

A. Jorgelina Zeoli

Alzheimer's

(A memoir)

Flashback Series, Part Seven
Dawn of the Broken Heart, Vol.2

Notes

1. *Alzheimer's, Journey of a Caregiver*, was initially written as a collection of separate booklets, therefore the occasional repetition of content.
2. Punctuation and formatting irregularities are intentional.

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For an updated list of Jorgelina's work about trauma, grief  
and recovery through the integration of spirituality,  
psychotherapy and creativity,  
visit [www.jorgelinazeoli.com](http://www.jorgelinazeoli.com)

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Part One -The Heartbreak

Introduction

When my mother, Nenette,
began showing symptoms
of memory loss
and dementia,
I panicked.

What would happen now?

What awaited ahead of us
was unfathomable,
terrifying.

The ground was disappearing
from under my feet.

I could not envision
going on through life
having to incorporate the disintegration
of my mother's mind.

The mental structures
that made day-to-day possible
were collapsing.

What would happen now?

After months of denial,
not wanting to face the truth
about
Nenetita's condition,

the path to follow
eventually became clear.

Of course
I was going to take care
of her.

Till the end.

I was
her daughter.

Who could ever take care of her
better than I could?

That was the way it had always been
back home,
in Argentina.

The extended family
took care of the aging loved ones.

Except
there was no extended family
here,

for I was
alone with my mother
in the United States of America.

The Heartbreak

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My mother's ability  
to  
function independently  
had been deteriorating rapidly.

No longer able  
to keep her apartment in  
senior housing,

in 2001,  
I brought her home  
to live with me.

The tension  
between my mother and me  
had been excruciating  
for endless years.

We had lived enmeshed  
in a symbiotic relationship  
until, at age thirty five,

I finally found the strength  
to separate from her.

Nenette had been unable  
to comprehend my decision.

She simply  
could not understand  
that I had the right to have my own life  
away from her.

Nenette felt abandoned,  
betrayed by me.

She believed  
that I didn't love her anymore,

and that false belief  
had placed  
a tremendous strain  
on our relationship.

And then,  
the miracle happened ...

As I began  
to take care of her at home  
due to her advancing dementia,  
her belief  
that I had stopped loving her  
melted into nothingness,

and  
our mother-daughter relationship  
began to heal.

A horrible disease was taking my Nenetita away from me.  
That same disease had also brought her back to me.

For many months I experienced  
what I had thought would be the impossible:  
the absence of conflict in the relationship with my mother.

Fear, defensiveness, manipulations disappeared.

Closeness, trust, tenderness took their place.

I was now able to express my love for my mother, freely,  
without having to suffer rejection after rejection  
after rejection.

I could hug her and hold her and kiss her.  
I could tell her how pretty and funny she was.

We laughed a lot together,  
and I cried a lot alone.

For many months, I satiated my thirst for loving connection  
with my mother, drinking the magical elixir of each  
lighthearted moment with Nenetita.

I didn't want to know what lay ahead.  
I didn't want to think about it.

I lived one day at a time, one moment at a time.

~~~~~

As Nenetita's health continued to deteriorate,
both mentally and physically,
my responsibilities as her only caregiver
continued to increase.

The weight on my shoulders was getting heavier and heavier,
yet I continued carrying it day after day after day.

The situation was consuming me.
I was exhausted beyond words,
yet I continued pushing and pushing and pushing,
for I was going to take care of my mother 'til the end.

Concerned friends and my psychotherapist
had been hinting at the possibility
of taking my mother to a nursing home,
but I wouldn't hear of it.

I would never take my mother to a nursing home.
I simply would *never* do that.

I had heard horrors about nursing homes.
Taking Nenetita to one of those places *was not an option.*

~~~

And one day at home she became lethargic,  
only I didn't know what *lethargic* meant.

She had been sleeping all day.

“Let her sleep,” I thought to myself. “She needs to rest.”

Then she got up and came to the kitchen, stumbling.  
She leaned on the stove and began sliding down.

I tried to catch her, and we both ended up on the ground  
under the kitchen table.

She was trying to speak but couldn't.

A slur of meaningless sounds  
was coming out of her mouth.

I called the doctor's office.

“She collapsed? She can't speak?  
CALL THE AMBULANCE,” the doctor said.

That day I learned that perhaps, after all,  
I was not qualified to give my mother  
the best possible care.

That day I realized that  
I didn't know how to monitor her symptoms.

I didn't even know that in such extreme circumstances  
I was supposed to call an ambulance.

Later I learned. And boy, how I learned...

~~~~~

My mother
had a urinary tract infection

- also called a UTI -

the first of many to come.

People die of UTIs.

Lethargy is one of the symptoms.

*And
lethargy
became a red flag.*

~~~~~

One night, I heard a knock on my bedroom door.  
A police officer was standing on my doorway and asked  
me to come downstairs to my mother's bedroom.

Another officer was already there with her,  
sitting by her bed, reassuring her.

She had called them, she had opened the front door for  
them, she had told them that someone had been killed.

Psychosis was taking hold of Nenetita's mind.

"We can call someone to help, ma'am,"  
one of the police officers said.

"That's alright," I replied, "I'll take care of it."

I believed I could take care of it all.  
Well, I couldn't.

~~~

Soon I couldn't leave the house, for I couldn't leave her
alone, and I couldn't bring her with me everywhere,
although I tried. God knows I tried.

I couldn't find people to help me.
I couldn't afford to hire help.
Not 24/7 help anyway.

The system helped, and friends helped,
but nothing was enough.
She needed round-the-clock care and that was not
available.

Life had become unmanageable.
I was reaching the end of my rope.

And one day, at one of our visits to the ER,
she was admitted, and after a few days at the hospital,
she was released, too soon ...

Collapsed on my sofa, I feel the inward battle.

I will take care of her 'til the end,

I can't, I can't

I will, I can't

back and forth, and back and forth

~~~~~

It was a dangerous battle.

My determination to keep her at home  
and the awareness that I simply could not do it anymore  
were equally powerful, conflicting internal forces.

I could not let her go,  
and I had no strength left to keep her with me.

And then, for a fraction of a second, I gave up the fight  
and the scale tipped over to the side of reason.

In that fragment of a second,  
I picked up the phone and called the hospital.

All of a sudden, out of nowhere,  
I heard myself yelling and screaming at the doctor:  
“She was released too soon! I can't take care of her!  
I can't keep an eye on her every moment of the day!  
I find her crawling on the floor! Crawling up the stairs!

She could fall!  
She could get hurt!  
**She could get hurt!”**

I was hysterical, and it worked.

The doctor re-admitted Nenetita to the hospital  
to begin the process of transferring her  
to a nursing home.

~~~~~

Sometimes hysteria does the trick,
although I wouldn't recommend it.

Hysteria happens when one feels helpless.

Hysteria also happens when the one you love the most
is being torn away from you and there's nothing
you can do about it.

Hysteria is sometimes part of the process
of losing a loved one to that horrific disease:
Alzheimer's.

~~~~

I had learned that, in order to take Nenetita to a nursing  
home, she had to be transferred from a hospital.  
Transferring her from home would involve  
a much longer and more convoluted process.

My decision to call the hospital for help  
had been very faint.

It had only lasted a fraction of a second,  
and I acted fast on it.

There had been a tiny window of opportunity  
and I had seized the moment.

What would have happened  
if I hadn't made that phone call?

What would have happened if reason hadn't won over?

What would have happened  
if I had collapsed of pure exhaustion  
leaving Nenetita without an advocate?

What would have happened to her?  
What would have happened to me?

~~~~

~~~

The day I led Nenetita out of our home,  
knowing that she wasn't coming back,  
was the worst day of my life.

*I couldn't stop crying*  
*I couldn't stop crying*

That day,

when Nenetita left home,

she walked to the car with her walker  
as an innocent lamb would to slaughter.

Friends were with me.

*I couldn't stop crying*

*I couldn't stop crying*

*I was losing her again*

*and my heart*  
*was breaking*

*I was losing her again*

*I was losing her again*

~~~

Epilogue

Letting go of my mother – my sweet Nenetita –

accepting our separation, accepting her decline
and all its crisis,
and ultimately accepting her passing,
brought one heartbreak
after the other
after the other.

I thought I would not survive the agony, but I did.

Seemingly against all odds, I survived it all.
The tears haven't stopped
and perhaps they never will.

Still, in the midst of it all, life does go on,
and comfort and healing for the broken heart
do come, in time.

No matter how excruciating the journey may be,
beauty and joy
and warmth
and laughter
can get to be experienced again and again
and again.

And so, one small step in front of the other,

I continue on my path,
crying and laughing and sobbing and dancing.

*Jorgelina Zeoli
March 2015*

Part Two - Overdosed

~~~

What follows is a memoir,  
a portion of my journey with my mother  
in her final years  
as we both struggled with the horrible disease  
that was taking her away from me:  
Alzheimer's.

