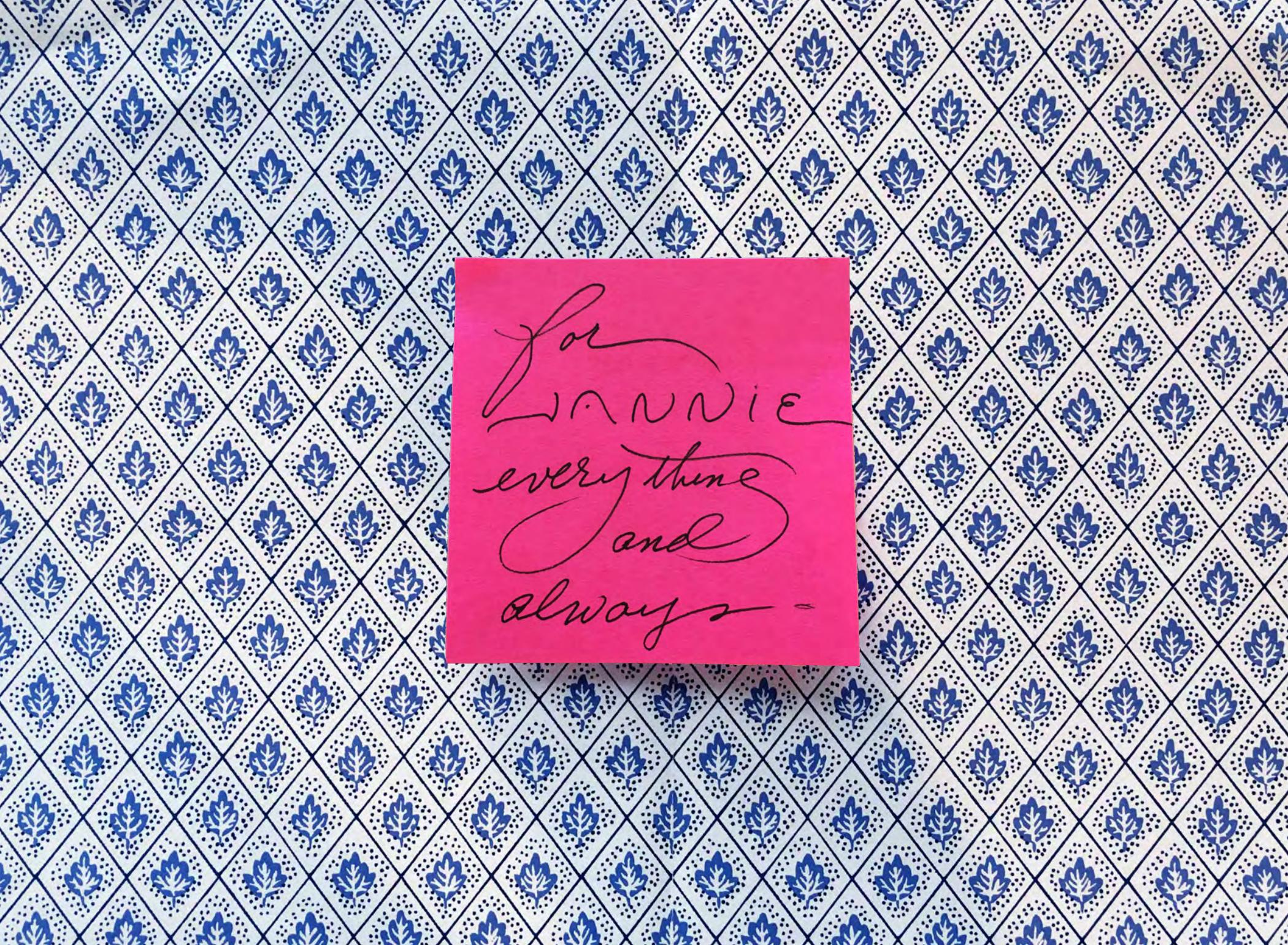




*Someone's missing -*



A pink sticky note is placed on a background of repeating blue leaf motifs within a diamond-shaped grid. The text on the note is written in a cursive script.

for  
LANNIE  
everything  
and  
always -

Someone's missing



... and  
I think  
it's me



# SOMEONE'S MISSING...AND I THINK IT'S ME

Our Great Adventure with Dementia

J.L. GAUSTAD

VCU LIBRARIES  
Richmond, Virginia 2020

*Someone's Missing...and I Think It's Me: Our Great Adventure with Dementia*  
by J.L. Gaustad.

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# LETTERS

My first night away from you in our long married life, I dumped a box of letters from your first wife and the woman you left her for into our bed. I'd always known they were there and never thought to read them. Was it a way to be closer to who you had been, long before your beautiful brain became so tangled?

I would grab a letter from the pile where you should be, read it, shove it back in the envelope and throw it over your side of the bed. A story began to unfold—your young-man affection for this young woman who you blamed—how clearly I see her side, and believe her, when she says she did not break up your marriage.

Around midnight, halo-haired Nate, our art-kid caregiver, came to the back door to check on me. We laughed at my flannel granny gown, warmth needed in the warm spring night, and your brown T-shirt that I held tight like a teddy bear. Was I chilled by the crazy way we had moved you to the facility that day—like a carefully orchestrated crime we may have gotten away with?

# Someone's Missing...

By JL GAUSTAD

I walked into 9 North to find my still so beautiful husband in a faded, flowered hospital gown. Biting into the apple I brought him, he said, "Someone's missing," then looking at me with a mischievous smile, he added, "and I think it's me." Lying on his bed, I grabbed a crayon to write it down. So often as his brain grew more tangled he said stunning, seemingly unforgettable things that were soon erased by the drama or trauma to follow, the worst bringing us here, the "Psych Ward."

Still smiling, Jerry mused about the bruises covering his arms, bruises I had feared were being inflicted when I heard, soon after our parting kiss the night before, that he had been seized and forced into an ambulance, having bolted, after only one week, from the lovely assisted living facility I had thought would save us. Howling helplessly in my car, I raced to the emergency room where I was denied any access to my husband or even knowledge of how he was until morning. "Is this even legal?" Only the pastors would speak to me. "Do you have a spiritual practice?" they asked. "I used to be a Buddhist!" I spit out, forgetting everything I thought would sustain us. "Fuck the moment!"

For years I had been trying to convince Jerry's doctors that

something was wrong but with his fit body and seductive wit they would respond, "Leave the poor guy alone. Everyone should be so healthy." And he was amazing, a speed-walking, weight-training yogi. ("Joan changed my wicked ways!" he'd wisecrack...five packs a day...fried everything...)

This wild Chicago artist was admired in genteel Virginia for gorgeous paintings that showed his joy in life. A ravenous reader, his compassionate nature came through when he put aside his stacks of books, *New Yorkers* and *Nations* to read every obituary from 9/11 in *The New York Times*. He was still a fascinating painter and teacher, beloved for his badass humor. And yet there were crazy times like when—in Hurricane Gaston, our basement flooding from the walls like Niagara—he began filling a bucket at the tap, "If we are going to mop we'll need water."

Heart sinking, I knew the first diagnosis of attention deficit disorder could not be the whole story. The result of a cognitive test had been, "He doesn't test well." The MRI, CT scan, PET scan and draining of spinal fluid were not as convincing that something was wrong as Jerry's failure with the "draw a clock" test. His incredulous neurologist went pale.

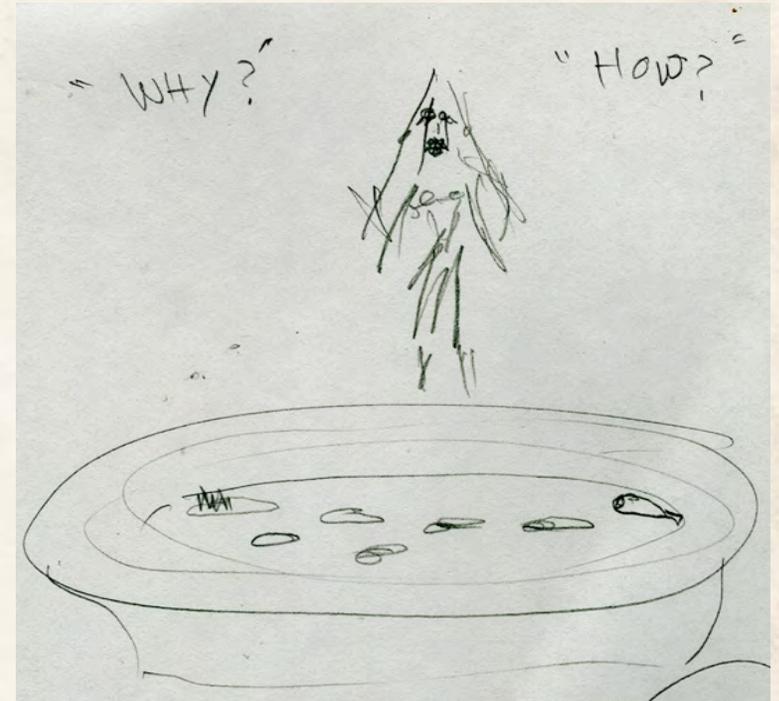
At the university Jerry was the

classic absentminded professor, adored by his students and for their sakes he took early retirement, never admitting his fears and joking "I've looked at enough bad art and now I need to make more bad art of my own."

My hope was that he would be able to continue to paint as his favorite artist, Willem de Kooning, did beautifully into the last stages of Alzheimer's disease. Jerry's work had become watery and lovely, unlike the rich layers and colors, depth and raucous humor he was known for. His signature and alter ego, the earless Mickey Mouse, "Mr. Man," was gone. His paintings were diluting, dissolving, disappearing.

I could not bring myself to help Jerry make art as I did with seemingly more intimate tasks. This was something I encouraged our young studio assistant to do. The upcoming retrospective of his work at the university gave good reason for hiring even more helpers without him having the sense of being watched.

I had hesitated to join the "Early Onset Support Group" wanting to hold onto the denial of where we were heading, only to find we were deeper into the illness than most of the other "care partners." In the care "giver" side of the meeting I asked how people were dealing with some of the craziness Jerry



and I were starting to experience. Everyone looked at their hands, no comment. "If we can't talk about this here then how do we help each other and the ones we love?" I asked. I broke them down and we were able to laugh when we weren't crying and sometimes when we were. Meanwhile Jerry was stirring things up, in lifelong fashion, on the "cared for" side, inserting scatological words into "You Are My Sunshine" to the delight of everyone, especially himself.

Staying in our home and creating our own way to deal with this illness

had been my plan. "The bathroom issues are usually the deal breakers" our counselor said when one morning I found—instead of urine down the hall or on the windowsill or me—what I hoped was poodle poop floating in our tub with rubber ducks, shampoo bottles and bath brushes. "There will be no deal breakers!"

I strung Christmas tree lights to the toilet and painted the bathroom walls bright coral to make the fixtures more visible. Still Jerry would be up all night putting on as many of our clothes and hats as he

could. “Next you’ll be in a suit of armor,” I teased, (“Your Knight in Charming Armor” our young nieces once called him.)

Then things got scary and sleep impossible. He would try to leave the house—“Can we go home now?” I could not turn my back. Our exhaustion made for more confusion and then aggression. His heartbreaking “Where is everyone? What have I done wrong?” became a terrifying “Where are they!” screamed into my face, forcing me to flee.

I tried to get him to talk about what was happening, “Jerry, you are always the one I can turn to and now what’s most on my mind you won’t hear.” In the few times I broke through the denial, his grief and fear were so profound that I never wanted to take him there again. He rarely commented on the losses: driving, dressing, reading, writing, speaking—only five words at a time—I would count on my fingers. He still had his humor. “Come here often?” he would always ask on our walks and I would always laugh. Finally he added, “Too much?” Three plus two: five.

We had been together my whole adult life, and as our art dean friend said in the article about the retrospective, “No one ever says ‘Joan’ or ‘Jerry.’ It’s always ‘Joan and Jerry.’” It was a life of art making, reading and endless talking. All lost to us now, we compensated. Never having listened to music with lyrics because it conflicted with our constant conversation, we began to play opera with dinner and dance to Muddy Waters and Son House.

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**JL GAUSTAD** is an artist working on a picture book about brain illness.

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His mind could no longer discern the difference between a toilet and a sink or even know what certain body parts were for, trying to pee with the strings of his sweat pants or his scrotum. “Joan—this isn’t working,” he’d laugh. And I would too.

And yet once, while out walking our little pound poodle, Jerry suddenly stopped with an expression of intense sorrow as he looked at a dying dogwood tree. The empathy was so pure. I asked my dear friend Sharon, “Why is it that I think the confusion and violence are the illness, but the compassion is the real Jerry?” “Because it’s true,” she said. And it was.

The nature of self was something I wanted to contemplate in the chaos. The realization that he could not help it made me wonder how much any of us can. Still, I faulted myself. Jerry was the one with the dementia yet I felt I was losing my spirit, my soul. My counselor asked “How can that be when you fall in love with him again at every stage of his illness?”

The first time he denied me as his wife, we were in the bathroom together. (We who always said, “Separate bathrooms are the secret of a happy marriage,” but could no longer be separate.) I tried to laugh as we both did when his razor couldn’t get through the toothpaste he had smeared on his face. “No... we are not married,” he said, then

seeing my tears added, “But I really like you.” His sympathy for this sad stranger was stronger than his bewilderment at why she was claiming him as her husband. How could I not laugh now? Jerry, still, so Jerry.

That our second assisted living residence was a dysfunctional family worked in our favor as they tolerated behavior more professional institutions might not. When Jerry saw me coming down the hall the signs of his delight were sometimes x-rated. The staff would

laugh and say “How long have you two been married?” “Oh, I’m so sorry! Does he do this often?” “Only for you—true love.”

The care he had shown his students was even more evident with his fellow patients in their “locked unit,” comforting the ancient aristocratic Mrs. Hale in her wheelchair, she kissing his hand as if he were her long-lost sweetheart. He would twirl tiny Rhoda—the 92 year-old former ballerina—to Van Morrison, and brush crumbs off the old men’s laps while eating their desserts, still the life of the party, the mischievous smile.

The young, severely bipolar “Weeping Alice” terrified the others with her grasping hands. Jerry walked with her clamped on his arm like a pet falcon, feeding her the grapes I brought him. When his protective rage sent an aide to the hospital and us back to the psych ward, one day later Alice showed

## “The bathroom issues are usually the deal-breakers”

up too, lost without him.

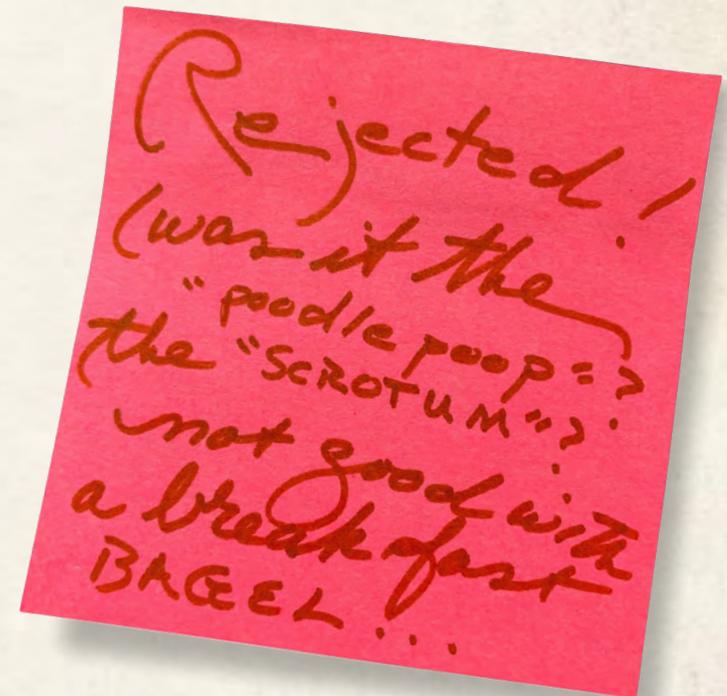
I tried to explain to the doctor that Jerry had a sense of purpose and begged for an alternative to the choice of a mental ward where he could be harmed by more aggressive inmates or sedation with damaging drugs. Dr. Despot shouted, “There isn’t enough brain left to work with!” and stormed out. Thinking Jerry unconscious I wept, my head on his heart. He put his arms around me “Poor, poor, poor...” Dementia and drugs could not take his compassion.

