



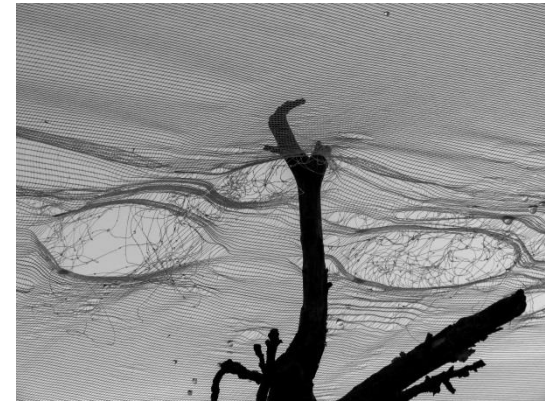
Darkness and Stars

Rhyming reflections on the everyday lives of my ALS-patient
friends

Nina Ben Moshe

What have I got???

Aching back and fatigue, waning strength and distress,
I can no longer blame this on aging or stress,
So I visit my doctor... he's so self-assured,
You're not dying, he quips, take a rest and be cured.
Then I go to a second, a third and a fourth,
Am referred to and fro, East and South, West and North,
Time is slipping away, I am lost in a trance,
Till I find a neurologist par excellence,
One who knows, I can tell, he is so self-assured,
Sits me down... ALS... I will never be cured.



Should I Tell?

My voice is turning hoarse and frail,

A friend enquires if I ail.

“A common cold... must be the breeze.”

“...Hey, you can tell me, I'm your friend,

Long time... you should be on the mend”,

“It's true... I have this rare disease.”

Just a Flu

A mighty lion met a mouse and fixed him with a glare,

“I wonder why you're small,” he roared, “so small you're barely there.”

The mouse let loose a sneeze and sniffled out a muted squeak:

“Oh nothing serious, it's just that I was sick last week.”



Rilutek

Ril-u-tek, the only drug that “promises respite”,
Will-you-take this risk to win a few months of “delight”?

Though every now and then we hear the ram’s horn trumpets blare,
As “major breakthroughs” are announced in treatment and repair,
A week goes by and toned-down bleak disclaimers cloud the day,
It turns out that a working drug is years and years away.



Red Tape

The doors to the Welfare Department are locked,
My discount's denied and my credit is blocked,
My Social Security refund is late,
I'm begging for mercy and told I must wait.

My voice has expired, a slow painful death,
I must go in person, I'm all out of breath,
From office to office to office and back,
The red tape is solid, not even a crack.

With nothing in hand at the end of the day,
I head to the Wall and I break down and pray:
“Dear Lord I request neither fortune nor wealth,
Just make me first cousin to the Minister of Health”.



Caregiver

At long last she arrives, seems naïve and unknowing,
She starts learning the job but does not get much better,
Then she seems discontent with the way things are going,
For she calls “Worker’s Hotline” and hands us a letter.

Says she’s working too hard and deserves better pay,
Then gets sick for a week, and is gone the next day.

p.s. Not a typical case – with our very own eyes
We have also seen angels in human disguise.



Calm Yourself

I am drowning in agony, gasping for air,
Someone says: “Calm yourself, you must flow with your pain,”
What the hell does he know? How on earth does he dare?
If I could, I might shoot him point-blank in the brain.

And yet, when I’m alone with my choking attacks,
Then I counsel myself to unwind and release,
And my stress fades away, and my airways relax,
And my body and I once again make our peace.