All characterizations of care received  
are my own personal opinion.

Others' experiences may have been  
quite different.

I offer my personal experiences  
merely for the lessons that I learned  
that may be of help to others  
as they journey with their loved one  
in a medical institution.

~~~

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After taking care of my Nenetita  
at home  
for as long as I could,  
the time had come.

I simply couldn't do it anymore.

~~~

Keeping watch by Nenetita's
hospital bed

yet again.

Having her with needles
in her arms,

in her beautiful hands,

yet again.

What would happen now?

~~~

She and I were standing  
at the doorway  
of the nursing home experience.

~~~

A case worker at the hospital
found a nursing home for Nenetita.

I had to give the okay, so I went to see it.

There were high ceilings and chandeliers,
and beautiful carpets,
long corridors,
spacious living areas.

I had no idea of what to look for.

How would I know
if this was a good place for her?

I just didn't know.

I had heard about residents getting beat up by the staff,
but the staff here was so friendly;
they seemed to be good people.

I just didn't know how to recognize the red flags.

Eventually
I learned that the beauty of the carpets
and the height of the ceilings
and all the chandeliers in the world
have no relevance

–none whatsoever –

with regard to the quality of care
a nursing home might provide.

Walking through the facility
that would potentially become Nenetita's new home,
I saw many residents in geriatric chairs,
long recliners for those who were "out of it."
Their mouths wide open, their eyes blank, their limbs,
their bodies, all twisted in horrible contractions.

Months later I gave the geri-chair a new name:
the chair from hell.

I called the souls in agony laying on them
the living dead.

~~~

At the time, it didn't even cross my mind  
to check a few other places.  
I was in a daze, in a state beyond depletion.  
All I knew was that I couldn't take care of Nenetita  
at home any longer, and I didn't know how long the  
hospital would be able to keep her.

I needed a place for her, somewhere, *and soon.*  
And I gave the okay for the transfer.

~~~

From the hospital, Nenetita was taken to a nursing home.

I followed them in my car,
and I helped getting her settled in her room.

"Don't leave me here! Don't leave me here!"
she cried out, but I had to. What else could I have done?

I left her there, I left her there.
The anguish of that moment, I will never forget.

~~~

*On my way back home, alone in my car,*  
*my heart shed tears of blood,*  
*for I had left my Nenetita at a nursing home.*

~~~

A new leg of the journey had began.
I needed time to regroup.
I had to look for work, I had to get my house ready for sale,
I had to find a place to live.

Nenetita was receiving round-the-clock care.
I could breathe now and replenish. Or so I thought ...

~~~

The nursing home was far from where I lived.  
I visited her as often as I could  
and we talked on the phone in between visits.

In the beginning, it was horrible.  
Every time I was about to leave after a visit  
Nenette would yell and scream at me,  
uttering the most hurtful words.

The same was true during our phone conversations.

*She hated me, she hated me,*  
and she'd always cry: "*Don't leave me here!*  
*Take me home! Take me home!*"

And there was nothing I could do about it.  
Absolutely nothing.

~~~

I remember thinking in those days,
how strange this life is.

The agony Nenette was experiencing
at the end of her life was the same agony I had felt as a
child, going through repeated episodes
of neglect and abandonment.

Ours was the same scream: "Don't leave me!"
Except Nenette cried out loud.

my scream was silent

~~~

During those first months at the nursing home,  
contact with Nenette was so painful, so destructive,  
I considered breaking the tie.

It would be best for both of us.

I'm glad I didn't though, for it proved to be only a stage.

It had seemed that her hatred toward me  
was there to stay, but it wasn't.

Gradually, things did get better.  
Besides, Nenette needed me.

I didn't find out until later how much  
she truly needed me.

~~~

Eventually we settled on our new routine,
adjusting to this strange place that wasn't home
and would never be home.

She seemed to be content.

Her appetite was good, she fed herself,
she was cheerful and chatty,
and she walked regularly up and down the corridors
with her walker, getting a fair amount of exercise.

Lost in the world of her dementia,
Nenetita didn't seem to mind being surrounded
by *the living dead*.

On my end, however, and being the empath that I am,
I could not stop feeling for them, particularly at meal time,
for food was placed in front of them
and taken away untouched.

The living dead could not feed themselves,
and I saw no one attempting to feed them.

As far as I could tell,
they had just been left there to die of starvation.

~~~

I rarely saw any visitors.

*Where were their families? Did they have any family?  
Was there anyone advocating for them?*

But I wasn't supposed to look.  
Many times in months to come I was told:

“Do not look at the residents.  
Do not look. Do not look.”

What I didn't know in those days was that  
*overmedication can cause muscle spasms and lethargy*

and that  
*residents might have been systematically overmedicated,*  
particularly those who became agitated,  
to keep them “manageable” for the staff.

And I also didn't know  
that nursing homes were understaffed  
and that the staff is usually overworked  
and underpaid.

So many things I didn't know,  
but eventually I learned.

*And I learned the hard way.*

~~~

~~~

Nenetita was going blind.  
She needed cataract surgery.

The idea terrified me.

Would the anesthesia wipe out  
the little clarity of mind she still had left?

But going blind would be a major blow  
to her already-low quality of life,  
so I opted for surgery.

Life in those days seemed to be  
one stressful event after the other  
after the other.

*I was so tired, so tired ...*

*"Once she gets through surgery I'll be able to rest,"*  
I thought to myself.

Oh, how naïve one can be ...

~~~

And Nenetita had cataract surgery.

Back from the hospital, at the nursing home,
the nurse said:

“We’ll keep an eye on her,”

and I believed her.

As I was leaving, I turned around.

I had to give my Nenetita another hug, another kiss.

And I had to make sure that
she was all right.

I found her sitting in the activities room
with the other residents.

There was only one staff member watching over them
and Nenetita was scratching her eye.

No provisions had been made

– none whatsoever –

for her care after surgery.

And I exploded.

~~~

“Are you asking for a one-on-one?”  
the head nurse asked.

*“WHAT I’M ASKING IS  
WHAT KIND OF CARE DO YOU OFFER  
FOR A RESIDENT WITH DEMENTIA  
WHO’S JUST HAD SURGERY  
AND IS SCRATCHING HER EYE,”*

I replied,  
holding Nenetita.

~~~

Nursing homes are simply not equipped
to offer the individual attention
residents need and deserve.

Family members
are supposed to pick up the slack.

Only I didn’t know that.

I wish somebody had told me.

After the blow-up at the nursing home,
I had no energy left for Nenetita, and I took a few days off.

When I went back to see her I found her
on the chair from hell.

Her body already starting to contract,
she was wearing her eye patch
and socks on her hands
to keep her from removing the patch.

Seeing her like that broke my heart
and I thought to myself:
*"This was necessary
so that she wouldn't go blind."*

~~~

I had been writing to my friends and family  
in Argentina and out of state.

On November 2, 2004, I wrote:

"I can't count on the nursing home  
checking symptoms, either.

If you don't sit down with Nenetita  
trying to decipher the stream of nonsense  
coming out of her mouth,  
you will never identify the symptoms.

Yesterday she said: 'Oh! Lightning!'"

The surgeon had said that if Nenetita saw flashes  
I had to bring her back to the hospital right away.

And back we went.

~~~

Soon after, I got sick and I couldn't go to visit.

And I couldn't talk to her on the phone either,
as we usually did,
for every time I called she was sleeping.

~~~

On November 10, 2004, I called the nursing home.

“Oh, honey, she's out,” somebody said.

That same day I called my cousin Julita in Utah, crying:

“Nenette doesn't talk to me anymore!” I said.

And Julita suggested that I call the doctor.

I had been so overwhelmed,  
the thought of calling the doctor hadn't occurred to me.

~~~

After my call, the doctor ordered labs, X-rays, etc.

Nenetita had a UTI.

The question is:

*Wasn't the nursing home's responsibility
to keep track of Nenetita's symptoms and call the doctor?*

*For how long had she been lethargic
and staff had done nothing about it?*

*What would have happened to Nenetita
if I hadn't called the doctor?*

~~~

On Monday, November 15th,  
Nenetita drunk from me  
about seven cups of cranberry juice,  
one after the other  
after the other.

*She was dehydrated.*

~~~

On Wednesday, November 17,
I found Nenetita trembling and shaking.