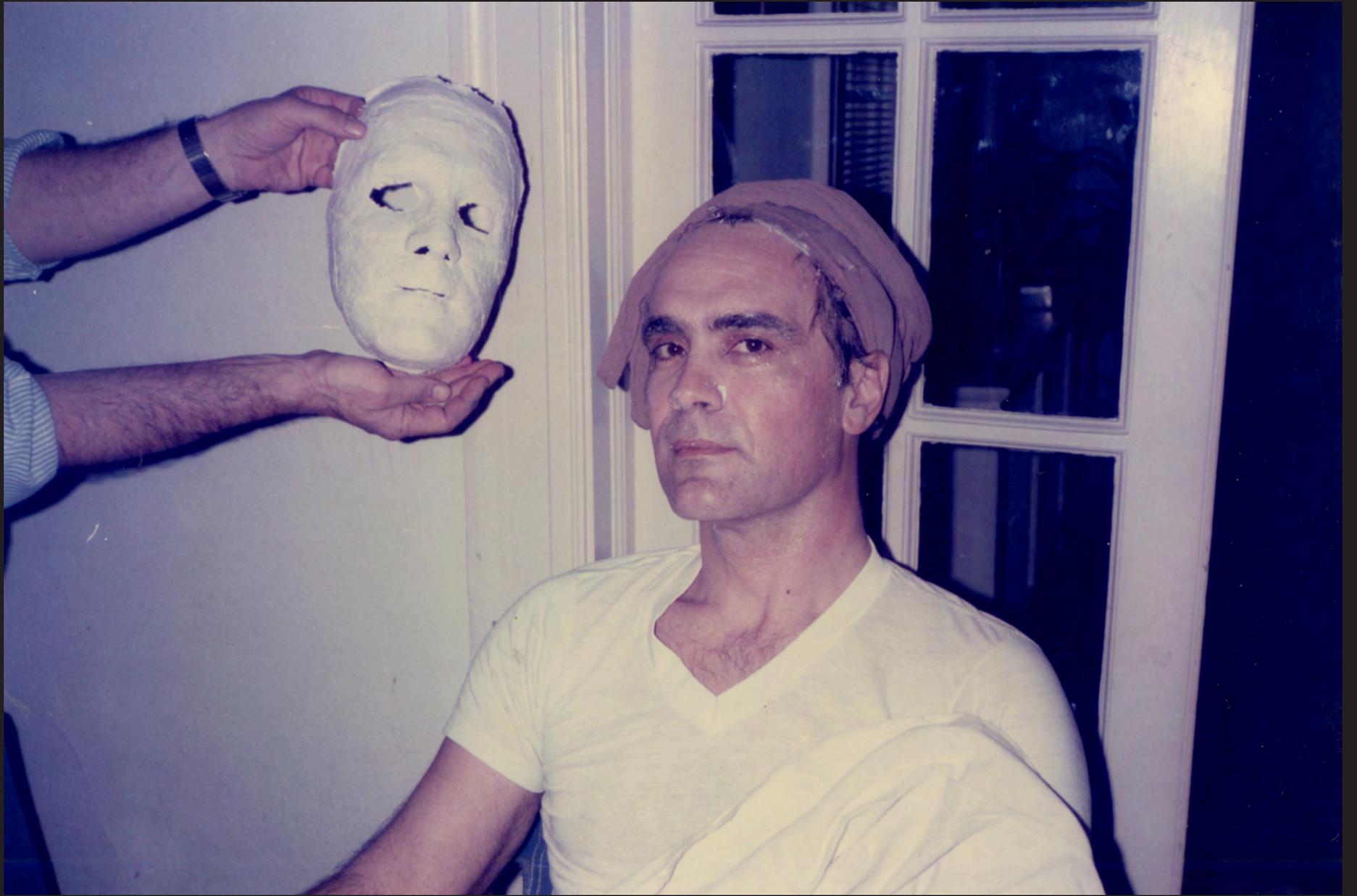
When he arrived in an ambulance at the final assisted living facility I jumped on and we laughed like the escapees we thought we were.

There was no escape, not from Dr. Monster’s orders to keep Jerry bed- and wheelchair-bound as the drugs diminished his life.

I rolled him into the winter sun and circled the frozen fountain hoping the children’s voices from the nearby playground would cheer him. We lay in his caged bed looking at the moon as he snapped his fingers to Marvin Gaye and Billie Holiday but I grieved that I could no longer bring him joy when he was unable to speak or even smile.

Still, Jerry was not “missing.” When new aides came they would always fall in love with him even as he fought their care. His nurse said, “It’s the way he looks at you.” Eyes full of love, until they closed for the last time, on Valentine’s Day morning.





Which baby will get away with stealing hubcaps  
and which will be arrested for stealing stamps

for  
which  
smiling

out  
three  
degrees?

Which  
which baby will  
for stealing

arrested



Which baby  
Which baby will  
and which baby will be arrested for stealing stamps  
for his stamp collection?

caps,  
caps



# MET

I met Jerry Donato at a party where he was happily holding court, chain-smoking True Blues. With dark circles under his dark eyes, I did not yet notice the lashes, bunched in the inner corners—a double row like Elizabeth Taylor. His mutton chop sideburns and fried-looking hair, in my mind, fit the raunchy ridiculous banter that everyone else seemed to delight in.

I was at the party with my presumed boyfriend—and professor—who I had intended to surprise (but actually appalled) by returning from Europe to his college in Virginia. What he had wanted, I realized too late, was the fantasy of a long-distance romance.

I had come to Richmond (that dusty old town, my mother called it) the year before, after two army-bratting years in Vietnam War-era Bangkok where my dad was deployed. This New Yorker professor, whose art classes I modeled for, was the only person I encountered who had even heard of Edith Piaf. We met up in Paris and he had professed love. Now, we were going through face saving, social motions until the end of the semester, when I would bolt back to art school in Germany.

Then there at the party was my Jerry. He put his hand on the back of my pink shirt. “You look naked,” he said. Just grotesque.



Days later he stopped me on my bike as I rode by his print studio.

"Tell your roommate I'll give her a buzz." Eye roll, the first of thousands to come. (The eye roll is said to be the surest predictor of relationship failure. Jerry lived for my eye roll, worked for it.) 'I'm sure she'll be thrilled,' I say, riding away.

Not thrilled, "He'll date anyone." But hot girl Courtney delighted in going out on her boyfriend so she agreed to a day trip to Williamsburg.

Sunday morning found me ditched by my pretend boyfriend and Courtney refused to leave me alone. She would not go without me. I felt stuck. 'I don't want Jerry Donato thinking of me as his second date!'

In truth, I'd just seen Jerry at a Halloween party and was intrigued. He was dressed in white as a gangster and I (don't ask) as Anne Boleyn, my pallor painted paler. We sat on opposite sides of a large round bed and lying back found ourselves head to head. He turned to me. "What are you supposed to be?"—'A hand tinted photograph.' "Very subtle," he laughed, and left.

Annoying, and yet did I catch the scent that became my sustenance until it somehow evaporated with the illness—only to return when the memory medicine was stopped? (Aricept was the drug and my friend said the same thing happened with her father and Nameda.)

MADE FOR  
TEACHER  
OTHER

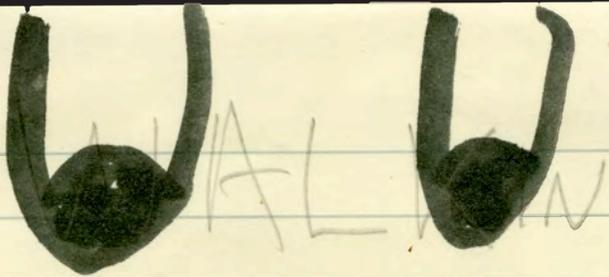




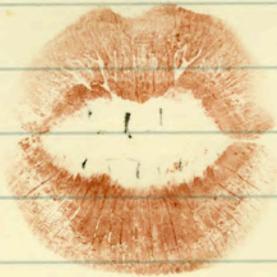
The night after the Halloween party, Jerry came to our apartment to see the wayward Courtney, and as I admitted to him after many anniversaries, it was no accident when I wandered “sleepily” from the bedroom in my silky blue shorty pajamas, interrupting a potential make out session. He laughed and said “Well it wasn’t Courtney I wanted to ‘buzz’ when I stopped you on your bicycle.” ‘Really?!’

In Williamsburg he was all graciousness, undaunted by the triple date. Courtney twittered off, uninterested in us or the Bruton Parish Cemetery. Jerry and I looked quietly at the time-washed, wafer thin tombstones and then up at each other.

It was a moment we both remembered—as long as we both could remember—of recognition.



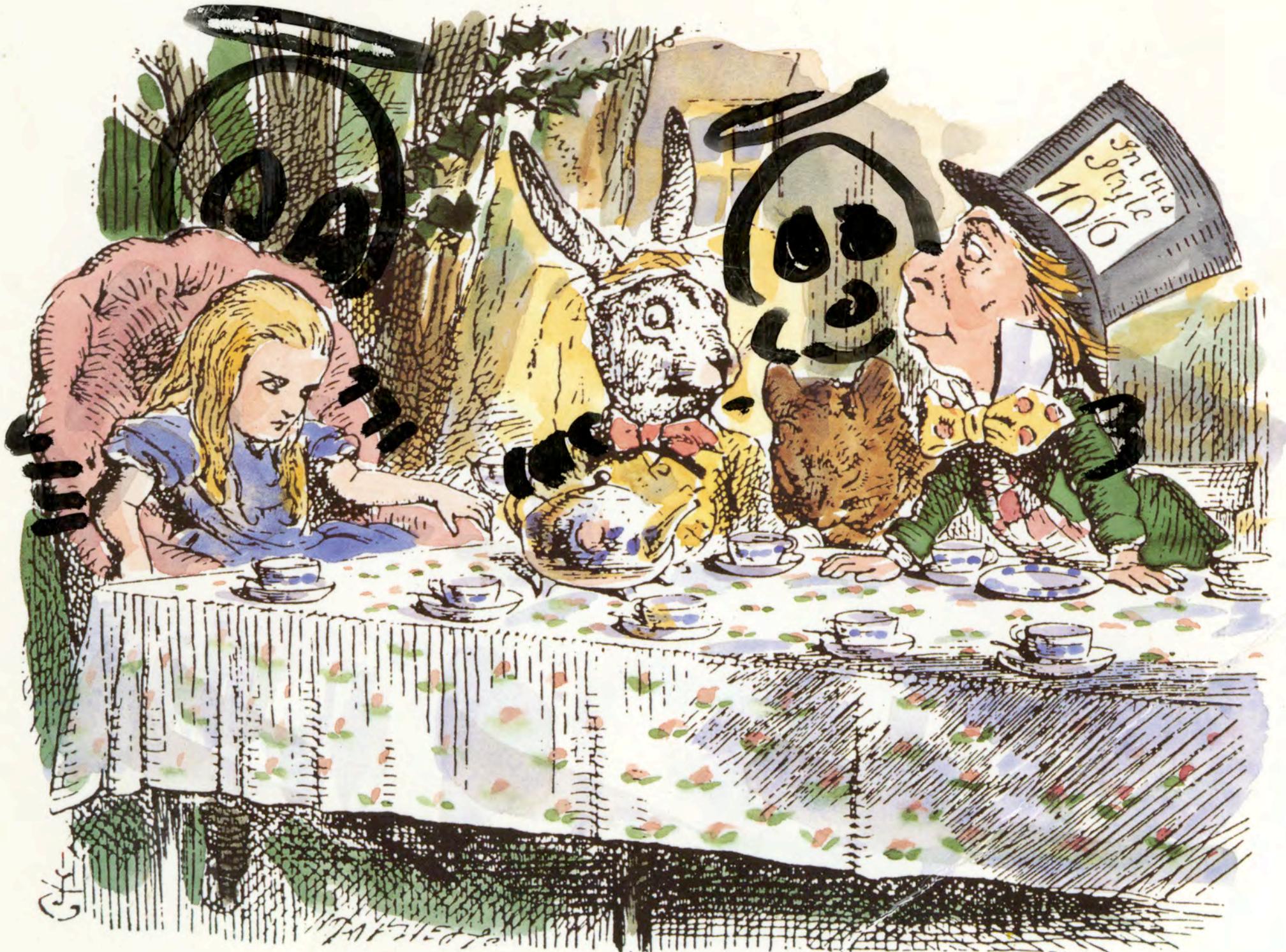
WALLEN



LOVE

J.J.





# HUMOR

I fear my humor may be too dark for you but it got us through so much.

This gallows humor was learned in the MCV Infectious Disease Clinic's lunchroom. I had reluctantly volunteered to work in the pediatric HIV clinic, unsure of how I would teach art to kids of different ages and abilities while they were being treated for such a terrifying illness.

The children filled my heart in ways I hadn't thought possible—I didn't even want to break for lunch. When the staff insisted, I was unable to eat while listening to the nurses, doctors and social workers banter about things that seemed grotesque, unmentionable, unthinkable. Before long I was joining in the feasts, brought in by drug reps as bribes, laughing and learning about what it's like to be in the medical trenches.

We need humor to face devastating, humiliating illness and even death. This education was a great gift for what I was too soon to face.



Still, it can't be denied there were times when the humor was a little perverse.

Early on, while walking around a pond at Jerry's dad's retirement village, every time we crossed the arched bridge Jerry would ask, "Do you think those swans are male and female?" And every time I would laughingly answer, 'No they are gay and they adopted the five little cygnets.'

"Oh," he'd respond every time.  
A silly inside joke that kept us going round and round.

And I still laugh when I think of Jerry at the elegant Westhampton Theater watching *Brokeback Mountain*. The long lovely opening scenes—"Does anything ever happen in this movie?" He must have been the only person in the audience who could not remember what the film was about. The tent scene came as quite a shock.  
"Whoa!" Yes, something happens.

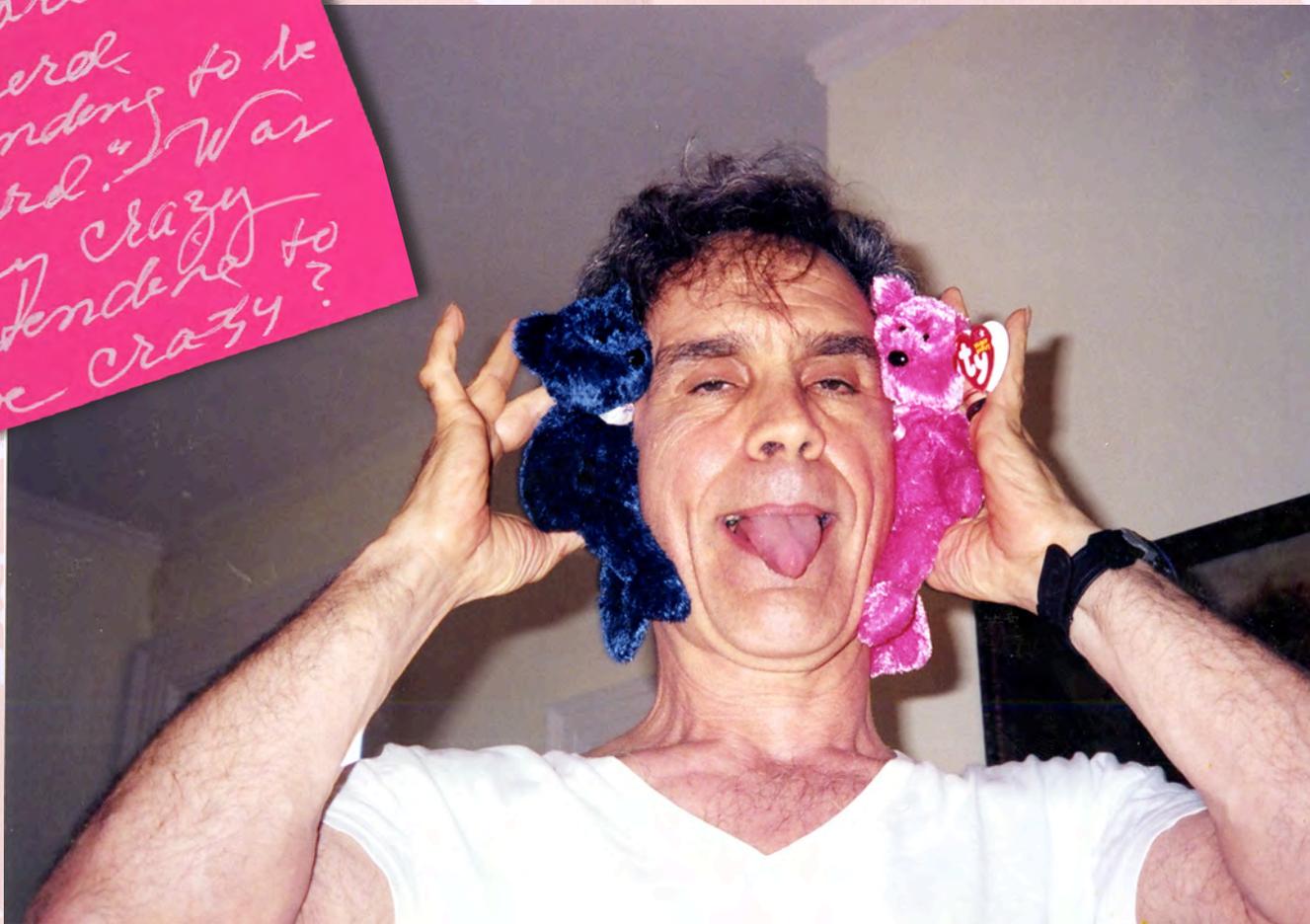
Still, he was deeply moved when the lovers reunited and held my hands tightly. Later, while watching the Academy Awards (the sort of thing he was now willing to do), the theme music played and he took my hands in the same way, a part of him connecting the sound to the passionate love that had been so real to him.



*And Poochini, our little pound Poodle—who friends worried would add to our burden—helped us laugh when Jerry was still home and at all the “homes” after.*

*In what had been the embarrassment of having to be dressed and bathed, flossed and shaved we focused on the funny little humper and were able to pretend things were not what they were.*

Elizabeth  
jokes that  
her Carleton  
is a nerd  
pretending to be  
a nerd. "War  
Jerry crazy  
pretending to  
be crazy?"