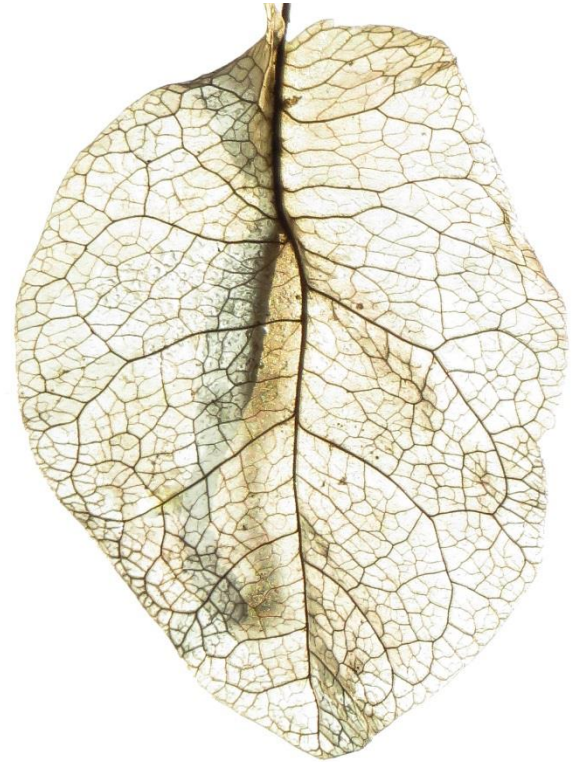
Left Behind

The party's great, you're feeling fine,
A brilliant wisecrack comes to mind,
You start to write, then pause for thought,
You trim it back, concise and taut,
You're almost ready to attack...
The conversation changes track.



Time

People running in the streets at such a frantic pace,
People chasing time, though they can never win this race.
You are lying in your bed without too many plans,
When you realize that their fleeing time is on your hands.
Don't succumb to boredom, let once more your chase begin,
Think, invent, connect with loved ones, you will surely win.



Is it Purim Today?

Then we have to rejoice!
Though for ALS patients it's no easy choice
To consume so much wine they can no longer tell
Between blessed Mordecai and cursed Haman-from-hell.

May your darling kids paint your cheeks polka-dot pink,
And your wife (though she shouldn't) prepare you a drink
So intense you will fail to distinguish with ease
The sweet blessing of health from the curse of disease.



Hands of Light and Gold

Hands of diamonds and gold have delivered me Roy.
Even though he is young, not much more than a boy,
He has already mastered a Chinese technique
To relieve aching muscles and heal bones that creak.

When my neck and my back were unbearably sore,
Like an angel on earth he appeared at my door,
And I lay on my bed, and the showdown began –
An unmerciful duel between muscle and man.

For a long painful hour the battle raged high,
Till my muscles gave in, and my bones ceased to cry,
And I rose up refreshed and contented and strong...
I can feel it right now as I write down this song.



Thumb

Since Roman times until today,
Thumbs up means Yea, thumbs down means Nay,
And now that I have lost my voice,
I really haven't got much choice
But to employ my trusty thumb
To answer questions as they come.

I wish my friends all understood
That double-questions are no good,
“To raise or lower?” “Give or take?”
“Is this news real or is it fake?”
“Is she your cousin or your aunt?”
(Impatiently) “What *do* you want???”

“I want you all to understand
That double-questions should be banned,
It really isn't very nice
To ask a thumb to answer twice!”



Can't Eat

ALS is relentless, it never lets up,
Masticates our insides with the zeal of a pup,
It has eaten our throat and our palate and tongue
(Just a lunch-break, perhaps, on the way to our lung),
And has rendered us mute and with no sense of taste
To distinguish fresh food from degradable waste.

In the old days our meals were familiar and plain,
We had olives and flatbread, as steady as rain,
And on Friday a lentil-stew dish for a change,
To enrich our nutrition and broaden its range.

But today we are deep in the age of gourmet,
And our gullet is gone – what a steep price to pay!
We're bombarded with MasterChef dishes and meals,
We can see, we can smell, we can sense how it feels,
We can hear the applause that a grand feast may bring,
But we can't for the life of us taste a damn thing!



Abyss

“We will not be ashamed,” yes, you know, so they said,
All your friends in the previous life that you led,
And your family too, but you cope, well... you try,
And in truth, for the most part you almost get by.

Then you reach the abyss, this unbearable void
That appeared when your previous life was destroyed.

From an athlete and father of two to a “tot”
In the span of a year, would you ever have thought
You’d be pampered and changed, and your food would be ground,
You’d be tucked in at bedtime and driven around?

It’s this rift between you and the man you had been,
It’s the gaping abyss that is drawing you in.



Aesthetics

Farewell, our fair lady of beauty and grace,
Our expert on fragrance and figure and face,
From dawn until dark we have sought your advice
On houses and hairdos and all that is nice.

Those days are behind us, it's time to part ways,
We cannot abide with your critical gaze,
An evil affliction is taking its toll,
Devouring our body, our heart and our soul.

We spare you the details, they'd just make you cry,
Go on perfect lady, we bid you goodbye,
Leave us to our longings, unseen and unheard,
For beautiful days when we worshipped your word.



A Fly

It spirals in space,
Swoops in and whips back,
Then hovers in place,
Computing a track.

In black or in gold,
All glittery fuzz,
Persistent and bold
With God-awful buzz.