She was only wearing a turtle neck.

Her woolen Argentinean *poncho*, which she usually wore,
had been taken to be washed
and they hadn't covered her with something else
to keep her warm.

"She is cold!" I said, covering her with my body.

She was more than cold. Nenetita was very sick.
She simply could not, or would not open her mouth.

~~~

On that day,  
I found my mother on the chair from hell.

She was lethargic, her teeth were clenched,  
her jaw tight.

Her body, her beautiful hands  
were all twisted in horrible contractions.

*She had become  
one of the living dead.*

I remember that day,  
standing by Nenetita's geri-chair,

*the helplessness I felt.*

*I didn't know what to do, I didn't know what to say.*

*There was so much still  
to be learned ...*

On that day, however,  
all I could do was  
to stay planted by my mother's side.

And because I stayed planted  
expecting something to be done,  
somehow the decision was made  
to send her to the hospital.

~~~

In the ambulance, on the way to the ER,

she was rigid

her eyes were gone

she looked dead

The admitting diagnosis was:

UTI, lethargy, dehydration.

~~~

”November 18, 2004

Dear Juli, Nenette has seizure-like tremors and horrible blisters on her lips. She's completely 'out.' They've stopped the antipsychotic medication.”

~~~

“November 18, 2004

Dear Jorgi, Have they given her a diagnosis? Could it be the antihistaminic they gave her when she was removing the eye patch?

Could they have exceeded
the appropriate dosage?
Common meds oftentimes
have strong side effects in the elderly.”

~~~

Julita had identified the problem from the start, but I was so overwhelmed, so ignorant, so naïve, I didn't hear her words.

I didn't even know what an antihistaminic was. The word *diagnosis* had no relevance in my mind.

It was only months later that, studying the nursing home records, I found out that the doctor had prescribed *for three days* an antihistaminic that had been administered *for eighteen days*.

*It seemed that she had been overdosed..*

The importance of keeping an eye on her meds closely had never occurred to me. *I knew nothing about meds. I had just assumed that monitoring meds was the nursing home's responsibility. Well, I was wrong. Oh, so wrong.*

~~~

On day two at the hospital, with a nurse,
Nenetita responds to my presence and opens her eyes.
There's something white on her lip.

"She needs to be cleaned," the nurse says.

"Honey, open your mouth," she says,
and a mouthful of white stuff spills out.

Nenetita had been holding meds in her mouth,
unable or unwilling to swallow them.

~~~

"November 19, 2004

Dear Juli, I thought she was dying  
but she's starting to respond to the antibiotics.  
Looking back, I'm furious. The hospital tells me that,  
according to the nursing home report,  
Nenette didn't drink or eat since surgery,  
meaning *she was without food or fluids  
for over two weeks*  
(except the little bits she took from me  
when I was able to visit).

*WHAT KIND OF CARE WAS SHE RECEIVING  
WHEN SHE WAS SO ILL AND  
I WAS UNABLE TO BE THERE?*

I believe that not only hunger and thirst  
aggravated her illness, but also the devastating  
experience of abandonment she's gone through,"  
I write to Juli.

~~~

"November 21, 2004

Dear Jorgi, How truly discouraging it is when we
can't trust those who are supposed to help
with health problems.

And what about those nursing home residents
who have no advocate?
Those are "the disposable people."

And we think we are a civilized world.
What an embarrassment.

Love, Julita"

~~~

They seemed to have left Nenetita  
abandoned and ill on the chair from hell.

They kept telling me that they were giving her shakes.  
Obviously, she had not been taking them.

~~~

Laying down on the chair from hell
among *the living dead*,

becoming one of them,

being fed meds that she might have sensed
were making her sick,

cut off from me, who couldn't visit,
who couldn't reach her by phone ...

how abandoned
she must have felt

how abandoned she must have felt

"November 19, 2004

Dear Juli,
Trying to feed her at the hospital,
any fluid that I tried to give her
would spill out of her mouth.

It was a triumph when she was able to swallow.

It seems that she has forgotten how to eat
but now, with me, she is responding.

With each bite I have to tell her to swallow
and to open her mouth
because she forgets and half of the time
is non-responsive.

Feeding her takes me about two hours.
I go twice a day.

She is receiving fluids, apple sauce, yogurt, ice
cream, milk, and crackers. It was also a victory when
she managed to hold a cracker and take it to her
mouth because her arms had been dead.

It seems the tremors are gone.

I must tell you, it's such a relief
having her in a good hospital, giving her decent food,
with good doctors and great nurses.

What a contrast with the nursing home!"

~~~

"Dear Violeta,"

I write to my music teacher in Argentina,

"You are right, we haven't lost our humor.

Yesterday I was feeding her baby-style.

The food kept falling out of her mouth  
and she ended up with yogurt all over her face.

And I lost my patience.

'NENETTE, YOU DON'T EAT YOGURT

WITH YOUR NOSE, YOU GET THAT?'

and she exploded in laughter.

She may be in the land of the dead but it seems  
she still understands when I talk to her.

And you should have seen me

when she wasn't opening her mouth.

I had to use all my muscle strength to pull it open!

One time I managed to get a finger

between her teeth

and she wouldn't let me pull it out!

Can you imagine that?

Or she wouldn't let me

pull the spoon out of her mouth.

'NENETTE. DON'T EAT THE SPOON.'"

~~~

Unfortunately,

there wasn't a whole lot of time for laughter.

"November 21, 2004

Dear Juli,

The situation is uncertain.
She has stopped eating and drinking.
I had to decide about resuscitating her
or not, if it came to that.

On Saturday I tried to feed her
but she started coughing.

The doctor has told me
to suspend any attempts to feed her

because if she chokes
she could get fluid in her lungs
which would cause serious problems,
including pneumonia.

She sleeps almost all the time.
When she awakes for a little bit
she is in a daze and barely says anything.

The tremors are back.

I have cried so much, I have no tears left."

~~~

"November 22, 2004

Dear Paula, She's not eating, not moving, not talking.  
Right now is the battle between  
letting her die or helping her come back.

Chances are, she'll die.  
Would you help me plan the funeral?"

~~~

And Nenetita kept going, up and down and up and down,
battling between life and death,

and my heart kept going up and down and up and down,

*from despair to hope,
back to despair, back to hope,
on and on and on and on*

~~~

*I was so tired, so tired ...*

Consumed by Nenetite's condition, I was unable  
to take care of myself.

Fighting for Nenetite's life I was giving up my own.

Looking back to the years of her illness,  
my health suffered, my career suffered, my life suffered.

Of course Nenetita deserved to have an advocate,  
as any helpless human being would.  
But I paid a very high price. Caregivers usually do.

Does it need to be that way? *Does it need to be that way?*

## Epilogue

The hospital ran many tests,  
yet doctors were unable to find the etiology  
of Nenetita's lethargy and tremors.

Nobody ever mentioned  
that she seemed to have been overdosed  
with an antihistaminic that made her drowsy.

*Did anyone ever take the time  
to look at her records?*

*Or perhaps they knew  
and neglected to tell me?*

*And that, we will never know.*

~~~

Eventually,
Nenetita was nurtured back to life
at another nursing home.

And that is another story.

Part Three - Lethargy

~~~

### **Introduction**

I had witnessed Nenetita being close to death  
and I could not remove from my mind the thought  
that overmedication might have played a big part  
in her sudden decline.

The helplessness I felt, for the system had failed me.  
I had trusted my mother to their care  
*and she had nearly died.*

Through that experience,  
*a thought was burned with fire on my psyche:*

*I want my mother to die of natural causes  
not due to improper administration of drugs.*

~~~

From the hospital,

Nenetita was transferred
to River of Life Nursing Home (ROL)

and with a shattered trust
and my anxiety level sky-high
the next leg of the journey began.

~~~~

## *Lethargy*

At the time Nenetita was transferred  
to the Alzheimer's Unit at ROL  
she was still fighting for her life,  
and I was doing the same right by her side.

She was still lethargic and had great difficulty  
opening her mouth, chewing and swallowing.

She seemed to have forgotten how to eat.

“They stop eating and then die,”  
a nurse had said.

~~~

I could not bear the thought.

*I was not ready
to witness my mother dying of starvation.*

I was not.

Fighting her lethargy, feeding her,
bringing her back to life became my obsession.

I would literally stick my fingers between her teeth
and try to pull her jaw open
so that I could feed her.