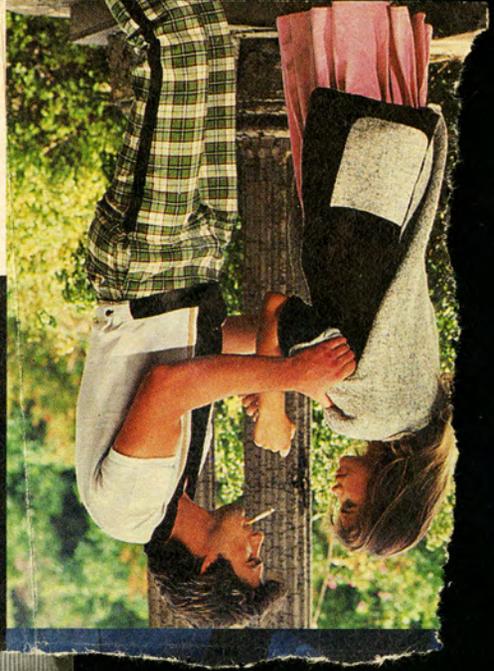
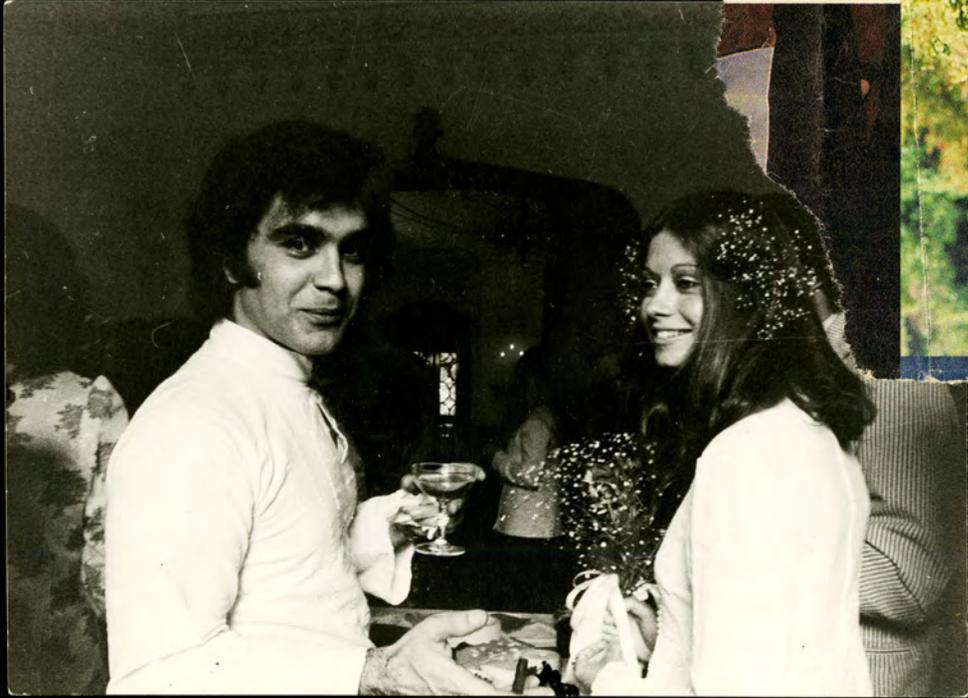
## PRIVACY

Jerry, is it betraying your privacy to tell about your big “Pink Girl” painting dragged down the wallpapered halls at Windsor Assisted Living and repainted with poop?

You, who at a patron’s wallpapered house in Colonial Williamsburg, a generous reception, went around asking “Who took a shit in the fireplace?”  
“How terrible! Who would do such a thing?”

No one would, no one did. Who would make up such a crazy story?

(I married you anyway.)



## SIGNS

"I'm not good at puzzles," Jerry had said of my lame gift of a Rubik's Cube on our first Christmas. And indeed, he could not fit a key in a lock. ('Big part into big part,' I'd tease.) He did have brilliant sense of space in his art—a painter not a sculptor—I thought.

The first real strangeness could absolutely be attributed to stress. Two artists, hit with handling a complicated lawsuit for his family—we left the lawyer's office somewhat stunned. Jerry went to the elevator, jumped up and slapped the light. 'What are you doing?' I asked, mystified. "Ring for the elevator." "Do you really think they would put the button so high that people would have to leap for it?!" I laughed hard—comic relief. Brain issues never crossed my mind. He was in his forties with some newly discovered heart problems, but so fit.

We went off to New York for eight months, living and working in a former boxing arena where John L. Sullivan once fought, and the only aberrant behavior was a flash of violence; Jerry pushed me angrily against a wall. There had been another incident on our fifth anniversary, seven years earlier—hair pulling, that I had attributed to drinking—not this time. The next, third and last flash, until the illness was obvious, was two years later, right after his fiftieth birthday, and right before a trip to Paris—the wall again.

I told him, on Ile Saint-Louis, after a tear drenched dinner, that I could not be with him, never knowing when lightning would strike, even if the bolts came years apart. He begged and swore and was true to his words—until he lost them—and so much more.

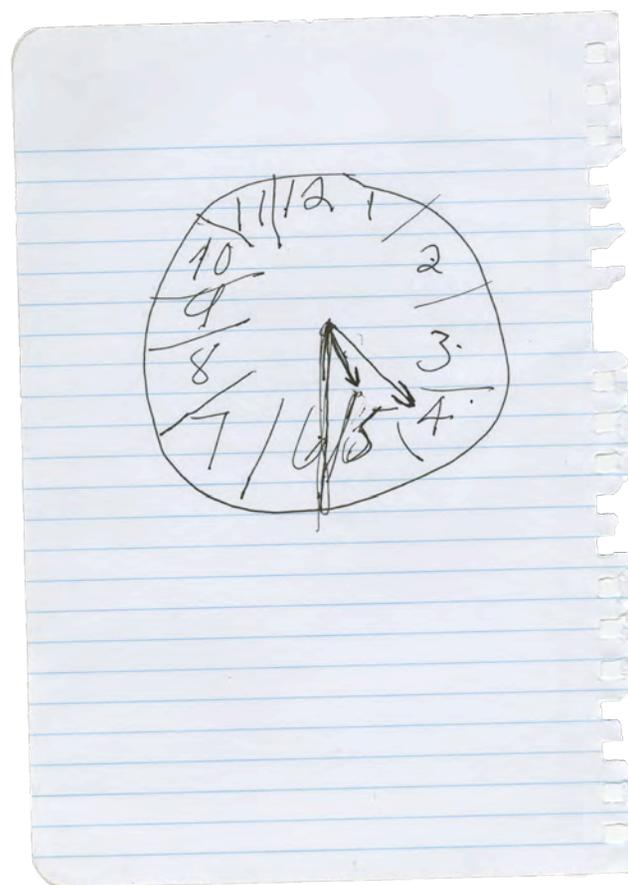
# LIES

I never lied to you, not even a lie of omission. (Well, except for the one about how the tile on our front porch was broken in the ice storm. "How the hell did this happen?" It would have only upset you to know that the drunk sent to clear a path for the art student party had used a hole digger instead of a snow shovel.)

Then all I did was lie.

The first came in a flood of need to take the look of devastation from your face as we stood in the searing sun, high on a hill in Charlottesville. We had come to see a semi-famous neurologist, hoping he would have more insight than the brain doc in Richmond who was wedded to his "absent-minded professor" theory.

The night before your appointment, we missed our turn to the hotel and in your anxiety, you started using the shift on our new Volvo as if it were a manual. You'd been driving automatic for thirty years. The honking around us as we stopped dead on a steep hill, the ripping sound of the car ripped through me. After an uneaten dinner we walked the moonlit mall. 'Jerry, there's an island with no cars, we'll move there.' Did you even remember what happened? You slept. I could not.



Morning came and we were somehow at the clinic. When Jerry went to the bathroom (I'd given him lots of water in this hope) the doctor said, "Is there anything you want to ask or tell me while we are alone?"

'Yes. If Jerry has Alzheimer's I want to know but please don't tell him yet.'  
"My colleagues may think I'm crazy," he responded, "but I think it's the black mold."  
The first ill-founded relief.

I left them to their exam, coming back in on the "Clock Test."  
"Draw a clock," the doctor instructed. Jere drew the circle, then slowly, carefully, the numbers. Again, relief.

"Make the clock say 6:20." Pointing an arrow to the six, Jerry wrote the number twenty next to it. 'Clever,' I tried to believe, but the sour expression on the doctor's face stopped me cold.

He leaned back and said, "Mr. Donato, I approve of your decision to retire, not just for your sake, but for the sake of your students."  
Could any words have hurt Jerry more?

Did he even hear "The fix will not be an improvement, just to prevent further worsening—but that's unlikely."? Talk of a PET scan. I just wanted to get Jerry away from this suddenly-cold doctor. We had gone from a neurologist who denied his illness to one who was denying his humanity.



Out into the stunning midday sun, I started spinning. 'Jerry, why are you upset? This is just what we were hoping for.' He looked confused, doubtful. I continued, 'We wanted a plan and now we have a plan.' His expression still said "No." I just kept repeating, growing my lie—'We hoped there was the potential to get better and now we know there is.' I fed us both dark chocolate and took him for coffee (deemed brain harming and denied him by his primary care doc) spinning, spinning until we both believed and drove too happily in the wrong direction through the rolling, spring-leafed landscape.

When we arrived home, Jere went in the house while I stayed in the garden to listen to the tape from the recorder the doctor let me leave on during the exam. All of my self-brainwashing was spoiled by hearing Jerry's pathetic responses to the standard questions: "Where are we? What year is this? What season? Who is the president now?" (When my sister Patti had asked, he answered "Asshole, son of Asshole").

I listened as the doctor's respectful approach became demeaning. Was he appalled and angry that someone in this condition was still teaching at a university? I had gone to Jerry's fellow faculty. He would forget meetings, they said, but with the student's work he was still right on and they adored him. He was given a full-time assistant to get through the last semester.



The next day, I call the nurse in Charlottesville. "You can't save him," she says.  
"Feed him ice cream."

I open to this seeming empathy.

'But we don't really know exactly what's wrong so how do we know it can't be helped?'  
"Well it's not pre-frontal or he would do things like comment on a woman's breast size."  
'Actually, he's always sort of done that,' I say—trying for a little levity—and it's sort of true.

"You should get an autopsy," she responds.

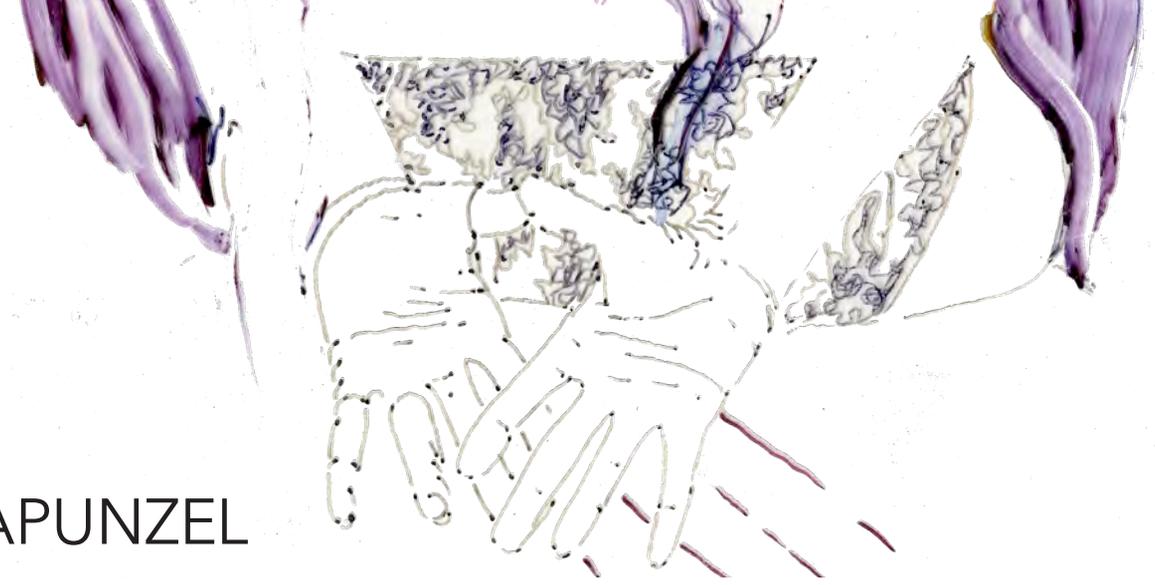
'But it would be too late...'

"To satisfy your curiosity, just a little slit at the base of the skull."

The sweet scent of husband neck comes to me. How does the sunlit window seat, where I retreat from Jerry's hearing, go so suddenly dark?

Still, I try to give in, 'Jerry, want bad children ice cream dinner?' while still totally believing I can save him. Save us.





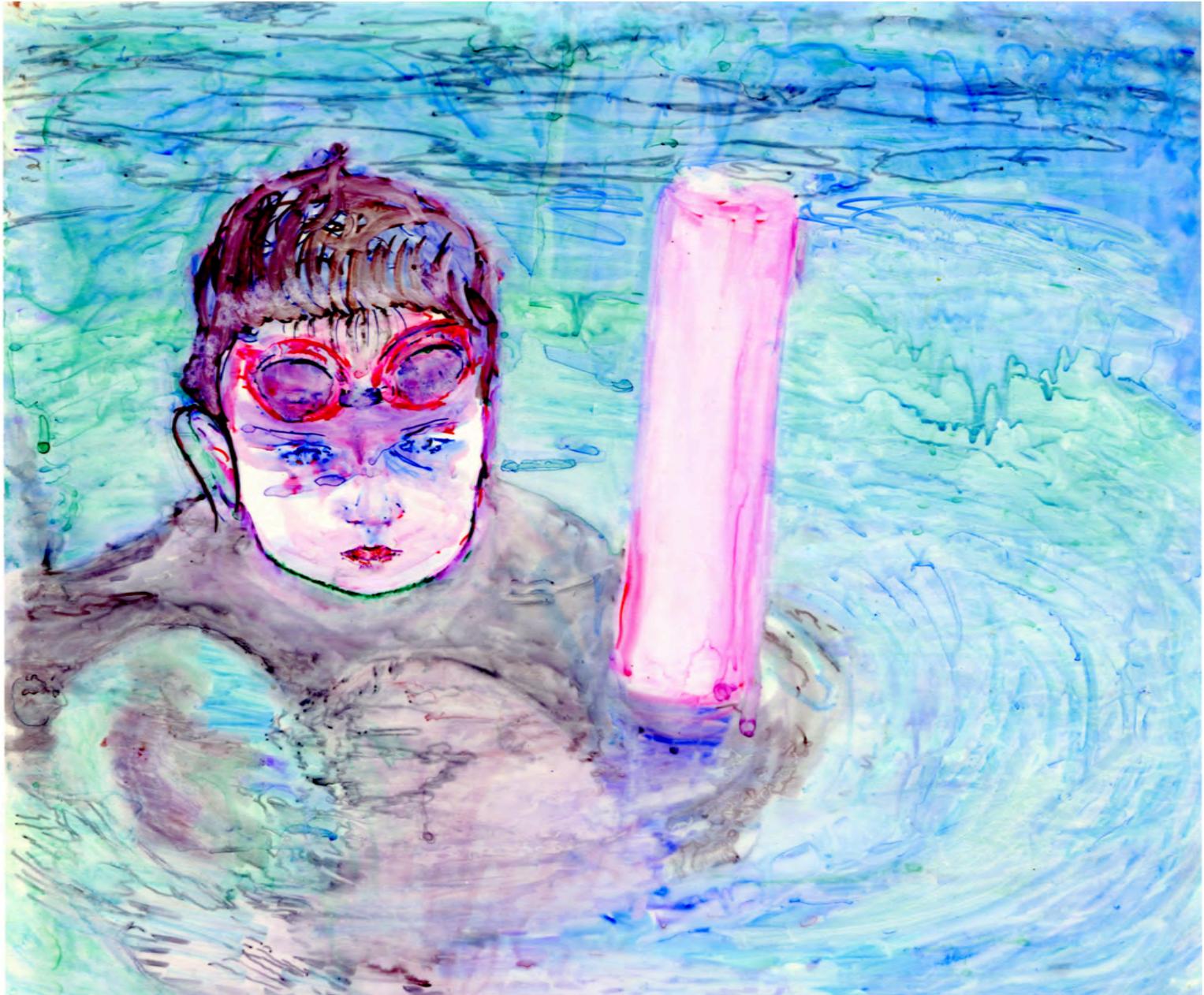
## RAPUNZEL

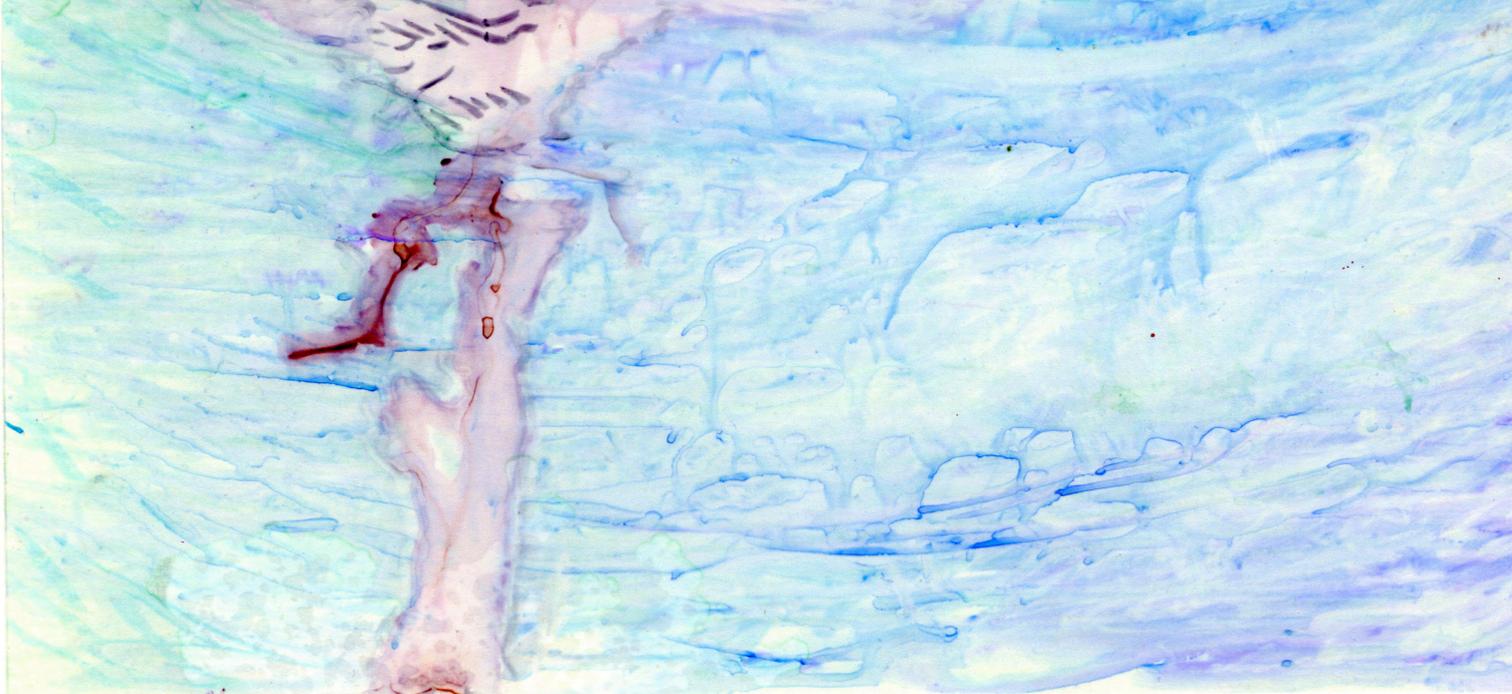
Our favorite fairy tale from childhood is said to tell the story of who we are as adults. “Rapunzel” was my obsession always. The girl is not rescued by the prince, she finds him and saves him, her tears healing his blind eyes.

