

Dear Dr. L: ALS

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Dear Dr. L,

Is it strange that I feel blessed?
You can't lose what you never had,
and I thank God I lost so much.

I thank God for the beach:
for my toes touching sand and legs riding waves,
and the coolness of the breeze hitting water on my skin.
Those waves washed me clean,
now replaced by hands that are not my own
but love me all the same;
and I'd take those hands over the ocean any day.

I thank God for my Country:
for the strength to fight a battle bigger than myself
and stand for something before falling for anything.
Some may think that the wheels of my chair
restrict me from standing up for my beliefs,
but it's funny how the body learns to compensate,
how the loss of one thing becomes the gain of another,
and my mind took on the strength my body once had;
my thoughts run faster than my legs ever could,
and even when my voice fails me,
my mouth still works just fine.

I thank God for my voice:
singing was never my strong suit,
but I learned to perfect my tone.
People would rather hangout with an honest jerk
than a kind liar,
so I choose to be honest even when it turns jerk.
My voice may have faded,
but my character continues to speak for itself—
after all, its “actions over words”,
and my actions are louder than my voice could ever carry my words.

I thank God for my music:
the soothing sound of the guitar,
the feeling of the strings,
the vibration of the chords—
they never truly leave you.
I still hear music in the voices of my loved ones
and feel the same rhythmic vibrations in their laughter;
and the rhythm in their heartbeat
plays the most beautiful tune.
My fingers could never replicate the same songs,
even before they began to ignore my commands.

I thank God for my daughters:
I've never known a 20-year-old to live in a 10-year-old's body,
or a 4-year-old to plan a heist,
but the maturity speaks for itself.
My daughters will always be my babies,
even after I lost the ability to carry them;
and yet, I will always carry them with me.
My fight turned fist to knowledge,
and I protect them more by teaching them,
and somehow simultaneously, they teach me
how to protect them better every day.

I thank God for my marriage:
the one thing I never lost.
My wife vowed "for better or worse,"
and somehow still made my "worst" feel better.
Her arms hold me up,
and her legs guide my steps.
I would call her perfect,
but she does have one flaw—
in how she keeps her word.
This is the only thing I'd ever change about her,
because this disease has changed the man
she made that promise to,
and she deserves all the things I lost.
I see the loving pain in her eyes
and the struggle she has with watching me struggle,
and this becomes the thing I miss the most:
the moments I'll never have with her.
A future of smiles and laughter
stolen without explanation.
She could easily find another man
who doesn't have to be so grateful for losing so much,
but while I'm forced to live through my worst,
my wife chooses to give me her best.
And I thank God for her best
because it's the greatest blessing He's ever given me.