I spent many days, many hours,
both at the hospital and at ROL

trying to get a response from Nenetita's mouth,
wondering if she'd remember how to eat, how to swallow,
ever again.

It was a daily battle,
a moment to moment battle.

She's eating, she's not eating,

she's swallowing, she's chocking,

she's dying, she's not dying.

*If I feed her, will fluid go to her lungs?
If I don't feed her, will she die of starvation?*

*up and down
and up and down*

*on a wave of uncertainty that went on
for months and years.*

~~~

*When my mother stops eating, I begin to die inside.  
When she eats, hope comes back.*

~~~

*“How much did she eat today?”
eventually became the daily question.*

~~~

*No words can possibly describe  
my state of mind and heart.*

*Only those who have lived through  
similar circumstances can truly understand.*

~~~

Around that time, I wrote:

“After the ordeal, my mother has stopped talking.

She speaks just a little, very few words.

I believe that she can talk more than she does
but it seems she has decided to speak
as little as possible.

I believe Nenette
needs acknowledgement of the fact
that she lived through hell
when she was overmedicated at Medton.”

Doctors agreed that the ordeal at the first nursing home
had contributed to her lethargy
and had led her to abandon herself
to the point of not caring whether she died.

*Death
from self abandonment,*

*what a sad death
that would be*

~~~

“I’m cold everywhere,” Nenetita said  
when she first came out of her lethargy.

She had felt cold, and she had been voiceless,  
unable to articulate her need.

*She was still voiceless. I had to speak up for her.*

~~~

When finally Nenetle became able to swallow again,
I'd bring fruit cut in small pieces and cereal
and she'd eat from the palm of my hand
as a little bird would.

I felt her life depended on me feeding her.

I was barely managing other areas of my life,

the responsibility felt so heavy

so heavy

~~~

In the beginning, at ROL,  
adjusting to the new environment was a challenge.

For a very long time, I was unable to figure out the system.

I didn't see any doctors on the floor,  
only nurses and aides who rotated from shift to shift.

I wanted to scream ...

**MY MOTHER IS VERY ILL.**

**WHO IS IN CHARGE  
OF HER CARE???**

~~~

Communication with staff was, by far,
one of the biggest challenges I encountered
during the years of the nursing home experience.

At ROL, however,
there seemed to be an energy of vitality
and ongoing renewal
where changes happened rapidly to improve conditions.

Eventually, it was decided
that I would call a social worker with my concerns
and she'd respond within 24 hours,

something she did faithfully
and for which I will be eternally grateful.

~~~

Through those years,  
I gave a lot of thought to the complexity  
of the interactions with staff.

Holding both, the negative and the positive  
- recognizing their good services  
as well as the aspects that were far from perfect,  
acknowledging my own human flaws  
and also my efforts at reconciliation of contradictions -  
it was not an easy goal to achieve.  
No. It was not.

And in my search for answers, seeking harmony  
in our common goal of caring for Nenetita,

on August 29, 2005, I wrote a poem.

*Gratitude is what I feel,  
when I go to see my mother at the nursing home  
finding her always clean  
in an ever-clean environment*

~~~

*gratitude is what I feel,
when I come at night and I find her warm
under the covers*

~~~

*gratitude is what I feel,  
when I see her eating on her own,*

*for after weeks of believing  
that she'd die of starvation  
she has responded to medication  
that stimulates her appetite*

~~~

*gratitude is what I feel,
when I see food that she likes on her tray*

~~~

*gratitude is what I feel,  
when I see the cheese that she had stopped eating  
has turned into a cheese sandwich she now enjoys*

~~~

*gratitude is what I feel,
when I attend a support group that helps me understand
the grieving process I'm going through*

~~~

*gratitude is what I feel,  
when I remember how it used to be at home,  
getting her out of bed, clothing her, feeding her  
taking her to doctors, giving her medications,  
getting her to the shower, keeping her entertained*

*I simply couldn't do it anymore*

~~~

~~~

*gratitude is  
what I feel*

*for the patience everyone  
has had with me,  
for my mother is leaving me  
piece by piece*

*yet her sweetness  
and her wit are still there  
as sparkling jewels  
for me to see,*

*jewels I had thought gone  
were nurtured back by good care*

~~~

gratitude is what I feel

~~~

One day,  
a doctor came to make an evaluation.  
It was lunch time and I was feeding her.

At that time,  
Nenetita was eating very, very slowly,  
chewing for the longest time  
even when she was on a pure diet.

Feeding her was like a meditation,  
tuning into her  
and waiting until she was ready  
for the next bite.

I signaled to the doctor that I would stop feeding her  
so that he could examine her, and he said:

“Don’t stop.

Feeding her is the most meaningful experience  
you can give your mother in this place.”

And he waited and waited  
and waited.

He didn’t seem to mind.

He seemed mesmerized by the sight  
of a daughter feeding her mom.

*What an extraordinary doctor this was.*

~~~

I remember that evening when I walked into her room
and found an aide feeding Nenetita.

The gratitude I felt.

Trying to get her to eat for hours at a time
had been exhausting.

She had been only receiving food from me.

And now she had began trusting the aides
and they were feeding her.

Now things had changed.
Now I would be able to rest.

The gratitude I felt.

~~~~

I also felt grateful  
for their beautiful, colorful crochet blankets.

Those blankets warmed my heart.  
They provided a feeling of home.

“They were made by volunteers,”  
an aide tells me.

The comfort I felt,  
time and time again,  
wrapping my mother in those beautiful blankets.

To the volunteers who made them,  
*thank you ...*

As time went by, Nenetete's ability to speak  
continued to deteriorate.

For the most part, her "conversations" were a stream of  
meaningless sounds. Now and then, however, she was able  
to articulate a few words that made perfect sense.

I found those glimpses of sanity fascinating.

~~~

In February of 2005

Nenetita was placed under Hospice Care.
She was dying and I was dying with her.

I said to the Hospice nurse: "Two days ago I thought she was
dying. Yesterday I found her well, cheerful, eating, talking,"

And the nurse replied:

"It will come and go for a while, honey.

"Her hands and feet will get cold, her color will change,
indicating that her circulation is slowing down."

~~~

"It is a horrible process," I write to my family.

"I hold her and ask God to take her.

Before, every time I came to visit,  
her face would light up with a smile.  
Now she doesn't respond, she looks dead.  
And doctors don't know what it is.

She is still present, talks very little, and that little  
makes sense, but it is a thread of life very faint,  
very far. And when I leave she still knows how to  
give me little kisses.

I've cried so much, so much ..."

~~~

February 2005

*Dear God,
I don't know where you are.*

*Nenetita is dying
and I don't know where you are.*

The anguish is so vast, it can't be contained.

*Nenetita is dying
Nenetita is dying*

*crying
sobbing
moaning*

*agony in sound
coming through
my throat*

Nenetita is dying

~~~

That time, and other times,  
Nenetita came back from her dance with death.

~~~

“My mother has been dying for the last ten years,”
I once heard a woman say,
and I could not believe her callousness.

Now I understand her.

The ordeal can suck every ounce of energy
out of a caregiver, leaving him or her dried out of emotion,
of tears, of empathy.

~~~

Nenette spent the last six years of her life at ROL.

Life in a nursing home, sitting all day in a wheelchair,  
in an Alzheimer's Unit,  
losing all her physical and mental capabilities.

*What kind of life was that?*

*Should I have let her go one of the many times that lethargy  
was taking her away?*

When she was so ill from  
her overdose at the prior nursing,  
I struggled with that dilemma not knowing what to do.

*Should I stop trying to feed her?  
Or should I fight to keep her alive?*

*back and forth  
and back and forth*

What an emotional rollercoaster that was.

Eventually, however, it became crystal clear:

*The Force of Life is too big a Mystery.*

I would not have sustained Nenette's life artificially,  
*but as long as I sensed Life pulsating in her,  
I had to fight by her side to keep her alive.*

Had I not done so, I would not have been able to  
live with my conscience.

I feel at peace for I did all I could to take care of my mother.  
When it comes to her, there are no regrets.

*I do regret not having known  
how to take better care of myself.*

Over the years,  
the stress of the nursing home experience  
took a toll on me.

One day I came down with pneumonia  
and for many months  
I couldn't go to see her.

By then,  
she had stopped responding to my presence.

Hugging her,  
trying to feed her,

was like hugging or trying to feed  
a piece of furniture.

Unable to go,  
I paid friends to visit her regularly  
and keep me posted about her condition.

When I became stronger,

wearing a mask

for I was a high-risk,

I went to say good-bye.\*

Ours had not been an easy  
mother-daughter relationship.

There were things I needed to say to her,  
and when I did

*she became very alert.*

*I knew she was listening.*

*I knew **she was still there.***

And now  
it's all behind.

*Thank God it is all behind.*

~~~

Nenetita

Regression to Childhood



The anecdotes in this collection
are fragments from
Jorgelina's letters to her family,
some of which were not dated,
thus the irregular format
with regard to dates.