Jerry wanted saving. His black-belt-in-karate uncle had dropped dead of a heart attack at forty-one and he knew his five-pack-a-day habit and fried-everything food was not a good path. We walked and yogaed and olive oiled ourselves onto a healthy road and over the next twenty years his blood was wine-washed clean.

Still, when we had his arteries checked at Intecardia, they were found to be hopelessly cracked. Vascular dementia? Time to give in?

*Why didn't I remember this (and maybe it's why I'm writing it now), all the long nights after 'All hope is gone,' when I tortured myself with thoughts of what I could have and should have done to save him.*





*I had been hardwired for survival guilt by the drowning of my older–then forever younger–sister, she almost seven at the time and always after. Our father had just retrieved us from Opelousas, where my young mother had fled the year before in fear of becoming “a hardboiled army wife.” I, almost two, sat on the side of the pool while he put on my life jacket, his back to Janet.*

*“Look Daddy, it blows me.”*

*He did not look.*



Last year my tiny mother and I lay in her single bed after she decided to stop her meds and join her "Honey."

'Mama, I'll miss you.'

"Nothing lasts forever Baby," she teased in her soft, sly Louisiana way.

I was grateful that she was finally letting me love her and we laughed at how she was turning hospice into her personal spa. "Here's your steaming face cloth Miss Margie, and your eye cream."

And we cried. She had blamed us. We blamed ourselves.

"I took you to a baby shrink."

'How little did I get?'

I hadn't been able to comprehend. "Let's go find Jannie." I clung to her and did not want anyone to leave my sight.

'How long did this last?' I asked.

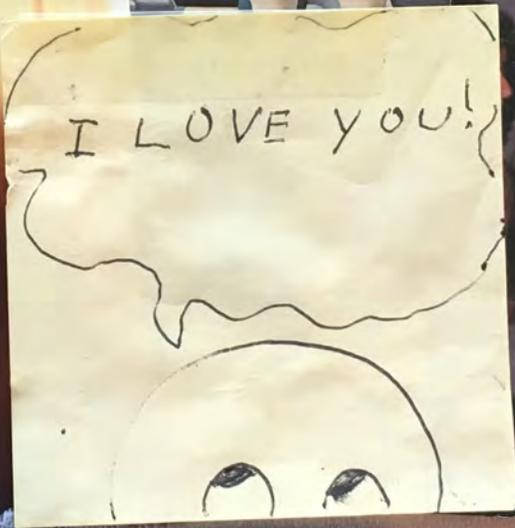
"Forever."

Once she had told me—her eyes filled with tears—that in my paintings all the girls had water coming from their mouths. I had not seen it or intended it but now it was undeniable.

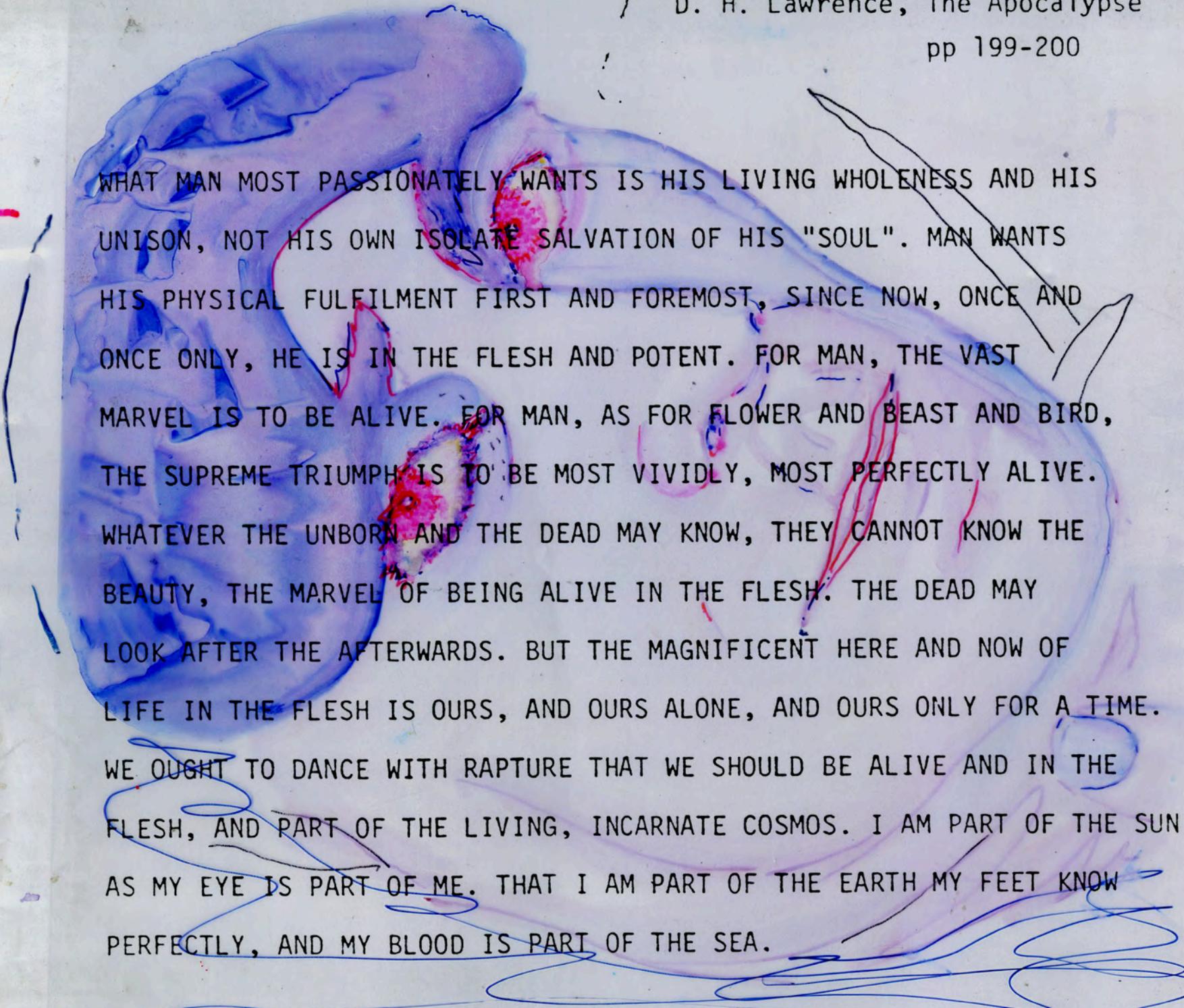
What had I seen that day? She always wondered.

My original motivation for this book was to create something that I so desperately looked for in more than 30 "fact" and fiction books that I first hid under the bed - and marked out titles so I would not see - The things I was looking for are here if you want/need to find them but this has become a LOVE STORY

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Jerry + Jean = LOVE



WHAT MAN MOST PASSIONATELY WANTS IS HIS LIVING WHOLENESS AND HIS UNISON, NOT HIS OWN ISOLATE SALVATION OF HIS "SOUL". MAN WANTS HIS PHYSICAL FULFILMENT FIRST AND FOREMOST, SINCE NOW, ONCE AND ONCE ONLY, HE IS IN THE FLESH AND POTENT. FOR MAN, THE VAST MARVEL IS TO BE ALIVE. FOR MAN, AS FOR FLOWER AND BEAST AND BIRD, THE SUPREME TRIUMPH IS TO BE MOST VIVIDLY, MOST PERFECTLY ALIVE. WHATEVER THE UNBORN AND THE DEAD MAY KNOW, THEY CANNOT KNOW THE BEAUTY, THE MARVEL OF BEING ALIVE IN THE FLESH. THE DEAD MAY LOOK AFTER THE AFTERWARDS. BUT THE MAGNIFICENT HERE AND NOW OF LIFE IN THE FLESH IS OURS, AND OURS ALONE, AND OURS ONLY FOR A TIME. WE OUGHT TO DANCE WITH RAPTURE THAT WE SHOULD BE ALIVE AND IN THE FLESH, AND PART OF THE LIVING, INCARNATE COSMOS. I AM PART OF THE SUN AS MY EYE IS PART OF ME. THAT I AM PART OF THE EARTH MY FEET KNOW PERFECTLY, AND MY BLOOD IS PART OF THE SEA.

# THE WIDOW

Yoga camp in Provence. “Who else would go to all the way to France to be with exactly the same kind of people they see at Ellwood’s organic market every day?” teases Jerry’s beloved boss, La Roth. Not true! Well kind of, but from all over the world.

When we arrived from Paris, Jerry was down hard with what turned out to be salmonella poisoning (That poulet sandwich on the train?). Our darling Frenchee-teacher, Francois, would say “Now Jheree, we know you have been sick, Jheree, but really you must pay attention!” as Jerry climbed under a yoga blanket at the back of the class with the two girl docs who helped to bring down his 104 fever. (I think it was even brain-burningly higher before we found a thermometer, his forehead on fire.)

An un-yogic group we were, with plenty of red wine flowing. There was one quiet American woman who kept to herself—a new widow, she was the age I would be—sixty-one. For her it was sudden; her handsome, charming, beloved professor husband—just sixty—went to play tennis and never came home.

Twenty-five years of students sent condolences. Overwhelmed, she responded with a quote from D.H. Lawrence, the writer of my young heart, same 9/11 birthday. I asked if she would please send me the passage.

When her letter came, Jerry’s tenacious salmonella had returned full force. (Do not take Imodium—it just holds the tiny terrors in.) His frailty was frightening and Lawrence’s words, bleak and heartbreakingly true, were of no comfort. I felt for the students and shuddered for our future.





NATHAN

THE PERFECT IS THE ENEMY  
OF THE GOOD



### BIRD FOOD

MAIL IN BROWN TRUNK

BY front door -

(Try to get it before)  
(+ just give him  
mags + junk)  
Please

NOTE Bedroom lamps  
4 are ancient/fragile  
15 Please turn on  
x 9 by cord switch  
4135

PRIORITY - 1.

Keep engaged as much  
as possible - not all the  
time but - helping -

MACON

I love smiling

if he can help - sweep -  
take out garbage - play  
music - ability varies  
but if he can just feel  
he is a part of whatever  
also - if he wants to show  
something - a book - art -  
a photo

Anything that gets him  
laughing - smiling - pets + babies  
Of ironing play Seinfeld

Hydration - lots of water - dilute  
juice - 1/4 - 3/4 water -  
coffee ok coke last  
resort + not past 2:00 PM







## ADVICE/FACILITIES

If you are checking out potential assisted living facilities go first on a Sunday, unannounced. The staff is low and you will see the place at its worst. I would pop in at lunchtime, as if visiting a resident (yes, I became devious) and was sometimes able to actually talk to some folks about how they liked the place. If there seemed to be potential I would call on Monday and make an appointment.

At Jerry's first "home," before we even moved in, I made sure that all the staff, aides, nurses, cleaning crew, cooks, servers on all the shifts, and the other residents—especially those in his boat (the "breakout bracelet" was a giveaway)—knew him. I learned the names of their children, their dogs, and they knew our little poodle pup, Poochini. I tried to let them in on Jerry's charm. They were wonderful and I thought we were home free.

I realized too late that the most important person is the DON, Director of Nursing, who pretty much runs the show. Ours was inexperienced and disastrously stupid, giving Jerry the very medicine (Haldol) I had told her turned him into the Hulk.

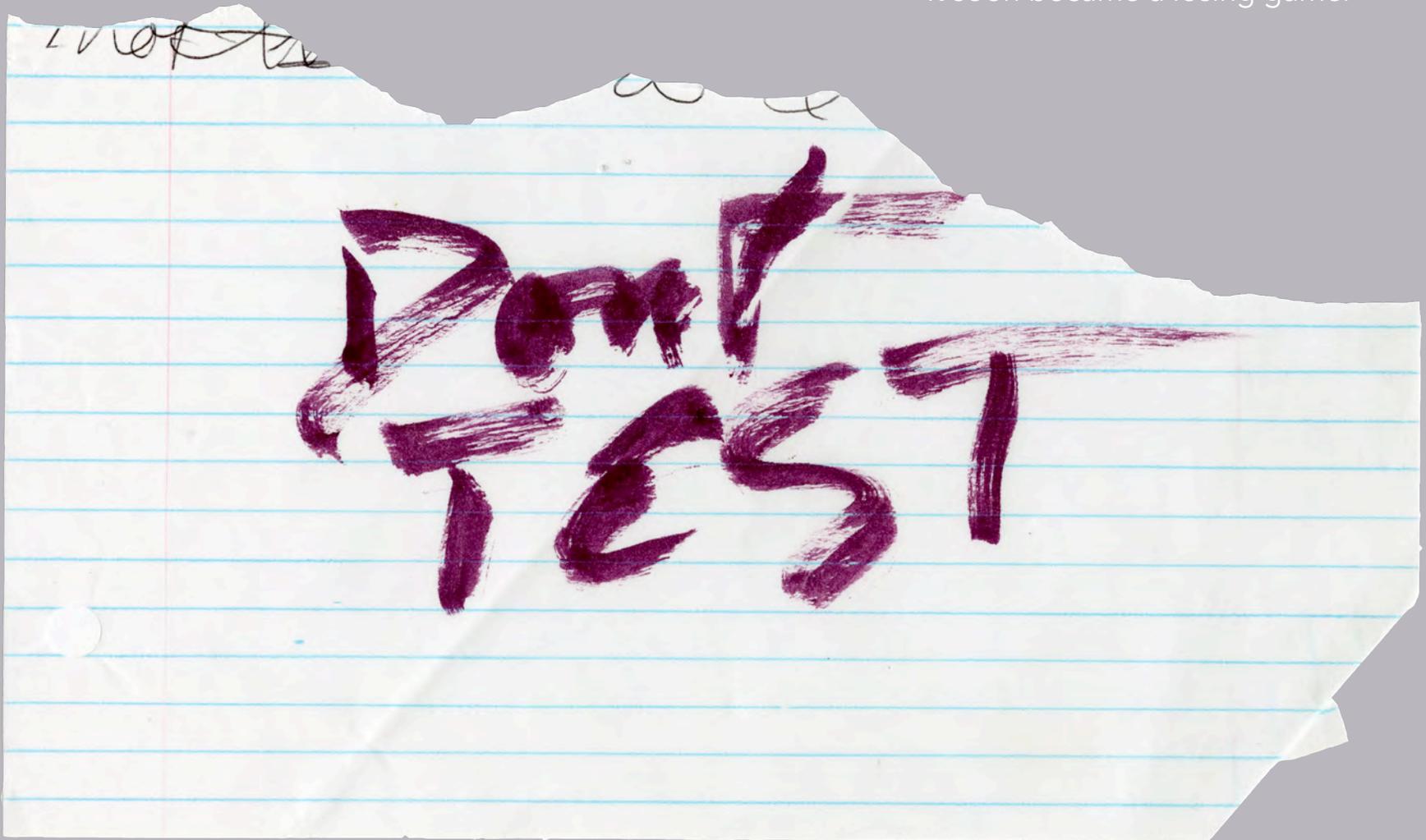
What I learned (really not soon enough): Put everything in writing, and get it signed. I was able to be "hands on" with bathing, eating, entertaining for quite a while but when that became impossible for me to handle alone I found even those things needed to be documented; when, what, how much, how often.





"They" say not to test but I found it hard to resist, when walking home, for example, to see if Jerry would remember where he lived.

It soon became a losing game.





YOU ARE

- PERFECT

+

I

ADORE

You

Joanné pao

RE: DONATO, Gerald  
MR#: 161703  
DATE: 01-15-02  
PAGE: 2

Because his wife, who is also a professor of art, has a fairly keen idea about this, she also is fairly and strongly convinced, and has convinced the patient, that his functioning memory, useful memory, active and working memory at this time are somewhat impaired.

.D.  
M.D.

NAME: DONATO, GERALD  
MR#: 161703  
DATE: 04/25/2003

I spent an hour today with Dr. Donato and his wife. We talked about his past history and their current concerns about his memory. We agreed in the past that he has attention-deficit disorder, increased distractibility, problems with keeping appointments and problems with faculty reports. He has missed meetings with members of his student group. He feels that he does have increased distractibility but he also says he has decreased interest in meeting all the demands, some of which he sees as a waste time. He does feel less depressed on L-tyrosine. His painting is ongoing. He seemed witty and active and traveled to Berlin last summer with his wife.

We talked again at length about the potential treatment of this disorder with stimulant medication that could include Provigil, Adderall and Ritalin, either long- or short-acting. He will return again for follow-up after we repeat his MRI of the brain. A functional testing with Dr. Ted Peck will also be useful as we attempt to delineate what portions of this are due to any additional findings of ADD with or without any new findings of either depression or early dementing illness. No reversible features have been identified at this point. Since last seeing Dr. Donato, he seems to show no change at all in his interactive personal features with me. However, his performance in the professional setting is diminished according to his wife who accompanied him for his entire visit.

RE: DONATO, GERALD  
DATE: 10/21/2003  
PAGE: 2

His reversibility factors at this point are felt to be very low. However, his wife is determined to do everything she can do, keeping an eye on such small details as diet and cholesterol. They will come and see me again in approximately six months unless new changes occur in the interim.

## “HIS WIFE HOWEVER...”

Doctors blew me off again and again, for years. Jerry would charm them, even intimidate some with his wicked wit. He was always willing—even eager—to go but then would ignore the advice he agreed to in the office. “No coffee,” said his primary care doc. She was so wrong, as studies would show, but I became enraged—finding him with his second Starbuck’s venti—my fears kicking me into high control mode. I tried to coerce him into running up and down hills on our lovely walks in Maymont Park and in the Fan District’s steep alleys—aerobics having been prescribed for brain health.

I begged doctors to consider what (other than “absentminded professor” syndrome) might be going on. Some seemed to think I had Munchausen by proxy or was just sort of crazy. I would give up until more daunting symptoms emerged—that like radio static—would clear, giving me hope, only to return again and again.