It spirals away,
Then shoots up and goes,
Now where will it stray???
Boom! Right on my nose!



Daddy Cannot

And his son is but three.

Take me, he says, to the swing by the tree,

Noam my buddy is out in the park,

Please get up daddy, before it gets dark!

What is the matter? Your pillow is wet!

What... are you crying? You look so upset...

Okay... we don't have to go anyplace,

Look, I am making my funniest face...

Here, hold my Teddy, he knows when you're sad,

Hugs you so tight that you don't feel so bad,

Just give him back to me, please, when you're through,

Sometimes at night-time I need a bear too.



But Mommy...

“But Mommy, why won’t Daddy get out of bed?”
“I told you, my darling, remember I said
Your Daddy is ill and must sleep all day long.”
“So he should sleep all night and wake up real strong!”
“Then where will you go, tell me, what would you like?”
“We’ll ride to the beach, me and him on his bike,
We’ll splash and eat ice-cream and find me a shell,
And Daddy will always and always be well.”

Now Mommy breaks out in a teary-eyed smile,
And sends off her toddler to play for a while,
As she cleans and cooks and does all she can do
To carry the load that was once borne by two.

At sundown she kisses her darling good-night,
She tells him a story and turns out the light,
And hums as the boy and his favorite bear
Sail off to the dreamland the two of them share.

Her arduous daily routine then proceeds,
She takes care of Daddy and tends to his needs,
She gives him her heart, and a kiss, and she goes
And slumps on the living-room couch, and she knows
They’re just thirty-five and their lives are on hold,
Her little boy’s father will never grow old.

A flash and the sound of his bell make her start,
She runs to his bedside with dread in her heart...
And finds him there beaming and writing away,
As though he has something exciting to say.

“I finally know what to do with this life
I share with my son and my beautiful wife.
My head, don’t you see, has not weakened at all,
I’ll use it for thought – not for banging the wall!
I already have some ideas I should test,
I’ll show you tomorrow, right after I rest.”

And as they embrace and their sparkling eyes gleam,
Their boy and his Teddy-bear smile in their dream.



The Tongue

“Life and death in the ‘hands’ of the tongue,” we were told
Long ago, when we studied the proverbs of old,
But for ALS patients the tongue is inert –
Neither dead nor alive, never pleased, never hurt.

In the past it was flexible, agile and strong,
Served our voice and our love-life, it couldn’t go wrong,
Helped us taste and digest, made our words come out right,
And if someone annoyed us, it stuck out in spite!

It would glide like a dancer and bounce like a ball –
Now it sleeps like a baby, defenseless and small,
And we pray: “Should a burst of saliva erupt,
May our fearless protector of old interrupt
Its ridiculous slumber and rescue our soul
From the tidal wave threatening to swallow us whole.”



Outside the Circle

The dread disease is evident, and just as you had feared,
Your friends, your peers, your flatterers, have all but disappeared.
You find yourself outside the circle, banished from the crowd,
And you recall this Bialik* song you used to sing out loud:

*Around the barrel, in our garden, magic and romance,
The cabbage asked the cauliflower would she care to dance,
The beet and the tomato followed suit without delay,
It looked like it was bound to be a wholly jolly day.*

*Regrettably, the fava bean just languished by their side,
His body still, he leaned upon his creaky cane and cried:
“Poor me, I dare not ask a pretty veggie for a dance,
My pods are all completely empty – I don’t stand a chance.”*

For one sad moment, like that bean, you lean upon your cane,
And wonder if you’re destined to be left out in the rain...

But presently the ALS support brigade appears,
Your family-of-fate has come to hug away your fears,
Efrat the peerless leader and her team are on the scene
To guarantee that you shall never be a fava bean!

*Apologies to the late Chaim Nachman Bialik for the free translation.



Running Families

Dedicated to all participants of the eighth run for ALS patients

Oftentimes ALS patients lie in their beds,
No one running about but the thoughts in their heads,
Or they lean on their crutches or sit in their chairs,
Thinking how, notwithstanding their troubles and cares,
They prefer to see ALS shift down its gears
And sit still, just like them, for a couple of years.

Only one day a year, at the annual run,
They will gather their strength and meet out in the sun.
In their sports-shirts and sneakers they mix with their folks,
With the festive balloons and the hugs and the jokes,
And together they run with great courage and grit,
And for once – just this once – ALS takes a hit,
No imploring for mercy, no fighting back tears,
At the annual run ALS disappears.