**Nenetita
in Kindergarten**

“How do you call yourself?” *
the teacher asks.

“I never call myself,” she replies.

- ~~~~~
- In Spanish: “¿Cómo te llamas?”
 (“What’s your name?”)

to innocence

to tenderness

to purity of heart



Nenetita

Introduction

Many children of aging parents know the
challenges
and the heartbreak one goes through
when our loved ones decline, never to come back.

In my case, after my sister Christi's tragic death,
my mother, Nenetite, began showing
signs of Alzheimer's disease.

As this devastating illness took hold of her,
Nenetite experienced a regression to childhood
that turned her into a sweet, tender,
oftentimes very funny little girl.

I would like to share in these pages
some of those sweet, funny moments
that so alleviated the pain and difficulties
of the ordeal.

And here, with you ... *Nenetite!*

Year 1999

Nenette - already eighty years old - lives in senior housing, fifteen minutes away from me.

I drive her everywhere. I always call her when I'm on my way so that she waits for me at the entrance of her building.

"I'm on my way," I always say.

"I pee and go down," she always answers.

◇◇

I pick her up. She buckles up. As we drive, she begins doing acrobatics, getting in and out of the seat belt as the most skilled contortionist would.

"NENETTE, WHAT ARE YOU DOING?"

"I'm making myself comfortable."

◇◇

August 4, 1999

Sometimes she stays with me overnight.

At breakfast time, taking my pills:

"Gee, I'm so dumb!" I say.

"What did you do now?"

"I took a sleeping pill."

“Spit it out.”

“Nope. It’s yummy.”

◇◇

Later, Nenette, looking for a teaspoon, says: “Here is one!” Then: “Nope. These are your glasses.”

I call it “family life.”

◇◇

August 28, 1999

I give her simple tasks to keep her engaged. She always says, “When I finish this, what do I do next?”

◇◇

Seated at the table, cutting small pieces of scrap paper, Nenetita asks:

“Where does this go?”

“To the refrigerator.”

(She laughs.)

“To the refrigerator’s door.”

(She keeps laughing.)

“ON THE OUTSIDE OF THE REFRIGERATOR DOOR, DARN, I’M NOT A KNUCKLEHEAD, OKAY?”

Year 2000

January 12, 2000

I'm wearing a sweater with diagonal stripes.

"Nenette, do you like my new sweater?"

"I didn't want to say anything, but I think your stripes are crooked."



January 15, 2000

Nenette has been a victim of fraud. A "friend" used her credit card gambling and in order to protect him she got more credit cards and was paying one card with the other. Then she breaks her foot. While she is in the hospital, I take charge of her bills and - surprise! - she owes thousands of dollars, and the interest is mounting. I stop making payments and the harassment by creditors begins. Oh how fun.

Nenette is now due for court and I try to prepare her.

"Nenette, sweetie, you tell the judge that you have very little money. What are you going to tell the judge?"

“I’m not going to tell the judge anything because the judge hasn’t asked me anything.”

“And when he asks, what are you going to say?”

“I’m going to say I don’t know why I’m here. Why am I here? Did anyone call me? I will ask him how can I help him.”



Another day.

Eating hard boiled eggs at home.

“Do you have mayonnaise for the eggs?” she asks.

“Yes, in the fridge’s door.”

“I came to the fridge. Why did I come to the fridge?”

“To get the mayonnaise.”

“The mayonnaise for what?”

“For the eggs. With your bad memory you could drive everyone nuts in court!”

And we laugh.

Anyways, it’s all behind now. The creditor’s attorney saw her in the waiting room with her walker, looked at a few papers, and sent her back home. Things

didn't get to the judge. What a burden off my shoulders!



January 17, 2000

Darned car alarm. I spend the night holding on to the remote control. The alarm goes off, I click the remote, the alarm stops. The alarm goes off again, I click the remote, the alarm stops. Like that, many times. Because there's a storm with high winds wiggling my car away, and the alarm is going crazy, waking up the neighbors and keeping me glued to the remote. Oh well.

The wind calms down. Finally I fall asleep. Then the light in the hallway wakes me up. I hear steps on the stairs. "Nenette, is that you???" Nenetita - with great effort - is climbing up the stairs, my glasses in her hand.

"I found your glasses," she says.

"Nenette, it's the middle of the night! I don't need my glasses!"

“I thought you might need them,” she says, trying to be helpful.

AUAUAUAUAUA. DARN, THE CAR ALARM AGAIN.

And people ask how come I’m walking around like a zombie.

◇◇

In the car, Nenette trying to get oriented: “We went this way the other day, going I don’t know where to do I don’t know what, right?”

◇◇

Nenette has not worn her glasses in years. She gets into the car and makes the announcement:

“I CAN’T FIND MY GLASSES. I’VE BEEN LOOKING FOR THEM ALL MORNING!”

“Nenette, you don’t wear glasses.”

“Ah.”

◇◇

“What’s your name?” I ask.

“My name is long as a sausage. How do you expect me to remember?”

◇◇

We visit with my dear friend Maria Teresa, who offers goodies and wine to Nenetita, placing them on a tray on a small table next to her. The small table is actually a butler with a tray carved in wood. The butler – I'll be polite – doesn't look too good. Nenetita looks at him and says: "He's so ugly!"



February 5, 2000

Sitting at the kitchen table, Nenette stares at a saucer filled with date pits and says:

"Do you have any notion of how many dates you've eaten?"

"Nenette, *you* ate them."

"That's not possible."



February 24, 2000

Nenette has lost four pounds and has been running a fever. I take her to the doctor, she needs a urine test. At the doctor's office:

"Nenette, go pee, you have to fill up this container."

“I don’t want to. I’ve already peed.”

“You spend your day peeing away and now that we need it you won’t pee?”

“I won’t pee. I already peed. You should have thought about it earlier.”

“Ok. So here, drink water until you feel like peeing again.”

She drinks and drinks and drinks ...

“I can’t drink anymore, I’m up to here, I’m going to throw up.”

“Nenette, you don’t throw up water. You pee water.”

“I don’t want to pee.”

I give up. We leave the doctor’s office. The nurse gives me a small bottle and the cutest pee-holder. We get in the car. “I want to pee,” my sweet little old mother says.

◇◇◇

I call her later.

“Nenette, did you pee?”

“What pee?”

“What do you mean what pee??”

“Oh yeah, I think so.”

“Did you put it in the refrigerator?”

“Are you sure?”

“What do I know? I’m asking you: Did you put the pee in the refrigerator?”

“I don’t remember, I think I did put something in the refrigerator. Did I pee?”

◇◇

Later. I call her and read to her what I wrote. We laugh together and she says:

“This reminds me ... I have to go pee to put it in the refrigerator.”

“What are you talking about? Didn’t you already pee??”

“I don’t know. I don’t remember.”

◇◇

She calls: “At what time are you taking the pee? I want to come with you.”

◇◇

February 25, 2000

We go to the market to buy groceries for dinner. I leave her waiting in the car and come back a few minutes later with a small bag.

“That’s all you’ve got for dinner?”

“Well, I don’t know, this market is kind of weird, there’s no food in there.”

“So what did you get for dinner?”

“Shampoo ... oh, gee! I think I walked into the pharmacy!”

◇◇

March 2, 2000

“Nenetita, I brought you pills for your memory.”

“You think I have a bad memory?”

“I do.”

“Are you sure? Give me an example. What do I forget?”

“You forget that you have a bad memory.”

And we laugh.

◇◇

March 3, 2000

Oh, joy! Oh, happiness! Another urine test. Of course, because the first one showed that Nenette has too much protein, to be expected in a malnourished vegetarian. Oh well.

So I take her to the doctor.

“Nenetita, I’m on my way. Go down and I’ll pick you up at the rear door.”

“I’ll pee and go down.”

“NO! DON’T PEE!”

“No? Why not?”

“Because last time you run out of pee.”

Once in the car, I ask her:

“Did you pee?”

“DON’T TALK ABOUT PEEING THAT I’LL HAVE TO PEE. I’ve kept it in but it could sneak out.”

◇◇

At the doctor’s office:

“She doesn’t have to pee,” the nurse says.

“SHE DOESN’T HAVE TO PEE???”

“I DON’T HAVE TO PEE?”

“No. Let her pee tomorrow. And keep the pee in the fridge,” the nurse says.

And we get another pee-holder, and an orange jar to keep Nenette’s pee in the fridge, tomorrow. Tomorrow she has to pee all day.

“I want to pee,” says Nenetita.

“No,” says the nurse. “First we have to draw blood.”

And I say, that’s the law of karma: Those who don’t pee when they must, won’t be able to pee when the urges come.



March 6, 2000

“Doesn’t fit in the fridge,” Nenetita says.

“What doesn’t fit?”

“The pee.”



And the time comes to take the pee to the doctor’s office. Before leaving Nenetita’s apartment, I check the bag she has given me with the big orange jar with pee. Hmmm. What’s this? It is not the cover of the orange

jar; that much I can tell. Covering the orange jar there is a small container of blue cheese sauce. It has been placed there with utmost care. I must say, the blue cheese container fits perfectly on the orange jar. The only problem is, it doesn't turn and it could come off easily.

Scientists send astronauts to the moon but don't make ridges on blue cheese containers to cover pee jars. Decadent humanity.

"NENETTE, YOU COVERED THE PEE WITH BLUE CHEESE SAUCE!"

"That is not possible."



Nenette sleeps in her woolen socks with stripes. In the morning, holding a sock with stripes in one hand, the other one still on her foot, she says: "Where could my other sock be?"

(The mystery of the third sock. Oh well.)



We talk on the phone in the middle of the day.

"Rest well," she says before hanging up.



After taking her shower, Nenetita runs around naked down the hallway.

“Nenette! You can’t go around like that! There are people in the house!”

“Oh really? And so what? It would give them great joy to see my pretty legs.”



March 15, 2000

I’ve bought a dining room set. Nenette trying one of my new chairs: “How peculiar. It’s inflated.”



March 16, 2000

Seven a.m. I lay on the sofa, in deep sleep. Nenetita appears, rejoicing:

“I have news! I have news!”

“Nenette, let me sleep.”

“I have news!”

(Oh great, I think to myself. Did she wet herself? Not on my new mattress. No. Please no.)

“The Pope ...,” she says.

"The Pope apologized. Nenette, let me sleep."

"If you get up now, I'll fold your blankets."

Some offers can't be refused.



Later.

"Nenetita, what would you like for breakfast?"

"What a question! The usual!"

"What's the usual?"

"I don't remember."

April 10, 2000

"Nenette, I wore the jacket that you borrowed the other day and I found two socks inside the sleeve."

"I don't have socks."

"NENETTE, THERE WERE TWO SOCKS IN MY JACKET'S SLEEVE."

"And how do you think that could have happened?"

"I think it has to do with you borrowing my jacket."

"That's not possible."



April 12, 2000

Scene with variations. In the car: “Nenette, your seatbelt is crooked.” “Nenette, you have to grab the buckle. Like this, see?” “Nenette, you are all tangled up!!”

◇◇

Nenetita calls me at work.

“Jorgita, are you coming to pick me up?”

“I’ll pee and I’ll be on my way.”

In the car, I get tangled up in the seatbelt. AAAAHH! Getting old is contagious and hereditary! I’VE BEEN CONTAMINATED!

◇◇

June 19, 2000