We ran into his new, handsome young doctor at Ellwood’s organic market. Jerry recognized him. I did not. “Who has the memory problems?” the doctor laughed. Embarrassed, I responded, ‘But our friends are saying...’ With a concerned look he said, “Your friends need more to think about.” Of course, he meant me.



## Composition Book

Name Interactivi

School writing

Grade \_\_\_\_\_

Wide Ruled

9 3/4 x 7 1/2 in. 100 Sheets  
(24.76 x 19.05 cm)



Dear Jerry will you play inter-  
active Journal with me? - by which  
I mean we write each other each day,  
in one sentence, the highs and  
lows of that day, for example,  
yesterday my low was feeling so  
low that I had ~~unlucky~~ ~~staying~~  
in Chile, looking for LAB corp. and  
I would like for the high to have  
been in my studio but due to a Qi  
deficiency I felt happier walking  
home in the lovely fall almost  
breath-like air and of course being  
and ending the day in your arms.

06/12/03

as I write this Joan is phone,  
talking to her mother. She is  
telling Maria about how bad  
she feels. I don't feel like doing  
a <sup>long</sup> work. Instead I will do a year  
in the year.

I wonder what the faces of this couple on their 30<sup>th</sup> wedding anniversary say to you - I wonder.

In my favorite fairy tale Rapunzel saves her prince - her tears heal his blind eyes when she finds him - but he has been searching for her too - they both are seekers.

I wish so much I could help you but the very idea that you need help insults ~~of~~ you - your memory problems are not real to you and maybe they are not real at all - It breaks my heart that you play games not with me but against me - the 7-11 napkin waved in my face - why? -

I have no idea of how at this point to continue this relationship - I will try

to relinquish what you perceive as control

If Dr. Harris had said there was no hope for you I would just love & care for you but I find myself bitter - angry - and ever more mean because there is hope for you to improve and when you hear from the doctor you seem interested in doing so -

I do not know if you want or you simply can not do even so much as re-arrange your bathroom - you fight me instead of taking my loving offers of help - you act emasculated you could re-masculate your self by taking charge of some things - like

getting the ADT system  
reconnected - -

But you can't or won't  
I know I just have  
to accept this & figure out  
how to continue - I hate  
myself in this relation-  
ship - I am mean - out  
of fear & frustration &  
I must stop -

I love you - truly  
& have to assume if you  
could help yourself &  
me you would -

I'm feeling deeply  
sad about this - but  
deeply happy about  
other things - Life goes  
on

Joan

Dear Joan. 12-19-03

It is very cozy here in our  
warm winter room. I am looking  
at you - with your big dick <sup>STAY</sup> on  
your lap.

Oh, so I have to write about the  
highs and lows of my day.

I have been turning the Christmas tree  
lights on on off several times today.  
More than likely these tree lights would  
not ~~burn~~ BURN.

I don't like what I have been writing,  
it is not interesting in any way!  
<sup>writing</sup> ~~writing~~ about not ~~being~~ <sup>about</sup>  
to write, is what I, am doing. I think  
it may be somewhat more interesting  
than other things I might write  
about!

How could  
I have been  
so clue blind?  
As if Jerry  
could even  
make a phone  
call at that  
time

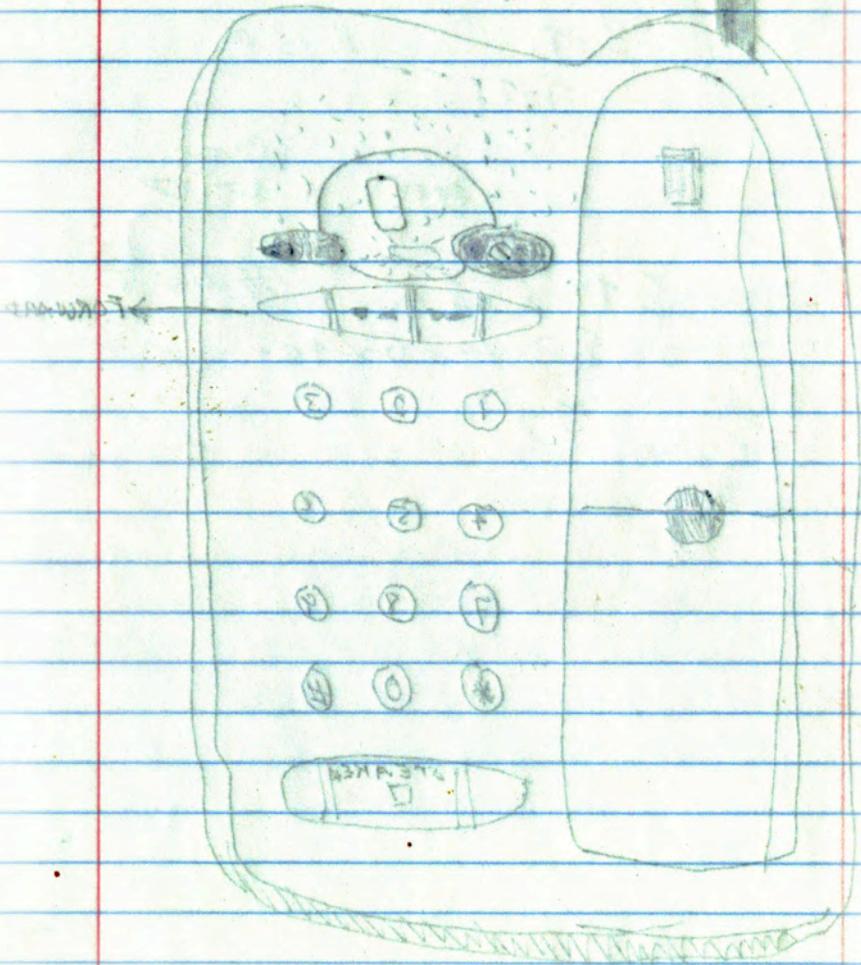
Words for Joan  
~~the words~~

Dear Joan, I am writing to  
to you. To you ~~again~~ I am  
enclosed.

It is getting very hot in this room.  
"Joan is ~~making~~ making noise  
with her mouth. But of course, since  
it is a noise coming from Joan,  
it is music.

Since I began these writing it has  
become cooler in the room - but not  
~~enough~~ in this room it ~~is~~ does  
not make much

PHONE BY DRAWING



I don't know what to write about.  
OK, I have got this pencil working, so  
it can write in such a way that one  
can read what has been written!  
The only problem is that I cannot  
recall what I was trying what I  
wanted to recall.

# META

The first inkling I had of what it would be like to be in Jerry's shoes, heart, disintegrating mind, was when I was driving back from the laminate supply place where I regularly rummaged for Formica scraps to paint on. It was right down Lombardy, a straight shot home and yet I suddenly found myself lost, shunted off to 95—which was terror territory to the inexperienced driver I still was. My META Volvo, sweet big buffalo of a car, scraped the cement barrier and my heart pounded.

Finding my way back, a bigger terror came over me.  
*'I have it too!'*

My next thought gave me the clearest insight into how Jerry must have felt.  
*'I don't want anyone to know!'*

The greatest fear: our friends and family, everyone will turn away, will deny us.



VA 1838670  
**OCT**

**VIRGINIA**

VA 6130995  
**06**

**META**



# EASTER

Friend Fredrika brought her grandbaby boy for Jerry's "joy rinsing," as the Chinese call it. He laid and played on the floor with the smiling child. We decorated Easter eggs to bring to the birthday lunch for Sharon, the kind wife of our art dean, who would someday carry Jerry's ashes.

The next day, grad student helper Vaughn came to be with Jerry on the premise of working in the garden together, but Jerry came out all dressed up for the party.

'Darling, this is an art girl thing, a lady lunch.' "Normally," in the past, he would have said, "I wouldn't want to talk about mini pads anyway!" but his heart visibly sank as if he'd been punched in the chest and his face clouded with barely-repressed tears.

"It's okay," he tried to say.

'Honey, Vaughn'—who he really liked—'really needs your help.'

No sale.

Whatever part of the brain that can help feign indifference to the tribal instinct that makes us fear being left out and abandoned was no longer available for Jerry.

MRIs show that the same areas light up when we feel excluded as when threatened by a killer tiger.



TALK LESS, BREATHE MORE  
TALK LESS, SAY MORE  
HATE LESS, LOVE MORE  
AND ALL GOOD THINGS ARE YOURS

GUIDE

September 2008

29 MAY

16 SATURDAY

SEPTEMBER 2006

Brownline  
2018

Daily Reminder

20

2017

MEDIA CAR

MCCO... JANUARY

# MEMORY–MINE

There is much new thinking about memory—about how experiences become distorted with time and are altered each time they are brought to mind. Still, as with all things human, we are each an experiment of one.

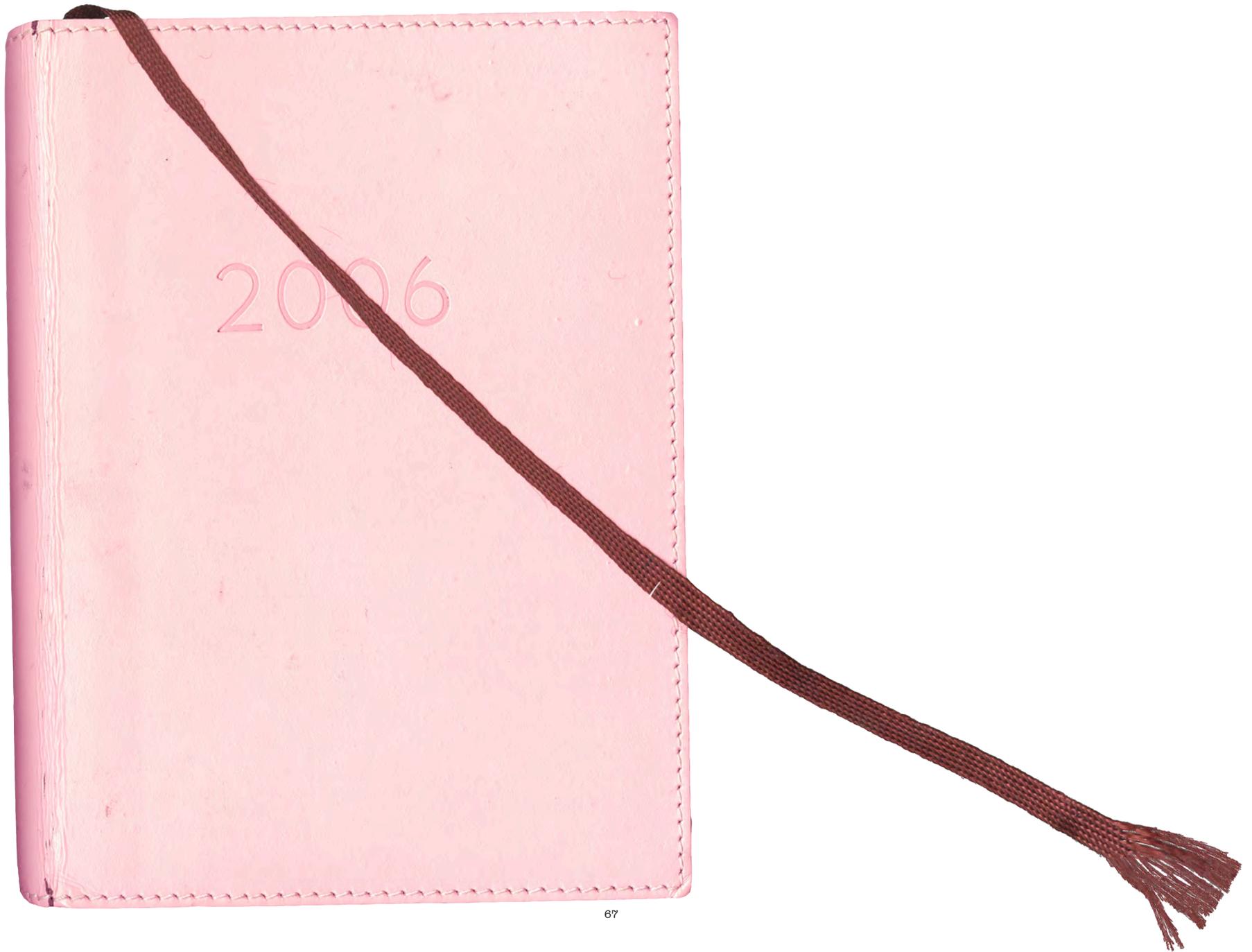
I have a curious and somewhat notorious memory, but like most people I often forget where I put my phone or whether I turned the sprinkler off. What stays are potent emotions and conversations. It freaks people out when I quote them verbatim—sometimes decades later. Maybe my solitary, silent studio life left space for words.

Once, in our pre-illness life, Jerry and I watched the newly released video of the Julie Christie movie, *Petulia*, which I had last seen as a teenager in Thailand, thirty years before. I started speaking the dialogue along with the characters. Jerry looked at me—“You’re scary.”

During “Our Great Adventure with Dementia” and for months after, I read and reread my diaries trying to find answers. How did we get here? Where did I fail? A snake eating its tail.

Years later, when I started this book, the stories poured out—almost exploded. After writing them down, I read the diaries as an afterthought, and the only surprise was what I’d left out—details I would have rather not remembered—but did.

And yet—Jerry helped me to remember and face things I’d spent my life wanting to forget.



New Year's Day

SUNDAY

8 This is it, the year of pure heart.  
 9 So many plans for this day - Park  
 friends, a Cupharia bath to gather.  
 but we laid low to gather instead.  
 10 I have confusion about how to  
 approach the year. My instinct is to  
 stay low, with Jerry and intense studies  
 and spiritual life. Meditate more.  
 Noon yoga classes & Perdue & Indian for  
 fun. But I fear isolation and would  
 love to be here again & stay connected  
 with the art life at school.  
 2 I think to take a computer class at  
 park - the thought distresses me.  
 3 He wants to be a part of this year  
 - desire - distresses me. And  
 4 now it feels time is short -  
 I think the work I did for  
 5 my show & the layers was  
 splendid & I want it to  
 6 be seen to exist in the  
 world - and yet - Jerry - So  
 7 Glad he is still here -  
 May be this will be the  
 year of healing & regaining  
 strength - } heaven }  
 JANUARY 2006 is here

MONDAY

8 The darkest of dark days w/ a call at  
 breakfast from P. - "Bad news" - beyond  
 9 bad beyond comprehending -  
 Kathy world of murder - her little  
 10 girls - her husband - murdered  
 New year's day - in their home -  
 11 We met Ashley - tears of sorrow & she  
 didn't know her - Jerry had robbed -  
 Noon he was her student & the prettiest girl  
 There is no making sense of it - little  
 1 girls 3 + 6 - It is lightning -  
 We went to help Cleo decorate  
 2 here but it was just meant to be me  
 but Jerry wanted to help - over eager  
 3 & broke ornaments - Cleo  
 was distressed & wanted to keep  
 4 them both happy -  
 I feel shattered - again & again.  
 5  
 6  
 7

Notes

S.I.E - was  
 I.L.I.S student  
 - all the same -  
 SORROW

2006

W	T	F	S
4	5	6	7
11	12	13	14
18	19	20	21
25	26	27	28

3

TUESDAY

8 The sensation of a tea cup filled  
 9 to the brim. The slightest jolt &  
 10 the tears pour out. Another dark  
 11 day, the picture of the precious  
 12 murdered children on the front  
 13 page - beyond enduring - comprehending  
 14 and Jerry's - doc - We try -  
 15 to have hope - Statins & more  
 16 wine that & more love & laughter  
 17 will not be grim - fructose  
 18 yoga - it is falling into place.  
 19 Paul M. called about  
 20 getting to gather in NY -  
 21 And Sara - for yoga -  
 22 And Ashley is a gift -  
 23 the universe just sent me -  
 24 Thank you - all these  
 25 dear people Phyllis & Dr  
 26 Mary - this morning  
 27 + Mary too - Sally  
 28 her way - Mary H -  
 29 Blessings all

ll

Notes

JANUARY 2006

4

WEDNESDAY

Jerry's beauty  
 kindness  
 loving  
 humor -  
 Moma - letter

This pretty little book should be filled w/  
 joyous thoughts - so look for them. We did  
 not go to the memorial service for Kathy & her  
 family. I don't know if it was regret but I felt  
 10 we are on grief overload - I spoke to Amy  
 Moore field about J's show - and we are late  
 11 on the studio script but she seemed ok about  
 that. She lives 5 houses from Kathy so  
 12 she is rocked by that.

Noon

Is it regret to have this show w/ J's  
 1 health unpredictable? Talk to Ashley -  
 2 It will be a beautiful show good for the  
 3 students. Maybe J. could be better or no  
 4 worse. It seems it will be ok if no  
 5 new work emerges - Ask Ashley -  
 6 We stayed in to day - accept a walk - I still  
 7 control - "No out door shoes" - when  
 8 he can't really even understand - Jeeze  
 9 I want to stop - "Don't put Jerry  
 10 on the records" - I will have a day  
 11 w/out one controlling comment - There  
 12 is a lot of sweetness and love -  
 13 but I know the controlling frustrates &  
 14 hurts J & even to day.

January

2006

Notes

angerd him for which  
 he apologized when on  
 the one at fault. I will  
 get better -

S	M	T	W	T	F	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

16

SATURDAY

8 Returned from Maya Tulum.  
9 infused w beauty -  
a transfusion  
of beauty

Noon

1

2

4

6

7

Notes

SEPTEMBER 2006

9, 18, 2006

So much beauty, splendor here at  
Maya Tulum and yet the setting is lovely  
The yoga teacher Susan & her friend Paul  
& Barbara are all fine friends. Jose  
has been deaf & disoriented when  
in the car. I am so patient until  
I am not & then I am childish &  
mean - enumerating complaints  
with my logic to a bewildered  
person whose perception is  
beyond my comprehension but  
his feelings are not -

with me w-y-



G.M.D.  
8.2.58

# MEXICO

4:30 AM

'Honey, we have to get up now.'

"Why? It's dark out," Jerry groggily replied.

'We're going to Mexico.'

