bright spot this year.

Half-Baked Philosophizing

I'm a long way from calling ALS my friend, but I must admit it has been a very good teacher. As various physical capabilities have

September marked the end of my attendance at yoga classes. I started the year able to drive myself, walk with my cane to the door, and get into the studio without any problem. By February, I needed help opening the door, and by March I needed help to make the one step up into the studio. By April, when I was no longer able to drive, Earl would take me to the studio, haul out a portable ramp, and help get me and my chair into the studio. By June, I couldn't stand up from the floor and walk over to my shoes after class – I'd crawl over to a bench, heave my body onto it, and then get assistance with getting into the chair. By August, I couldn't even crawl without assistance. *(Note: I may be one of the densest ALS patients ever. I knew that I wasn't going to be able to walk, but it was like getting the diagnosis all over again when I found I couldn't crawl.)* Quitting the yoga classes was a dark and bitter event, but only because the classes, the teacher, and the other students had become such a sweet and bright part of my life – and I am eternally grateful for their support, which allowed me to continue my modified approach to yoga as long as I could.

Family and Friends

It's said that a friend is someone who knows the song in your heart and can sing it back to you when you've forgotten the words. We could not have managed this year without our amazing family and friends. They strolled with us through the sunlight of the year, and they carried us, singing softly, when it was too dark for us to see.

A group calling itself Kathy's Circle looks after some of our basic needs; because of their efforts, we have fantastic heat-and-eat meals at least three days each week – which reduces the burden Earl now carries of getting the two of us fed each day. They also line up people to spend time with me so that Earl can continue to play in the 3M Orchestra and attend his yoga classes.

My sister and her husband built wooden walkways in our garden so that I could roll out there to enjoy the summer. Crews from Kathy's Circle built a ramp to our back door, planted our flower and

vegetable gardens, and helped with garden clean-up in the fall – they even washed windows and cleaned gutters!

My brother stayed with me for a week in June; we spent some time every day writing and talking about our shared childhood memories and our lived experience with ALS, and imagining a book that would compile our work on these subjects. My sister-in-law stayed with me in August so that Earl could take his annual canoe trip (his photos grace these pages) – a wonderful break for him, and a marvelous time for me, since Cheryl and I were friends long before she fell for my brother.

We've met wonderful people through our ALS support group – people who know just what we're going through, who can laugh and cry with us, and who can share their strategies and solutions for living with ALS. That's the beautiful bright side of the support group. The dark reality, though, is that we lose some of these new friends each year as ALS claims their lives; in the past year, more than half a dozen have died. The other bittersweet reality is that each meeting brings a new face or two – new people to know and cherish; new people with whom to commiserate; new people to mourn when their journeys are done.

In August, I arranged to have a home health aide get me up, bathed, and dressed on days when Earl isn't here. I have been richly blessed to have the same woman (Theo) almost every day, and I count her as a sweet, bright part of our "new normal." She's smart about her job, she does it with great tenderness and care, and she makes me laugh. Her shining presence shrinks the shadow that comes with no longer being able to care for myself.

Since October, friends from the yoga studio have come to our house every Sunday to engage in a lively discussion of *The Grace in Dying* by Kathleen Dowling Singh. These smart, funny people are willing to discuss and explore the meaning of life, of birth, of death. Together, we shine a bright light on the dark face of death, an act of

courage (I believe) that gives us comfort and hope on this journey.

Travel

We started the year with a two-week trip to England (with a short stop in Paris). We joined our niece Meghan, who studied theatre in London during January, had a week in London, two nights in Paris, and a short jaunt to Chesterfield to see some sites where *Pride and Prejudice* was filmed in 2005. The time in London and Paris gave me and Earl a chance for one more look at some of our favorite places – the Rodin sculpture garden in Paris and Hyde Park in London, for example. The weather was cold, I spent most of the time being pushed in a wheelchair (making subway travel impossible), and it was much more stressful than our usual travels. But it was a sweet delight to find a great Indian restaurant right next to our hotel in London, and to eat once again the extraordinary offerings of Paul's Patisserie Pur Beurre.

In March, we traveled to California with my sister and her family. I had never seen the redwoods, and Marcia's girls hadn't seen the ocean, so we flew into San Francisco and drove north. The redwoods were magnificent – so large you almost can't believe the photos when you get home. The first days were cold, windy, and mixed fog with rain, making the glimpses of coastline and stormy sea thrilling – but not very inviting for strolling on the beach. The last days of the trip had lovely sunshine; Marcia's pre-trip planning had identified some state parks on the coast that provided beach wheelchairs – so I was actually able to get out on the sand, close to the water. What a gift my sister gave me!

May brought a trip to Oregon to visit Earl's family, and it was lovely to be with them again. It was our first trip with the power wheelchair (which meant we had to rent a special van when we got there), and it made it clear that twosome travel is probably a thing of the past for me and Earl. If Earl is to get any rest on a vacation, we need to bring a third someone who can manage me and my growing list of