I take Nenette for a ride to get some fresh air. Nearsighted as I am, I don’t see a thing, and let’s not talk about her. Walking the narrow path around the lake, I see something on the ground. Dumplings. More dumplings. Dumplings everywhere. What’s going on here? It’s poop! There’s poop everywhere! Poop of all sizes! And the stink! What a horrible stink! “Nenette!

Skip over it! Skip over it!" And there we are, tiptoeing and pirouetting to avoid the poop. And whose poop might this be? It's goose poop! It's giant geese's poop! They are chasing us! Run! Run! And all of a sudden, out of nowhere, there appears a man with a huge dog that sits in front of me (the dog, not the man) and starts licking me with a huge tongue (as I said, the dog, not the man). Gee, the things we must endure in this life.

◇◇

June 23, 2000

In the car. We drive by a lake. Nenetita says: "The poop was there."

◇◇

August 13, 2000

In the car.

"What's that woman doing standing there?"

"That's not a woman standing there. That's a man crossing the street."

◇◇

Year 2001

Nenette has found a new reason to live: crocheting bedspreads for Alita and Diego. I get up early in the morning and find her on the sofa, crocheting for her grandchildren.

"I'm here doing this and I have no idea of what I'm doing," she says.

"You are crocheting a bedspread for the kids."



Later, confused:

"What am I doing here?"

"You are crocheting."

(She gets upset.)

"I know I'm crocheting, or do you think I'm a knucklehead? But *what* am I crocheting?"

"A bedspread for the kids."



Later.

"What am I doing here?"

Over and over again, I give the same answer. She gets upset.

“Anything I ask you, you always give me the same answer.”

“Because you always ask me the same question.”

“That’s not possible.”

What I don’t understand is how she remembers that the answer is always the same, but she doesn’t remember that the question is always the same.



“Jorgita, your eyes are red. Have you been crying?”

“No,” I lie. “I didn’t sleep well last night. I always forget to take the sleeping pills.”

“I will remind you.”

“That’s right. I’ll give you the pills for your memory so that you remind me to take my sleeping pills.”



“Nenetita, do you know who I am?”

“Who are you?”

“I’m your daughter.”

“How come no one has told me?”



She is growing more and more scared. I take her with me everywhere. We go to choir rehearsal. She asks me: "Are there many peasants in the choir?"

◇◇

And now she is fixed on the stairway, because when I go to my bedroom upstairs she doesn't like to stay in hers alone, downstairs.

"How on earth did you get yourself a stairway?" she asks.

"I didn't get myself a stairway, Nenette, I bought a house with the stairway in it."

◇◇

In the car.

"Where are we going?" she asks.

"Home."

"Which home?"

"The home where you live with me."

"The home where you live in the stairway?"

◇◇

We get home. She gets out of the car, looks at the neighbor's fence and says: "I bet he has chicken."



August 17, 2001

“Could I make a suggestion? What was it? I forgot.”



September 2001

Nenette has double vision. “How cute I am, am I not?” she says.



November 18, 2001

“I can’t find what I was looking for, because how could I find it when I don’t remember what I was looking for?”



Year 2002

Between sneezes, Nenetita announces: “I am not a modern woman.”



We eat watermelon on the porch. I make pizza, which we thoroughly enjoy. Then, a ripe mango.

“And now what are we going to eat?”

“What do you mean, ‘what are we going to eat’?!
We ate watermelon! We ate *pizzeta!*”

“I want *pitzetta.*”

◇◇

“Give me a *kissito,*” she says, and I kiss her.

“Sweet dreams, pretty little lady,” I say.

“I’m ugly,” she says.

◇◇

“Nobody kisses me,” she says.

“Nobody kisses you? I always do! And you say:
‘*Chuy!* Your nose is cold!’ Look. Look how it works.”

(I kiss her.)

“*Chuy!* Your nose is cold!”

“I told you so.”

“Couldn’t you give me a kiss without nose?”

◇◇

August 7, 2002

Nenetita is a sweet, peaceful little old lady. (Thank God the medication is working.) She still drives people nuts, though. (Just a little bit, so as to not forget how to do it. Such a valuable skill.)

Nenetita goes to day care five days a week, and every time the van comes to pick her up, she has to pee. First she has to find the bathroom (so many doors in this house!); then, pulling her pants up and down take a lot of effort and by the time she reaches the toilet she doesn't feel like peeing anymore. Finally, she gets on the van and off they go. On the ride, Nenetita removes her seatbelt, walks down the corridor, and taps the van driver on his shoulder. The driver stops, walks her back to her seat, puts her seatbelt back on, and goes back to driving. Moments later, there she goes again, down the corridor, to tap the driver on the shoulder. Like this, many times, and you can't tell her anything because before you started telling her, she already forgot. So they can't take her anymore and I'm back to being the driver. Oh well. Such is life.



September 2002

I call her at the hospital and wake her up from a nap.

“Have you seen Mami?” she says, asking about her mother.

“Mami passed away a long time ago.”

“Oh, really? Then who was I talking to?”

◇◇◇

At the hospital, my mother doesn't miss opportunity to remind me that I've gained weight: “Hey, you are full of round things coming out of everywhere.”

◇◇◇

September 10, 2002

Nenette in the hospital. A man with dementia is screaming.

“What is that?”

“That's a mister.”

“I don't know where have you been that you don't know anymore what a mister is.”

◇◇◇

At the hospital. She cuts scrap paper, I do my paperwork.

“What a face you are making.”

“I’m thinking.”

“You have a *cara de culo* ... wow, she has a thinking ass!” (Sorry, but it was so funny; the things this little old lady comes up with!)

◇◇

I come to see her at the hospital. I find her having dinner by the window. She has two cookies and wants me to have them.

“You eat them, Nenetita. Don’t you want the cookies?”

“It’s not that I don’t want them, is that this way we share.”

◇◇

I visit with her at the hospital. As I get ready to leave, she says:

“And now what are we going to do?”

“What are we going to do about what?”

“What are we going to do so that when you leave I don’t get traumatized?”

◇◇

Year 2003

At the nursing home.

“How do I go pee? Do I have to climb up into the bathtub?”

“No, Nenetita.”

“Where do I have to climb up into?”

◇◇

Year 2004

“I’m cold in the apple,” she says.

“The apple?”

“At the level of the apple.”

“What’s the apple? Where are you cold?”

“I said apple!” (She laughs.)

“Yup.”

“I just noticed.”

◇◇

At the nursing home.

“How do I go pee?”

“You pull down your pants, then you pee.”

“Darn! Where are my pants??”

◇◇

September 15, 2004

Nenetita is not able to speak much. She tries very hard, and a stream of meaningless words spill out of her mouth. "You know what I mean?" she says at the end. I hug her, "I have to go to work now," I say, and she says: "Aia, que feo." ("That stinks.")

◇◇

October 29, 2004

At the hospital, in the waiting room before cataract surgery. "Do you think they are looking at my legs?" she says.

"Nobody is looking at your legs."

"They are very pretty."

◇◇

Later. On the stretcher, waiting to be taken to surgery, she sees me standing. "Would you like me to move over?" she says, inviting me to lie next to her.

◇◇

October 30, 2004

The day after the surgery, in the emergency room.

"Can you hear poo-poo?"

“Are you making poo-poo?”

“Yeah. Can you hear it?”

◇◇

Later.

“Nenetita, do you remember who I am?”

“Who I am?”

◇◇

Later.

“Don’t touch your eye, Nenetita, you’ve had surgery.”

“You’ve had surgery???”

◇◇

I get distracted for a moment.

“Ay! You touched your eye!”

“No.”

“What did you do?”

“No.”

“You hurt your eye!”

“It’s there.”

“What’s there?”

“The eye.”



At the emergency room.

The doctor attempts to put drops on Nenetita's eye, squeezing the small bottle unsuccessfully. "Shoot! These drops won't come out!" she says. Well, it would help if she removed the lid.



The ophthalmologist is checking Nenetita's retina with a strange machine with lights mounted on his head.

"The retina is flat. The eye is healthy," he says.

"Doctor, if I may, she had surgery on the other eye."



November 19, 2004

At the hospital, Nenetita is having difficulty finding words.

"I need ...," she says.

"What do you need, Nenetita?"

"I need to make ..."

"You want to poo-poo?"

“Poo-poo is not good for me.”



At the hospital. I spend time with her. Then I say goodbye from the foot of her bed. From under the covers, she says: “Where are we going?”



November 2004

At the nursing home.

Nenetita seems overmedicated. She is lethargic, non-responsive.

I’m desperate, trying to wake her up. “Nenetita! Nenetita! How are you feeling?” I say. She opens one eye. “Like shit,” she says. And closes the eye.



Year 2005

Lunch with Nenetite at the nursing home. I give her a small cup of coffee with milk. She looks at it with repulsion and says: “Green. Dirty. Why don’t *you* drink it?”



February 13, 2005

Nenette doesn't want to eat. I tell her: "If you don't want to eat, that's fine, but you have to know that when you decide to stop eating, you are deciding to die." And she got scared! She spent the next hour and a half chewing!

And I feel hopeful again ... and the next day, again she doesn't want to eat ...



Nenette looks at me intently. "Tiny eyes like hard-boiled eggs," she says.



After lunch at the hospital, with Nenetita.

"Now I'm going to work," I say.

"And what do I do?"

"You stay here to rest and have fun."

"Why?"

"Because you are a retired little old lady, and retired little old ladies spend time resting and having fun."

"I am a retired little old lady?"

"Yes."

“I don’t like being a retired little old lady,” she says, making a funny puffy face.

◇◇

She liked bananas and watermelon and cereal.

Year 2006

January 16, 2006

“I think I’m making poo-poo.”

“And you don’t want to go to the bathroom, do you?”

“No.”

“Okay.”

“I may be able to suck it in.”

◇◇

Year 2007

January 15, 2007

“Tomorrow is your birthday, Nenetita. You’ll be eighty-eight years old.”

“What would you like me to get you?” she says.

◇◇

October 20, 2007

I come to see her.

“Mommy! Mommy! You are so pretty pretty!” she says.

◇◇◇

October 27, 2007

Nenette, feeling sick, says: “You always make me feel better, so don’t you worry.”

◇◇◇

November 2007

She says: “When I’m with you, I’m happy.” “You are so *buenita*.”

◇◇◇

A stream of words without meaning pour out of her mouth, then she says: “Why are you so sad? *Querés jugar a las bolitas?*” (“Would you like to play marbles?”)

◇◇◇

I find her awake.

“Hi, Nenetita,” I say.

She answers with a stream of meaningless sound.

“I am going to give you something to eat.”

“Have you got something yummy?”

◇◇◇

I find her asleep. She opens her eyes. “You are so pretty,” she says, and smiles. “We are both very pretty,” she says.

“Okay. Now I’m going to sleep,” she says.

◇◇◇

*Nenetita passed away
at age ninety-one
at a nursing home
in the United States of America*

*far, far away
from her home country,
Argentina.*

*Words cannot articulate the heartbreak
caused by a mother's death.*

*Even so,
having lived at a nursing homes
for eight years*

*and having lost all of her faculties
to Alzheimer's Disease,*

her passing came as a blessing

*to her,
to me.*

*She has moved on
on her eternal path*

and so must I.