"Why? Why are we going to Mexico?"

'I'm sorry.'

And all the raining way to the airport and all the way to Cancun, I did feel sorry that I had not canceled when the friend who suggested this yoga trip could not go with us.

And I anguished about my bewildered Jerry all the way to Tulum, where at the water's edge, the rush of beauty cleared the haze of his day and his days.

Still, it was a challenge. We would walk out of our little hut into the sand and he would say, "Get the car. Let's go home now."

Yet, in our netted bed he remembered how to be a lover and in the shower, looking out over the weed-filled sea, he slipped down my body like lather.

He had body memory of yoga too, oddly mirroring the teacher—which seemed far harder than following—and on dance day he ignored the salsa instructor to spin we three yoginis in complicated turns that left us laughing and mystified.

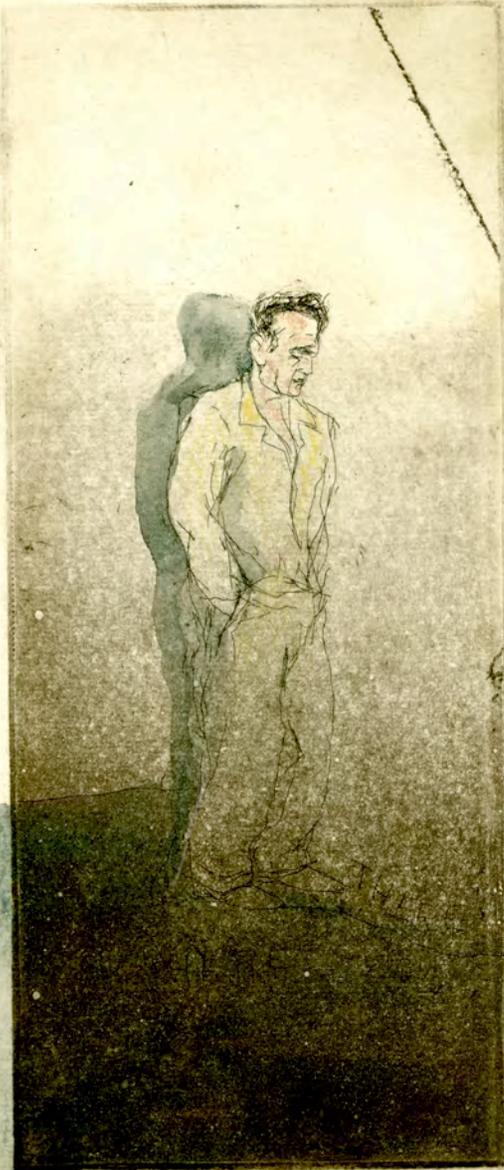
# THE VIOLENCE

The crazy aggression started in Jerry's fifties with driving. His road rage on the short trips from Starbucks to our studios (veering in front of oncoming trucks and buses) mystified and infuriated me. He had always been a dancer-like driver but now, on the way to visit my parents, he angrily aimed our old Volvo at a speed demon cutting in front of us. I became hysterical. 'I will never ride with you again!'

His rage at me seemed random. One morning Jerry was upset because he did not want to go on our friend's birthday tubing excursion, and was claiming bad weather as an excuse. Leaving for my speed walk, as he returned from his, I said in passing, 'Looks like a nice day.' He lurched at me—"Fuck you man!!!"—and I ran. His reaction to my contradicting him was out of control.

When Jerry turned sixty and the illness became undeniable, I was often frightened by unpredictable outbursts. The aggression toward me finally turned physical several years later when he was in care at Windsor Assisted Living. We were out back on a lovely evening with his old friend David Freed. Jerry pointed to the sky. "I love to show things." Suddenly, his delighted smile was stricken and I knew he had lost control of his bowels.

The aide—a young man from Ghana who believed Obama would be the next Jesus but that Sarah Palin was "very pretty!"—ran the shower while I tried to help Jerry undress. Understandably distressed, he looked at me with fury and grabbed my stick wrists. He could have easily snapped them but in that moment, I did not feel fear. I looked back into his beautiful burning eyes and he melted. "Why am I like this?" My head dropped and rested against his heart. 'I'm so sorry.'



FRIED  
GARY HERE + THERE

Wm. Dress

# THE BRAIN

# THE BRAIN

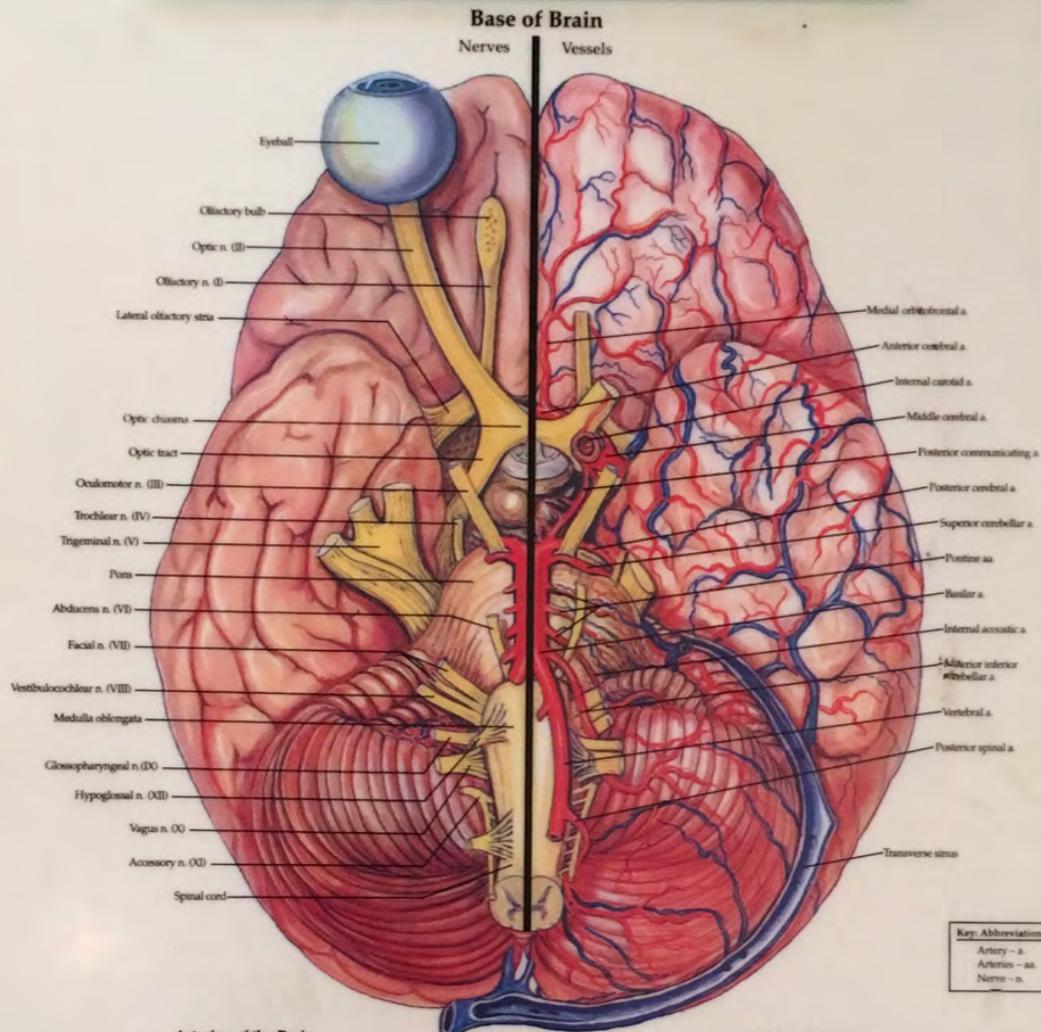
"Take this Yellow Pages directory, Mr. Donato, and find a steak house."

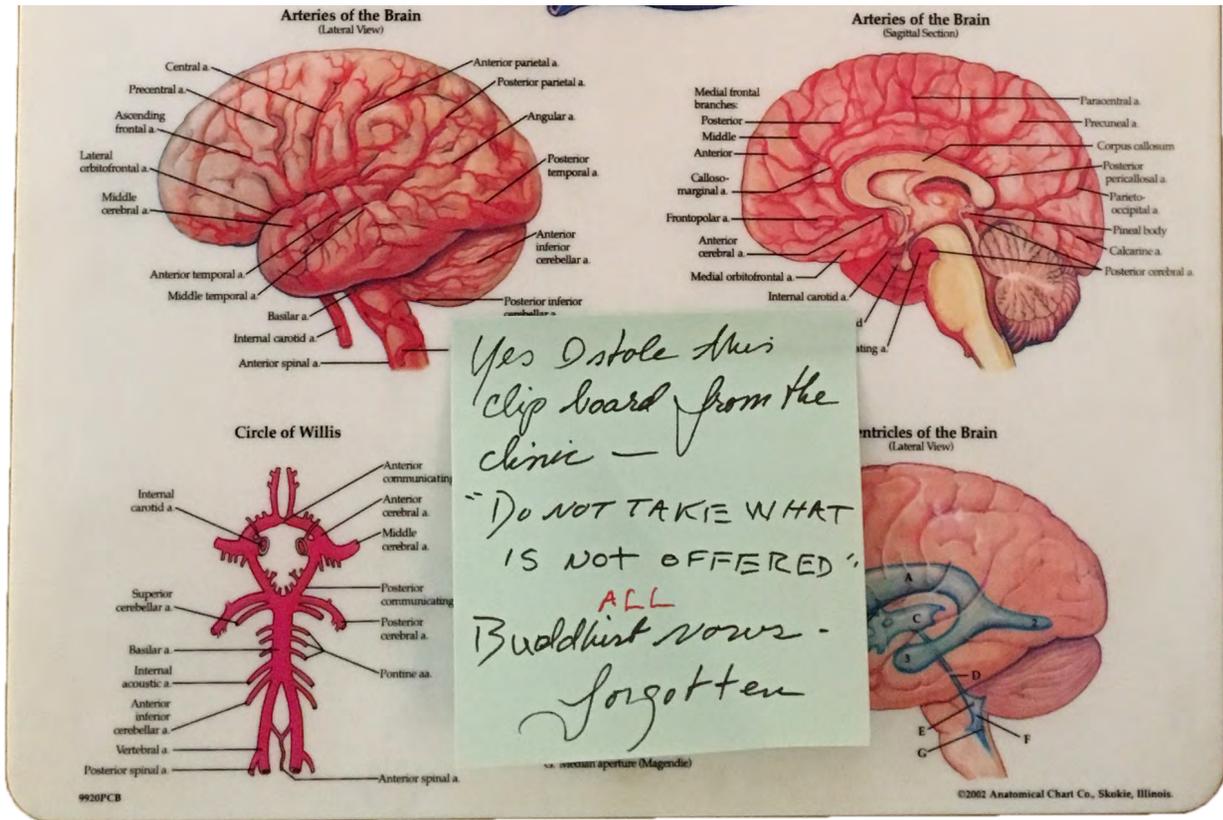
"I don't eat meat," my cagey darling evades.

I leave Jerry in the Brain Damage Clinic, with its anti-child-soccer posters, to read for my art theory class in the neutral atmosphere of Starbucks.

Nietzsche, take me. "We love to look at beauty because we long to be beautiful ourselves...because we think it will make us happy...and it won't."\*

Why does this make me bark with unstoppable laughter? Head down, hiding behind hair, I reluctantly slink back.





The sober young tester looks at me darkly and shakes her pretty head.  
 'But he knew "homunculus,"' I plead...

\*This "quote" is likely misremembered.



# TORN PHOTOS

I found the photograph of Jerry with Cat at the beach, arms around each other, under the bathroom sink, ripped to bits. He could not remember how it happened and she would not tell.

I was sure something had distressed him because of the time he was helplessly angry with me for not getting out of the tub where I lay flat in exhaustion.

"Get out! Get out!"

'Please Jere, let me rest a bit.'

"It's not fair!"

He put on an assortment of our hats, jackets and sweaters in the wrong order and told me he was leaving. I knew he would not go because it was storming and he had come to fear rain. He returned to the bathroom as I pulled my wet hair from the water.

"I miss my family," he said, his voice weighted with sadness.

On our bed I found the torn photo of his young self. Was this how he felt? In pieces...

Months later, at Windsor, I arrived to find him sitting, his head hanging, a sheet of paper in his lap.

'How are you my Jerry?'

He picked up the page and tore it.

"Like this..."



## EARLY ONSET SUPPORT GROUP

The first time we encountered the “Early Onset Support Group” was in a freight elevator at the Virginia Museum of Fine Arts. I had resisted joining in the misguided fear that we would see our future, not knowing that the group was also “Early Stage” and that we were deeper into the illness than most of the members.

When I broke down and called I was told about an upcoming excursion. The Museum of Modern Art in New York was developing a program for people with dementia to interact with images. They were sending a Persian poet with thirteen published books and a gift for connecting whatever part of a brain remained with beauty. Perfect!

As we entered the VMFA elevator with what appeared to be the support group, I looked around and tried to guess who was the “care partner” and who was cared for. Hard to discern the more disoriented, disheveled, distraught. (“You have to have a brain for two people,” a grandchild had said to one member. ‘And a body,’ I thought—bathe two, dress two, feed two—neither sleep.)

Ease came to me in that ride, no need to cover up, to protect, or hide.

Jerry was not happy, however. “No!” He did not want to be led. Art was still his domain. He was the dark-eyed charmer. Still when we took seats in the portrait gallery he fell under the spell of the painting and took joy in showing, five words at a time, what his heart still knew and loved.



# FIRE

Jerry's upcoming retrospective gave us both heart. The day before his work was to be photographed for the catalogue, I was upstairs in my studio bathroom and glanced out the window. Two lank-haired young guys were sitting, their backs to me, feet in the weeds, on the little deck between our building and the empty house next door. It was odd because of the eight-foot fence and locked gate. Odder still was what they were doing. Washing needles, it seemed, a lot of them. Deep breath. I called the police, hoping Jerry, down in his studio, wouldn't hear. An hour later they encountered the fellows on the street, informing them that I had informed on them.

That evening I found the side deck smoldering. Failed arson? I called the still-not-interested police to please keep an eye on the building overnight and lay awake wondering, worrying, is it on fire, the art in flames? No show. Jerry slept in innocence and was totally on for the shoot the next morning, playing *Sympathy for the Devil* on his turntable, dancing joyously with me and his paintings.

Later in the day while Jerry was being photographed at the gallery, I was on the studio roof with workmen. Exhausted and unthinking, I let Poochini take a flying leap over the edge. Instead of pulling him up by his halter I stupidly eased him down with his expando leash into the fenced, charred side yard. I went to unlock the gate and realized I didn't have the key. Heart racing, I raced home to get it, hoping no needles were sticking my little pup's chocolate chip paw pads.

Next, take the mess of taxes to the post office. 'I'm doing this... I'm doing this...' my mantra.

I lamely ask the clerk 'Do they count the due date by the post mark?'

She wearily, coldly responds, "I have no idea."

'I'm not doing this, I'm not...'

Looking down to write, my vision is blurred by a flood of tears too long held in check. I feel the warmth of a hand on my shoulder. The clerk had come around. The kindness. It saved me. Her life was likely harder than mine.

# THE CRIME

"You seem to think you always have to tell the truth!" said my incredulous Chicago-bred Jerry early on. 'Yes!' It wasn't out of bone-deep decency like my "Duty, honor, country" father. I needed accuracy. "Truth in packaging."

But once the deceit started—'I have to go to physical therapy,' the only lie Jerry would buy, again and again, when I needed to get away—it spiraled out of control.

Where did it begin—the biggest most horrid lie, doubted even by a damaged brain?

After his retrospective, which was like an Indian summer—heart and soul rewarming—it was harder and harder to get Jerry back into his world and bring his world to him.

"What have I done wrong?"

"Where is everybody?"

His poignant "Where are they!?" became ever more intense and angry.

'Darling, are you lonely?'

"I miss my students."

Our valiant little band of helpers, painter girl Cat, sculpture girl Macon and music guy Nate, who worked hard to keep the joy, were wearing thin. I told Jerry's adored Macon/Bacon, 'If he gets crazy, run or lock yourself in the bathroom, even if you think he is in danger. The real Jerry would be devastated to have hurt you.' "The same is true for you," she truthfully replied.

Nate (who I did not yet realize was the shaman musician Gull) spoke for them; "We can't do this anymore and neither can you." I tried for daycare and was high on hope, which I was coming to realize was asking for hurt. It was so nice. We liked everyone and of course they loved my darling, but they didn't know the whole story; the "bathroom issues" and the violence issues. Sadly, not for us.

HEARD  
BRAND  
FIELDS

Then one lovely, sun-setting-down-Monument Avenue-evening, we happened on an assisted living dwelling with a sign that said "Memory Care". I took Jerry and Poochini in to inquire for my elderly father. Just half a lie. We were shown suites with enchanting views of pre-graffitied Lee to the east and the fairytale lights of the "Sauer's Seasonings" sign on Broad. The curly wrought iron balustrades put us in mind of Paris. I went to bed smiling and called to book the next day even though Long Term Care would not kick in for months. Ten thousand bucks, who cared!





The kids were all in and painted the bathroom the same bright coral we had at home, although somehow here it looked a bit horribly pink. We moved in Jerry's giant drawing table, our guest bed, all of Mousey Cat's things, plants, the record player and big paintings and stocked the kitchen with drinks and snacks. We all went daily. Jerry and I ate in the dining room sitting with the other "breakaway bracelet" folks and got to know everyone.

And then the lie—I won't blame Cat—I hate myself and you will hate me too.

'Jerry, this is your emeritus suite, a great honor.'

Demented but not stupid, he asked, "Why are there nurses here?"

I've blanked on whatever awful bullshit I made up in response to his still-sensitive BS detector.