~~~

Guilt of the Caregiver

~~~

In October of 2015

I introduced my four-booklet series,

*Journey of a Caregiver*,

at the Hamilton-Wenham Library in Massachusetts.

*Guilt of a Caregiver*

is a response to the intense anguish, struggle,

guilt

and despair

that I sensed in my audience

at that presentation.

*I knew what they were feeling,*

*I had been there.*

Jorgelina Zeoli

February 2019

*May these pages  
bring insight and comfort  
to those  
whose heart is breaking*

*as they go  
through this most difficult journey  
of separation and loss  
of the one  
they love the most.*

## **1. Guilt.**

Our Alzheimer's journey  
began approximately in 1999,  
when Nenetita's symptoms began to intensify.

During those years  
as her only caregiver,

I found myself in unpredictable  
situations,

situations I didn't know  
how to handle,

situations

I was not prepared to handle,

situations that required support,  
and there was minimal  
or no support available.

As I coasted  
from one crisis to another

doing the best I could  
to take care of Nenetita,

I found myself struggling  
with guilt.

I was tortured by guilt,  
tied up  
in the twisted knots of guilt,  
immobilized by guilt.

~~~

Taking care of Nenetita,
alone with her at home,

I was reaching the end of the rope.

Life was becoming unmanageable
and yet I was determined to keep her with me

*for the very thought
of
taking Nenetita to a nursing home
was tearing my insides apart.*

Looking back
at my determination to keep
Nenetita at home with me,

I can see now
that I was expecting of myself to do more
than was humanly possible.

One person alone,
with very limited resources,
cannot take care
of a loved one with Alzheimer's.

It simply cannot be done.

I believed
that taking Nenetita to the nursing home
was “wrong.”

The thought of doing
what I believed was wrong
twisted my insides,

for I was going
against what I believed was right.

I had to let go
of the belief that taking her to a nursing home
was wrong.

I had to remove the thought:
“I’m doing something wrong.
I’m a bad daughter. I’m abandoning her,”

I had to replace that self-condemning thought with:
“This is heart-breaking but necessary.

I have no other option.”

Making
heart-breaking decisions,

decisions that would
potentially bring unwanted consequences,

did not equal
“doing something wrong.”

*I needed to look
at my own side
with compassion,*

*I needed to acknowledge
that I had been thrown
into an excruciatingly difficult situation*

*and
I was doing the best I could.*

Expecting
to take care of Nenetita at home
was an unreasonable expectation,

I was setting myself up for failure,
beating myself up for not accomplishing the impossible.

I had to let go of my unreasonable expectations,

I had to let go of the belief
that if I tried hard enough I'd be able to do it.

Once reason prevailed,

the tight knots of guilt,
slowly but surely,
began to loosen.

*Remembering
how deeply I've loved my mother,*

*remembering
that during the Alzheimer's years
I was
driven by that love,*

regardless of the mistakes I may have made,

*remembering
that my love for her shaped my thinking
and my actions,*

*it all helped alleviate
and eventually dissolve
my guilt.*

*Today,
my guilt is gone.*

THE HEALING POWER OF LOVE.

**Getting to forgive myself,
however,**

was not a simple process.

“Your responsibility is
to love your mother,
not to be her nurse,”

my therapist said to me
as I struggled with these issues.

It helped.

Except I don't believe that loving my mother
was my responsibility.

Of course
I loved my mother,

but not from a sense of obligation.

I loved my mother,
but
I also had many contradictory feelings
about her.

Conquering guilt
through the Light of Understanding,

as well as the process
of
healing many other emotional wounds

has involved
taking a hard look at my inner truth,

owning all of my feelings,

*including those which society says
I should not have.*

Looking
at my inner truth,

not always a pretty picture,

particularly for someone who
-like me –

grew up being “a good girl.”

Looking at my insides has not been easy
but it has paid off.

Releasing guilt
has been part of the good harvest.

2. *She's still there.*

One day in 2007,
I went to see Nenetita at the nursing home.

“Hi, Nenetita,’ I say.

She answers with a stream of meaningless sound.

‘I am going to give you something to eat,’ I say.

‘Have you got something yummy?’ she replies.” *

~~~

My mother had lost  
her ability to communicate,

and yet,

off and on,

she was capable of articulating  
a few sane words.

Her sane words were  
no chit-chat.

In this case  
the topic was food,

probably one of the last things she was able  
to enjoy in this life.

---

\* From *Nenetita, Regression to Childhood*,  
by Jorgelina Zeoli

~~~

I remember
one day at the nursing home,
at lunch time.

Sitting at a table,
Nenetita was feeling very sick.

As it had happened
so many times before,
a stream of meaningless sound was
pouring out of her mouth.

I remember standing
next to her,

feeling so helpless
so helpless ...

What could I possibly do to help her?

All of a sudden
she said:

“Don’t worry about me.”

How could the sanity of those words ever be questioned?

Not only was she still there.

*Her love for me, her concern for me,
were also there.*

Through
the nursing home years,
I held on
to my mother's glimpses of sanity.

I held on tight,
very tight.

I could see the disease
advancing in the background
yet I stayed focused
on her sane core
ready to respond when she was able to come through.

Remaining alert and receptive
to
those brief moments of real communication
sustained me.

In the final years,
powerful words were said,
words that brought about
very much needed closure and healing,
to her, to me.

3. Advocate.

As I walked through the fire
of the nursing home experience,

a deep realization gelled:

I had to stand up for my Nenetita,

I had to become her advocate.

Learning to become an advocate
was a long,
difficult,

excruciating process.

I wish someone had been there to guide me.

I needed support.

Oh, how I needed support ...

There was some,
but it was not enough.

I made many mistakes,
and I paid a high price for them.

Caregivers go through hell.

Caregivers need support
within the system.

Becoming an advocate meant,
among other things:

learning about Nenetita's meds,

being aware of their side effects,

monitoring her symptoms,

reporting to nursing home staff if I noticed
something was wrong.

Also,
I learned that being Nenetita's health proxy
I had the right and the power to say:

STOP THAT MEDICATION.

A right that I exercised.

I'm not a nurse,
I'm not a doctor,

but I *knew* when things weren't "right."

*I trusted myself,
I trusted my gut.*

Becoming a strong advocate
did not mean
a lack of appreciation
for the nursing home staff,

their hard work,

their dedication.

The staff kept me informed
timely and consistently
about any changes in my mother's condition
and medications,

something I'm deeply grateful for.

In spite of the flaws of the system,

I will never forget
that the nursing home staff
lifted off my shoulders
a weight that I could no longer carry.

~~~~~

***4. I couldn't let her go.***

A few times,  
I witnessed my Nenetita's dance with death,  
as she flowed in and out of lethargic states  
that threatened to take her away.

*I could not bear the thought  
of  
my mother dying.*

*Period.*

*If Nenetita died,  
I would die with her.*

I had to let her go  
*and I couldn't let her go ...*

~~~

As I struggled
through the nursing home years
to find closure,

to let go of Nenette,

it became clear that
there was still a lot of unfinished business
in our mother-daughter
relationship,

a relationship that had carried
a
Great Love,

and loyalty and beauty,

and conflict
and hurt

and confusion.

A relationship that had kept me trapped
for most of my life in a symbiotic relationship.

A relationship
that I needed to disentangle myself from,
in order to let her go.

During those years I carried an urgency:

I had to speed up the process of reconciliation
with my mother
before she passed away.

I did my work and it paid off.

Through psychotherapy, creativity and spirituality
I dealt with the unfinished business
that was keeping me tied up to Nenette.

The first three books of my memoirs,

which address extensively
my relationship with her,

were written and self-published
during the Alzheimer's years.

Still,
there were two more pieces that required resolution
before I could let her go.

Massachusetts 2007

At the nursing home

The two
most wonderful words
my mother
ever said to me.

Lost in her dementia,
a stream of words without meaning
pouring out of her mouth,

two words stand out from the rest:

“Perdonáme, Jorgita.”

(“Forgive me, Jorgita”)

~~~

Throughout her life,  
Nenette had never been able to say “I’m sorry”,  
she had never been able to acknowledge her mistakes.

It was only in her late eighties  
from the far away world of her dementia,

*that for the very first time ever  
my mother asked for my forgiveness.*

*It was only then that I learned  
that she knew she had hurt me.*

Her words also  
reaffirmed my conviction:

*she was still there,*

*and she too  
was looking for closure.*

*the power  
of two words*

*“forgive me”*

*the weight that was lifted  
from my heart*

*a weight I had carried  
for a life time*

*the relief*

*the release  
that I felt*

*no words can describe*

*my mother had asked  
for forgiveness*

*and I was not ready to grant it*

*In spite of all the inner work I had done*

*I was still chocked up  
from our lifelong toxic, abusive,  
dysfunctional relationship,*

***that** was our truth*

*great love*

*and great dysfunction*

~~~

it was now crystal clear,

to let go of Nenetita

I had to forgive her

nothing else would do

~~~

In 2009

I came down with pneumonia

and for many months  
I was unable to visit Nenetita  
at the nursing home.

When I became stronger,

wearing a mask  
for I was a high-risk,

I went to say good-bye.

I had written a letter to her,

*a very carefully written letter*

*I had  
to speak my truth to my mother,  
something I had never been able to do  
in our lifetime  
for  
she had never been able to listen.*

*Now,  
at the end of her life  
and  
from the space of her soul beyond the disease,  
I knew she would.*

*My mother  
was finally going to listen  
to what I had to say.*

*I had to speak my truth*

*with compassion  
and  
self-love,*

*for I knew if I wrote  
to her  
words of blame  
or self-condemnation,*

*those words would come back  
to haunt me.*

And sitting at her bedside,  
I read to her:

“Nenette,” I said,

“I know that you can hear me  
and understand me.

I have something to say to you:

I have loved you as I have never loved anyone  
and you chose to sacrifice me,

I have carried your weight through a lifetime,  
I cannot carry you any longer,

I took care of you the best I could,  
I cannot take care of you anymore,

I have nothing left to give you,

the sacrifice is over.

I am walking out of the prison you built for me,

I need to take care of myself now.

I have nothing left to give you  
other than my forgiveness.

You have my forgiveness,

and I know Christi forgives you too,  
and so does God.

You have been forgiven,  
you have a clean slate now.

Wherever you are, wherever you are going,  
you are being held in love.

I have come to say goodbye.

I wish you peace.

You need to move on, and so do I.

You need to move on without me  
and I need to move on without you.

Reach out to the Light,  
reach out to your own soul,  
reach out to God.

He's waiting for you  
with Open Arms.“

~ ~ ~

~~~

Dear God,

*I lift up to you
the deep suffering,
darkness and confusion*

*of those who experience
guilt
stemming from no fault of their own,*

*in particular those
whose parents,*

willingly or unwillingly,

*have tied the twisted knots
of guilt
in their hearts.*

*May your Light shine on us,
dear God,*

*may your Love
dissolve
the guilt we experience
in our innocence,*

*may we come to know
the sweet taste of your forgiveness.*

~~~



*My beautiful mother*

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