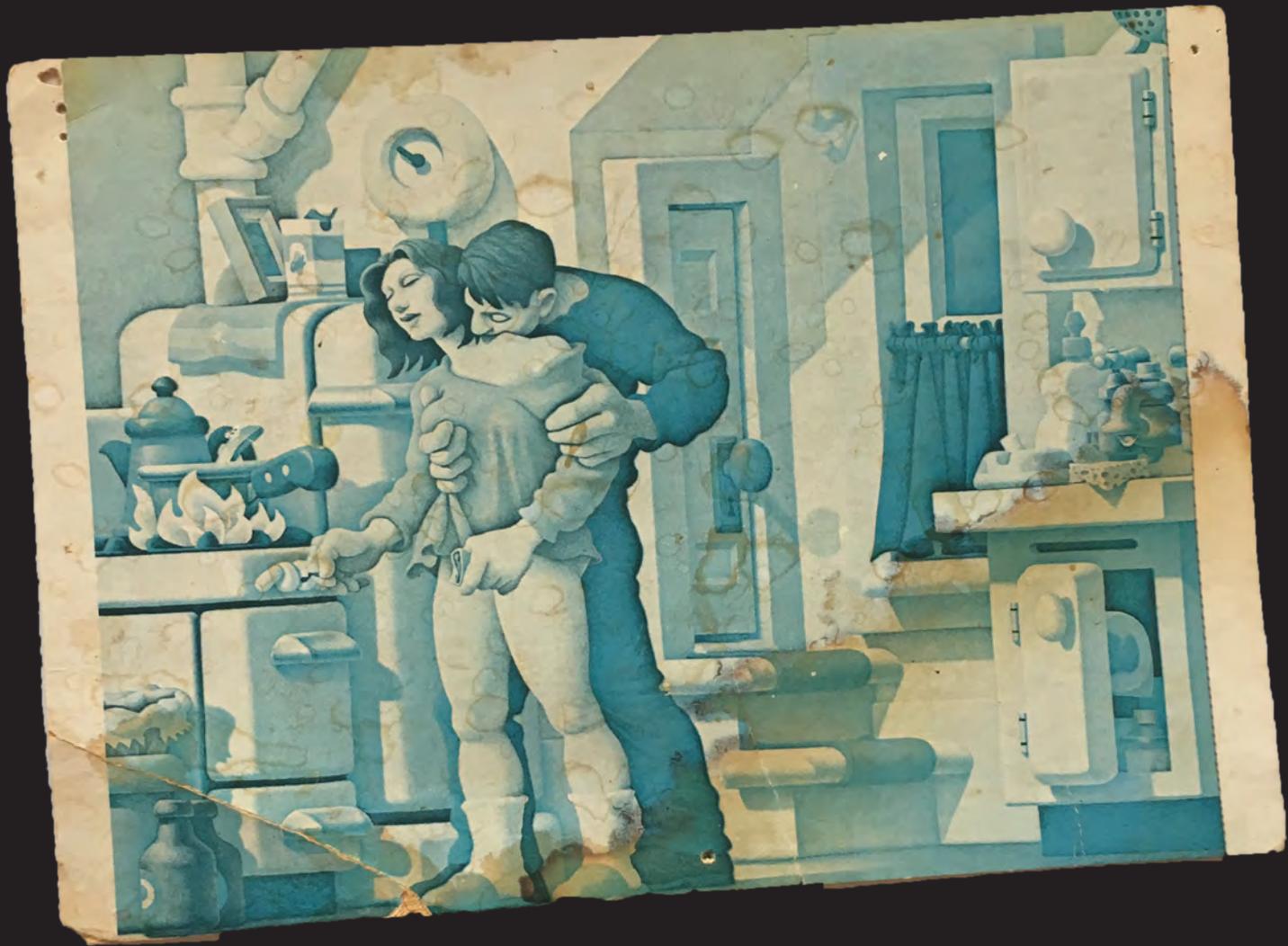
*Move-in day, leaving the home he no longer recognized as his own from outside or in—*

*As we closed the door for the last time I thought I heard him say, "It's the end."*

*'What did you say?' I asked.*

*"Nothing," he sadly responded.*

*Yes. Nothing.*



## ESCAPE

What I will never understand—and the diary doesn't help—is why I didn't stay with him. I would be out late with Poochini, walking, weeping, having left Jerry watching a Marvin Gaye special in the movie room. He had looked at me with sad confusion then back at the screen as I slipped away. I was sobbing with longing. Why didn't I just go back?

2 Friday  
Vendredi  
Freitag  
Venerdì  
Viernes

May 2008  
Mai • Mai • Maggio • Mayo  
week 18

..... F • Holocaust Remembrance Day

I have not wanted to write Torrow -

This morning as I walked over I feared Jerry anger or sadness - but he just gave me a sweet smile - Still he was so druggy drug - stumbling + ravenous -

I came back + 3:30 + more so I stayed long to feed + walk + bathe him because the new nurse was clueless - kept telling about him - even when he would say to her

"Who are you talking about!?" + I told her very strongly to speak to him -

Then she would talk to him like he is deaf - She made it much too hard to leave -

+ Jerry I look like Hell - Really - w/epiphora  
Nate even said "Look like I hadn't slept in a week"

May 2008  
Mai • Mai • Maggio • Mayo  
week 18

Saturday 3  
Samedi  
Samstag  
Sabato  
Sábado

..... F

Things seemed to be going well I spent 5 hrs + then came back to find I gone from the room door open up + down the flights. Fire alarm goes off - running calling "Jerry" Jerry! Jerry! Find him in the lobby after looking off the fire escape for a body on the ground - held him + sobbed + out for a walk as the fire engine roared up - returning to find the fire had pulled

May 2008 the alarm  
Mai • Mai • Maggio • Mayo  
week 18

Sunday 4  
Dimanche  
Sonntag  
Domenica  
Domingo

..... F

J + I are like the bad children of assisted living. They want me to go + I stay they want him to stay + he goes + We are making friends - It is like being on a ship - were all in it together  
7 hrs + 2

Slipping away in the bad part. for us both -

lie to



The common notion at that time, maybe still, was that the brain-ill person should be left in the new environment for two weeks without family contact to establish a new life. I thought: 'They know the illness, I know Jerry.' I was there all day, breakfast, lunch and dinner, and for our morning walks which his meds had reduced to a still-pleasurable shuffle.

Still, if I want to torture myself and apparently I did and do, I remember the night that the night aide tried to lure Jerry back up the steps as I was leaving. "You don't understand," he told her. "We have a bond." Yes. He knew that. And I? I kept going, weeping uncontrollably, as I do now and as the aide called after me, "Be with him. Be with him."

*Why, why, why? I will never understand. So much would have been different if I stayed.*

The next morning Jerry was sweet and easy, smiling and greeting the men on stoops as we walked down Grace Street, somewhat new territory for us, and through lunch with our new friends. It put me in mind of being on a ship, somehow separated from the life around us, in a not unpleasing way. Safe. I thought I had done the right thing by some crazy standard of this crazy new life. Then the director called me in with a horror story to tell, of Jerry raging through the halls, throwing an aide against the wall. She would be in the hospital for ten days, he said. We weren't being thrown out. The director seemed oddly passive. Was it the money?

I found out that Jerry had been given Haldol even though I had told the DON how that drug turned him into the Hulk during a hospital brain drain, causing him to rip the bloodily hard-won needle from his spine and throw me across the room. Later I asked the doctor—who I would come to despise—how they could have made such a mistake. “Luckily it wasn't you,” was his useless response. ‘I doubt the aide and her family feel that way,’ I barely say.

I have no memory of that night but the next day was new. I asked around about the aide. No one knew who it might have been. I began to wishfully doubt the director's story and it was garden day! All residents and staff were dressed to plant and rake and fill the birdfeeders outside the dining room windows. We worked together all morning, those with little memory digging deep into their histories. Jere had not enjoyed taking orders from his factory-worker father in their urban vegetable patch but here he seemed entranced. I was moved to see him go on his own to rest on a bench with his tablemates and grateful that they accepted him. It's true, high school never ends.

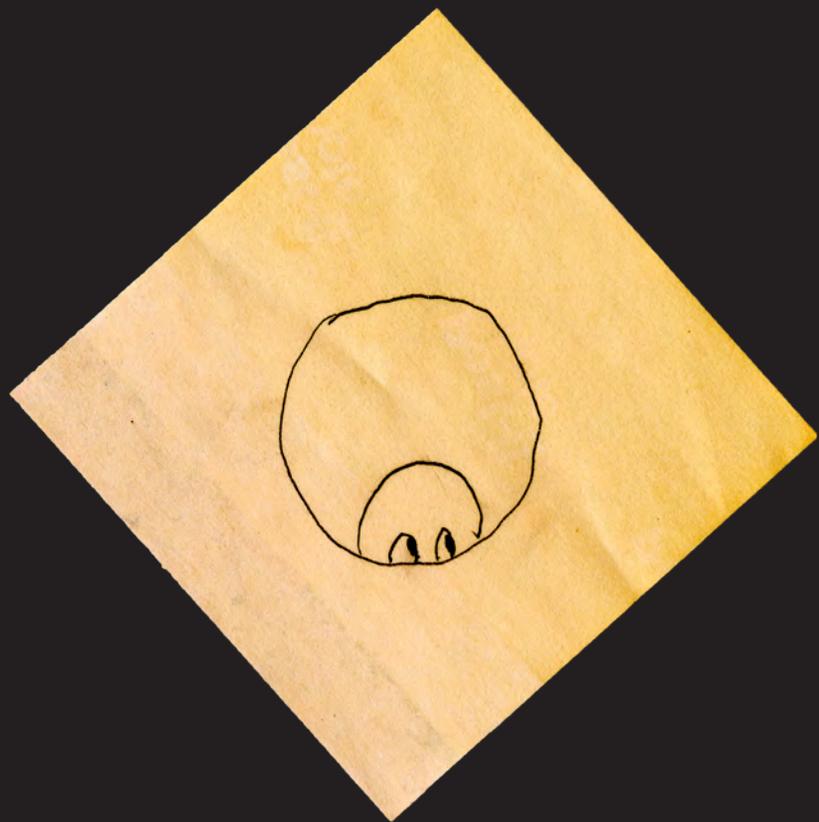


'This is working!' I told friend Ashley, who would soon be standing with me for three hours in the ER. I had just finished paying the bills that had been diverted to the studio so Jere could not disappear them while he was still at home. Then in the car, where they would remain until way past due, I flipped open my phone to a frantic message:

"Jerry escaped!" He had been seized by police on the VCU campus and taken to the MCV hospital.

Racing down Broad Street, I grabbed the ringing phone: "Not MCV! Mechanicsville!" I howled helplessly, no idea how to get there, terrified of the terror he must be feeling, knowing he would fight with all his powerful drugged-down might and be harmed. Lost on the way to I didn't-know-where, another call:

"Not Mechanicsville–MCV!"



## 9 NORTH

“Are you his mother?” asked the aide pushing Jerry’s litter from the emergency room where I had hidden with my unconscious husband since early morning. A kind heart had slipped me in after a too-long night of not knowing where or how he was. Through a maze of locked doors we came to a grim ward, a curtained-off room with a chair and bed. I called my dear friend Sally to bring my migraine meds. She showed up (how did she ever find us?) with the new *Artforum*—so dear yet so completely not comprehending, I thought—as she slipped it between the heavy doors to me.

Jerry woke, not questioning the questionable surroundings, and jumped right into the magazine, familiar territory. A nurse right out of central casting, a former art student, impossibly pretty, joined him and I left, sure I was hallucinating as they flipped by the infamous Lynda Benglis dildo photograph. Later Dr. Paul told me Dr. Sara had come by to check on Jerry and laughed at his beautiful girl karma even here in Hell.

I brought him a stack of art books and his catalogue, which he would lug around like Log Lady, bare-legged in his barely tied hospital gown. “Why am I carrying this shit?” Six words! ‘Because it’s you, Mr. Man,’ I thought.

While we waited for our advising team to advise, Jerry and I rocked the “lockdown.” “Nice dress dude!” Jerry teased an especially scary-looking inmate as we strolled the halls. Dr. Sara was amazed at my comfort with patients hanging on me as we talked. (In high school I had worked with brain-challenged adults—“retarded” as was said at that time—and I spent a second year of first grade in the scary-basement “Slow Class,” so I had a natural rapport.)





One day Jerry pointed to an incoming patient with a turtleneck up to her eyes and a hoodie covering her hair. "Isn't that...?" "Yes!" He could see what I could not. It was our friend's Paris-model daughter. She and her mother had made the Mr. Man cake for Jerry's retirement blowout and would later design the wacky, wonderful program for his memorial wing-ding.

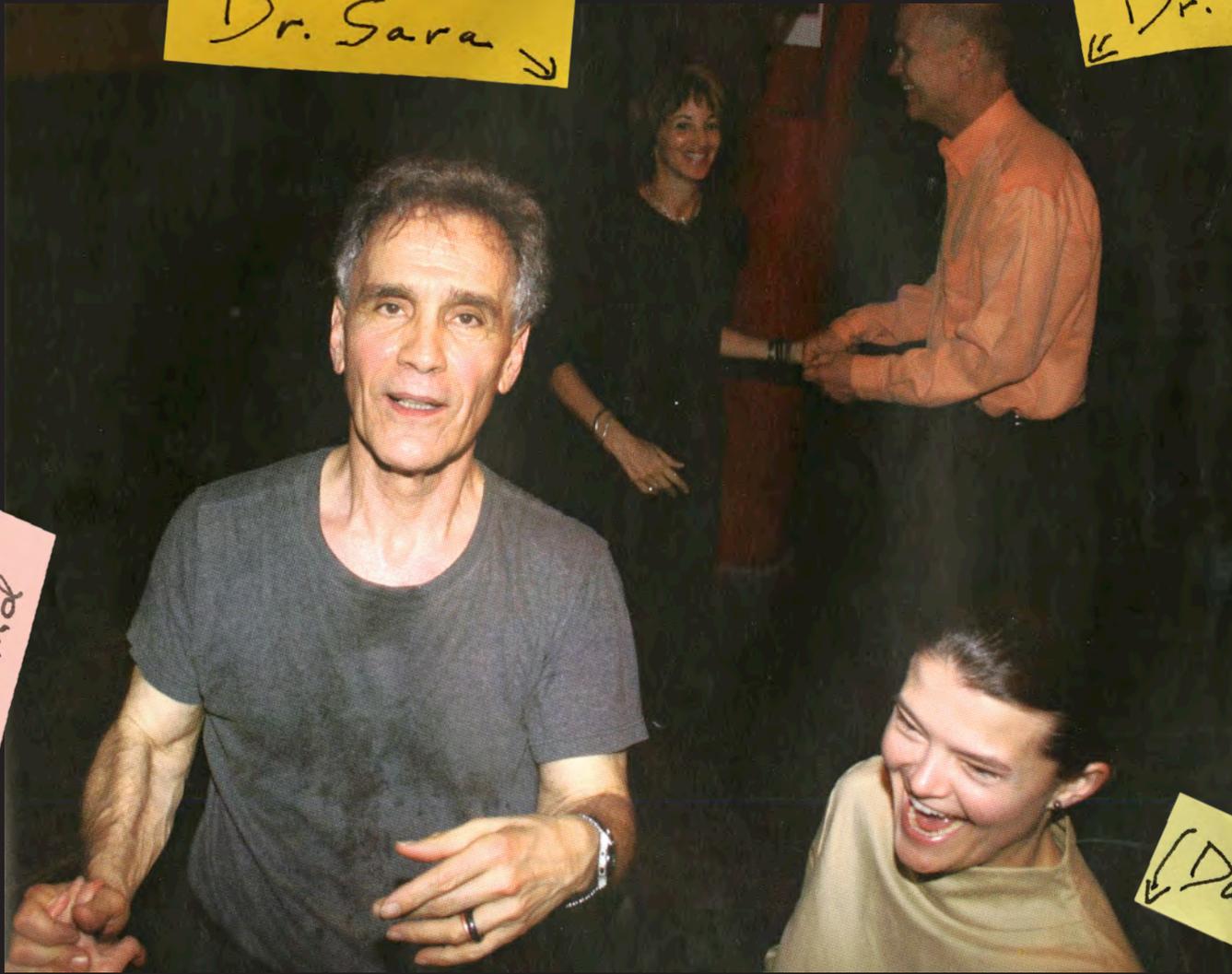
On May 20th, our anniversary, I brought a giant Jean Jacques Black Forest cake to the activity room for us to celebrate with our fellow inmates. Jerry proudly served, "A piece for you!" "A piece for me!" as if he were the happy birthday boy while competing dosages of Haldol were happily discussed by our new gown-attired friends.

A nurse arrived just after clean-up; "Happy Anniversary!" "I'm sorry you missed the cake," I smiled. Jerry was outraged. "Why didn't you tell me it was our anniversary?!" "And why didn't I get any cake?" (I realize reading this—did I notice it then?—that he was capable of more than five words, as new drugs took effect.)

I had convinced myself, as I so often did, that Jerry's escape and brutal capture was actually a good thing and that we would get the right medication and the perfect place, but a week went by with no action. A nurse whispered, "You are with the wrong team." The new team seemed to know the illness but had no grasp of or interest in the patient. The head doctor made me stay away. "We can't assess him with your fun and games." "Joan! Don't leave me here!" I crumpled in the hall and called Dr. Sara. "I know this is brutal, but he won't remember," she consoled.

In the surreal days I spent looking for a place for us—for Jerry—blue-rinsed hair and flowered wallpaper prevailed. One facility was like a theme park: a Harem Room, a Cowboy Room—beyond bizarre—no residents as yet, no surprise.

*Finally, the call—the perfect place—in Ashland! 'I don't want to be so far from him,' I protest. 'If it's the right place you won't need to be there,' is the cold response. 'We want to be together,' I say, and this time I don't have to obey.*



Dr. Sara →

← Dr. Paul

← wife hand

↓ Dance Student

# DANCING

'I've always asked myself, "In Jerry's situation, what would I want?"' I tell Christina as she kindly drives me to the no-longer-heartening farmer's market, 'But now I just don't know.'

"To be shot," she sadly responds.

Wincing, I take the hit.

Later that day I look at Jerry's euphoric face as he spins me to Big Band music in the fussy living room of Windsor, our new not-home, and think 'If she could see the joy he still has and brings...!' Then my eyes stray to a young family; the mother, in a wheelchair, is stunningly beautiful and shockingly thin. I point her out to Jere as we always like to share beauty. "No!" he reacts. Too thin even for Mr. Anorexia by proxy.

Then I see the two teenage girls and a boy about ten, and remember my veterinarian's story about her friend whose husband left her when she was pregnant with their last child, ten years ago. And now, after a boyfriend left as well, the friend had fallen down the stairs, hitting her head on the corner of a table, leaving her paralyzed from the chest down. This must be her. Them.

We spoke in the courtyard, where she smoked and despaired. She had come here hoping to stay with her ancient aunt but was not welcome. This facility could not serve her extreme incapacity. Soon she was gone. How long after that did the vet tell me that she had been placed in a nursing home—where she refused to eat? Her parents tried to intervene but the children supported her and she died.

I felt grateful that Jerry, with all his physical- and pharma-induced losses, still had the deep pleasure of movement. At his retirement party the year before, the "art kids" were kind of in awe of his dancing. Me too. The kinetic music was new to him and I looked around to see where he might be picking up the new moves. Just Jerry—his very cells knew how to party down.





# DOCTORS

## The unsympathetic geriatric specialist:

"You need to save yourself. This will kill you before it kills him. I've seen it again and again." A walk talk down the hall as he slides his hand under my jacket. ('Is this okay?'—I almost wonder—so the least of my problems.)

In the examining room, he icily asks, "Mr. Donato, how is your artwork going?" Seeing Jere at the edge of a sinkhole of sorrow that I fear he is about to fall into, I start to intervene, but he brightens. Looking at a stack of shallow drawers, "Well you see" he says, pointing at one after the other, "you have this guy—and this guy—and this guy—" all the way to the top, then sitting back, smiles proudly. I, equally pleased, say 'Jerry you are still so brilliant!'

The doctor's face sucks in, in disapproval. The young intern's face goes soft. (Jerry's Obama pin and the fact that he had voted "write in" when he could not write was cause for further doctor displeasure.)

Our next appointment is canceled. Office closed. "Inappropriate behavior with a patient." A bit mindboggling for a geriatric doc, but no time to think, just move. (At least three doctors, including the self-described "Voodoo Doc"—not to mention our financial advisor—were creepily familiar, some in the extreme. Is this a thing? Are wives of dementia patients somehow fair game?)



### The sympathetic geriatric specialist:

In the waiting room where we have been for over an hour, our friend, dear Dr. Sara, appears, as always, as if by intuition. Jerry, overly delighted to see her, does not want the newspaper to cover his excitement. Snickering sounds surround us. "What can we do?" she laughs. 'Snickers!' I say. 'Please, run and get a bag to distract him.'

Dr. Boling is respectful of Mr. Donato and smiles at the way I talk to Jerry, rather than about him. 'Should we tell the doctor about your dizzy spells and falling, darling?'—'Was it about five times last week?'—'Remember we wanted to ask about stopping the Aricept?'

On the drive back to the facility—that had failed to come through with promised transport—Jerry kept undoing his seatbelt and opening the car door. As we moved through city traffic, I grabbed the mini Snickers from the back, threw the bag in his lap, reached across, pulled the car door closed and kept going. The adrenaline from the hope that this new doctor would be our savior had me in full throttle.

The image shows a medical form with several handwritten annotations. At the top left is a logo of a brain. A yellow sticky tab is attached to the top with the text: "What is up w/ this date? Did the Doc have Brain issues too?". The form has fields for NAME and ADDRESS, both filled with "To whom it may concern". The DATE is "11/6/06". The main body of the form contains the text: "Mr. Donato, Gerald, will benefit from voting assistance on 11/7/06. He has neurologic disabilities". At the bottom right, an orange sticky tab says "2006?!". The form also includes checkboxes for "LABEL AS TO CONTENTS", "Dispense As Written", "Voluntary Formulary Permitted", and "Refill Monthly Only". A small box at the bottom right contains the text "Signature of Presc". At the very bottom, a small asterisked note reads: "\*If neither box is marked, a Voluntary Formulary product must be dispensed.\*"



*The Presidential Inaugural Committee*

*requests the honor of your presence*

*to attend and participate*

*in the*

*Inauguration of*

*Barack H. Obama*

*as President of the United States of America*

*and*

*Joseph R. Biden, Jr.*

*as Vice President of the United States of America*

*on Tuesday, the twentieth of January*

*two thousand and nine*

*in the City of Washington*

# INAUGURATION DAY

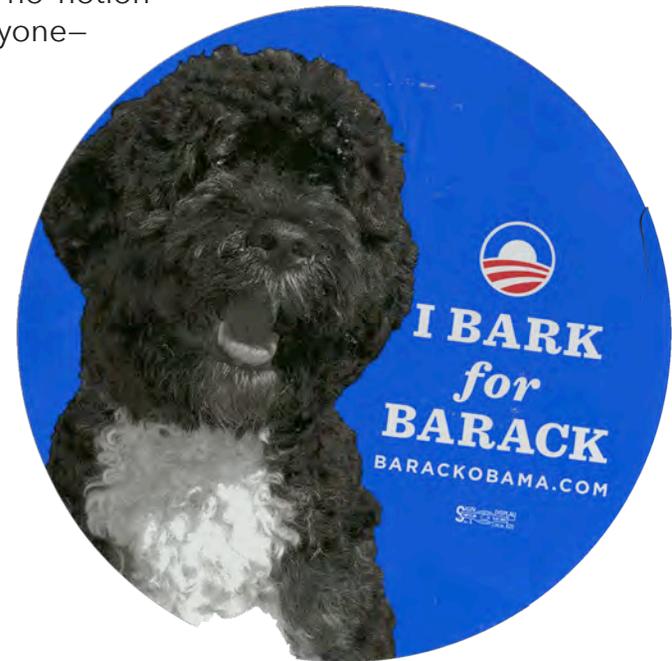
At Windsor, Jere had an Obama banner across his body and was beaming. I was weeping, as the always-beaming Rhoda's daughter did, because her mother—who had been a serious civil rights activist—had no notion as to why we were all—residents, families, aides, staff, everyone—gathered in the sunroom.

Just at the big moment of oath-taking, Jerry, who had been “literally” in love with Barack since we saw him speak at a Virginia Union rally years before (and had somehow received an embossed invitation to the inauguration), said he needed to go to the bathroom.

'Okay, of course. Pee or poop?'  
"Pee."  
'Good!'

We unzip, nothing, then a sudden look of happy satisfaction.  
'Oh no.'  
I look, to see falling from his pant leg...  
'At least they're firm...'  
Small victories!

Rejoining the celebration, Rhoda's daughter, who I often think of as her mother, laughs and says without knowing and yet totally knowing, “What we go through.” I laugh too. The room is radiating with oxytocin. Nothing can cloud it.



# BLOOD

My constant walking, waking fury was not at the illness but the indifference and ignorance that caused suffering to so many in these facilities, especially when, as so often happens, they change hands and always, wallpaper.

When our second place was bought out for the second time, I tried to have hope and dressed up to meet an actual doctor on staff, an elegant yet somehow sleazy gentleman who came from a country that the shawl arranged on my shoulders put him in mind of. He wanted to talk about conjugal visits. Did we want a lock? No. We did not.

In spite of not being internet interested or savvy, I went home and looked this fellow up. Just a feeling. OMG! He and his wife had been in prison for blood bank crimes. They had taken blood from emaciated, pregnant and HIV-positive donors. The new owners seemed shocked. "How did you find this?" Inept or just indifferent?

Still this place was close by and small enough for me to keep a close eye, unlike the expensive giants like "Our Ho of Hopelessness" or "The Bunker," which were said to have rampant theft of the residents' meds and rocking, waking staff parties in the wee hours. My friend Chris wondered why his father said he had to sleep on his good ear. What could be so noisy?

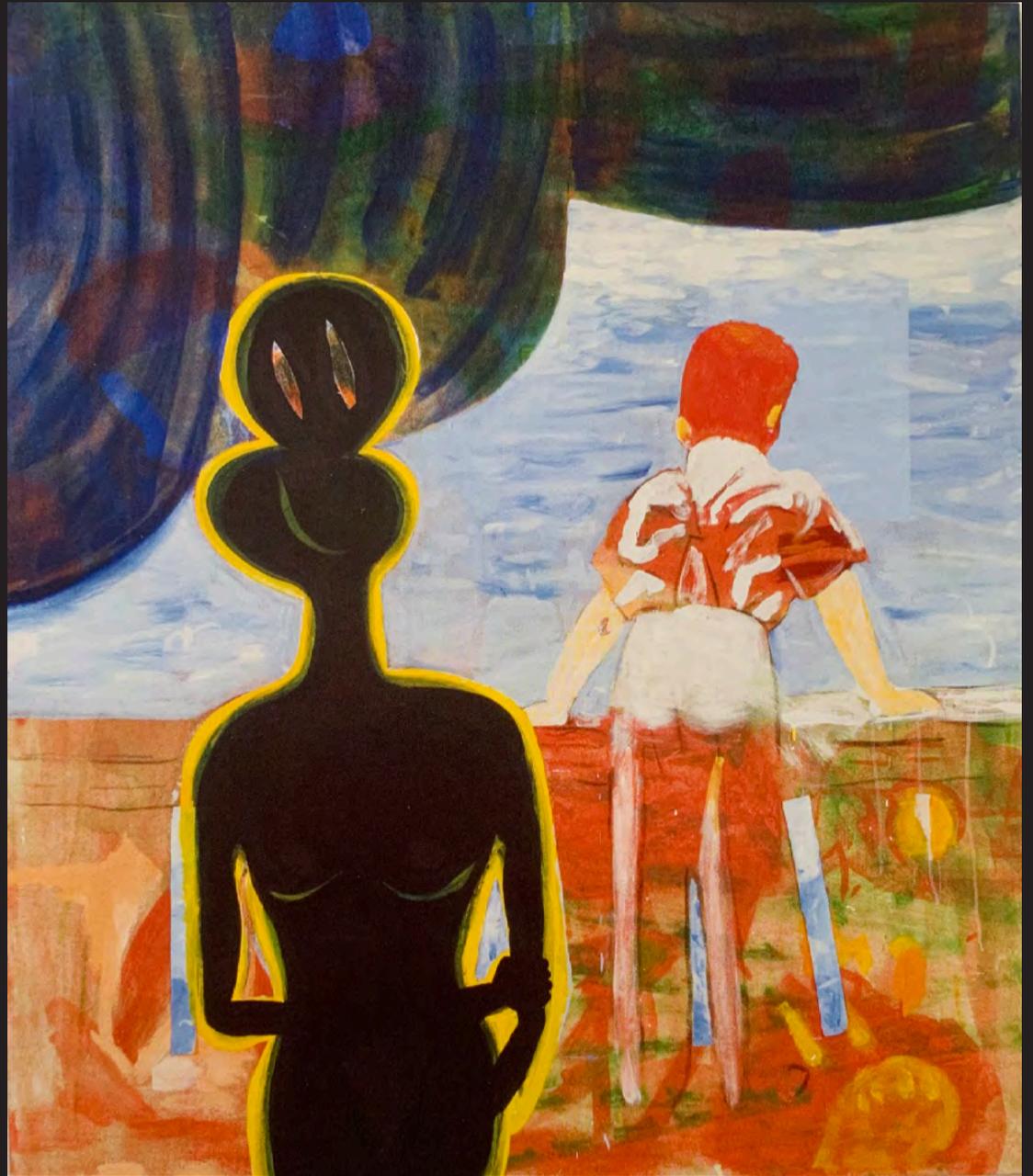
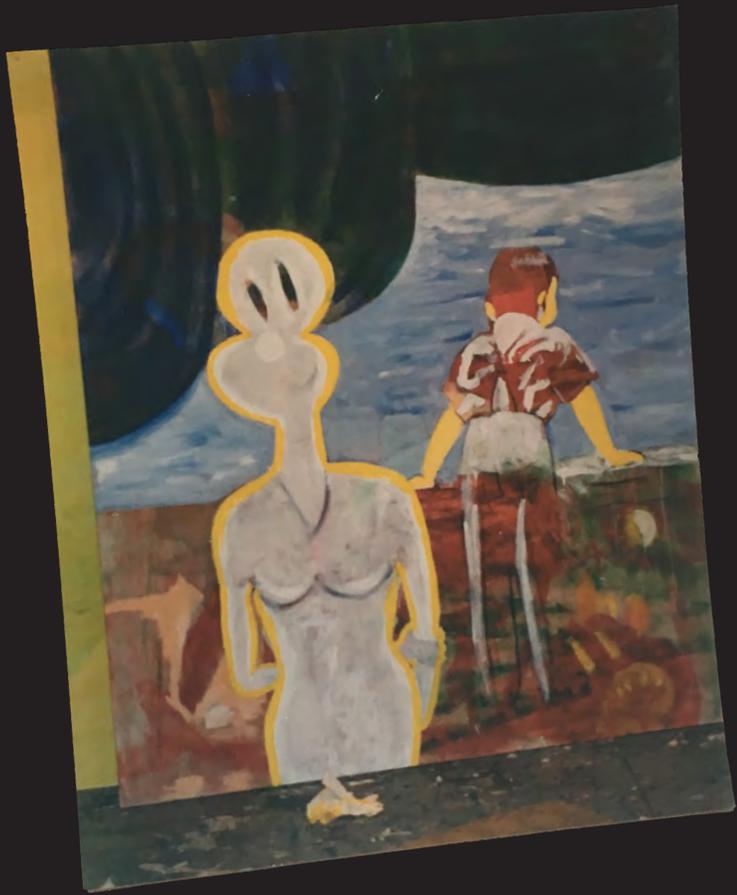
Our wonderful hospice group was also bought out by—it is not an exaggeration to say—monsters. Would humans happily profit from the suffering of the defenseless? I fired them in a fiery rage and was led to a lovely group by the staff of the third and last facility, where part of the attraction was that it had been in the same hands for fifteen years. Yes, you guessed it. Sold as soon as we moved in. I told the new director, slumped down in his chair, of complaints I had heard from the aides. "I don't know what's wrong with these people," he responded. No longer tiptoeing, with little left to lose, I bitterly bitingly say, 'Maybe it has something to do with their McDonald's-worker's wages.' He sat up and seemed to see.

Months later—in a new life without facilities or my husband—I left yoga class in tears because a charlie horse put me in mind and body of how freaked Jerry would be in the night, even before the illness, if he was afflicted. I would rub his shin and calm him. 'It's only pain. You're okay.' Who was there to ease him in the nights away from me? Across the parking lot I saw the director waving. He had been to the Donato memorial, he told me, having been intrigued by the paintings in Jerry's room.

"You are lucky your husband left so much of himself in the world."

*Yes, I was lucky. But what about Jerry?*





*Now I know that you stayed in Main Street where the cherry trees we planted survived 40 years of truck bashing and still shower pink blossoms. You talk to the child we never quite had and she and her parents, artists the same ages we were when we first moved in, are happy to have you.*

*I took the catalogue for your new show and Misha—new puppy, ghost-finder—to your studio. To look through the book at the paintings you made there was magical, just as you are always.*



# FUCKING TREE

Myron, Jerry's oldest friend and sometimes fierce competitor—until there was no competition—was now most loyal. He offered to come to the second facility, where I had agreed—as I had disastrously refused to do in the first —*'They know the illness, I know Jerry'*—to stay away for the first two weeks. I called Myron's cell and he picked up in the "Memory Care" courtyard.

'How is he?' I plead.

"Fuckin' ecstatic," Myron deadpans.

How hard it must have been to see his five-years-younger, brilliant fellow artist locked in prettily-wallpapered rooms with ancient residents. But he did it, again and again, every week.

Jere and I came to love walking around Windsor in all weather, taking pleasure in the jet-lined sky shows and the giant magnifying mirror meant for cars to see around the corner. Our distorted reflections were always a new amazement and amusement for him and I couldn't help but laugh too, every time.

The upside-down trees in the parking lot puddles were a source of wonder and he would become mesmerized by a fallen branch under the ancient firs out front, removing and rearranging the bark with deep absorption and satisfaction. Oblivious to cars driving by—in his own world—an artist still.

We lure Myron,

'Come see our favorite tree.'

"I hate fuckin' trees!"

'Well we have a FUCKING TREE for you and you will love it!'



TRIM

1 2 3 4

## HAVE YOU EVER WONDERED

Have you ever wondered, watching an old couple walking hand in hand, how many people know the last time they make love to their beloved that it is the last?

I had to know it was coming for us and yet it was never a clear ending. We loved and longed for each other always and held tight until Jerry's last breath and after.

When we were in the second "Home," with its ancient dear and demented inhabitants, we'd dance in the halls to Muddy Waters and Son House. My still-so-handsome husband would laugh and ask, "Have we ever had sex?"

Once, I came in with Poochini, carrying provisions, and heard the aides giggling. "How long have you two been married?" "Oh no Jere! Put it back! I'm so sorry. Does he do this often?" "Only for you—true love."

We'd pet like teenagers on a bench in the courtyard, hiding under his *New York Times* or a blanket in winter and sneak into the display room, in the not-"Memory Care" side of our not-home, to curl up together on the queen-sized bed.

But when I look back in the journals trying to find the last heart-melting-into-heart true love making, I come up against too many of the heart-blowing, mind-breaking stories that made up our lives as we tried to hold on to our sweet normal.



# SHOOT

Jerry's damaged mind could read mine. "You love me," he would smile, when I was thinking just that.

One evening at Windsor, I found him feeling low so I took him to his room to play records. Attempting to sit, he carefully placed one knee and then the other on his chair.

Unable to help him, I felt terror of where this illness was taking us and thought, 'I'm going to get a gun...' But when the image of ending our lives blasted too vividly into my mind I knew I couldn't do it.

An aide came to help turn Jerry and get him seated. I put on the Mamas and Papas and he pitched forward onto the bed. I tucked a pillow under his head and lay down with my head next to his. We dozed. A sudden sharp sound in the music startled him and he shot up.

"Joan Joan! Where are you?"

'I'm here.'

"Don't shoot me."

'I won't...I won't shoot us.'

At home I sat stunned on a stool in my new makeshift studio and tried to comprehend what had happened.





# MOMENTS

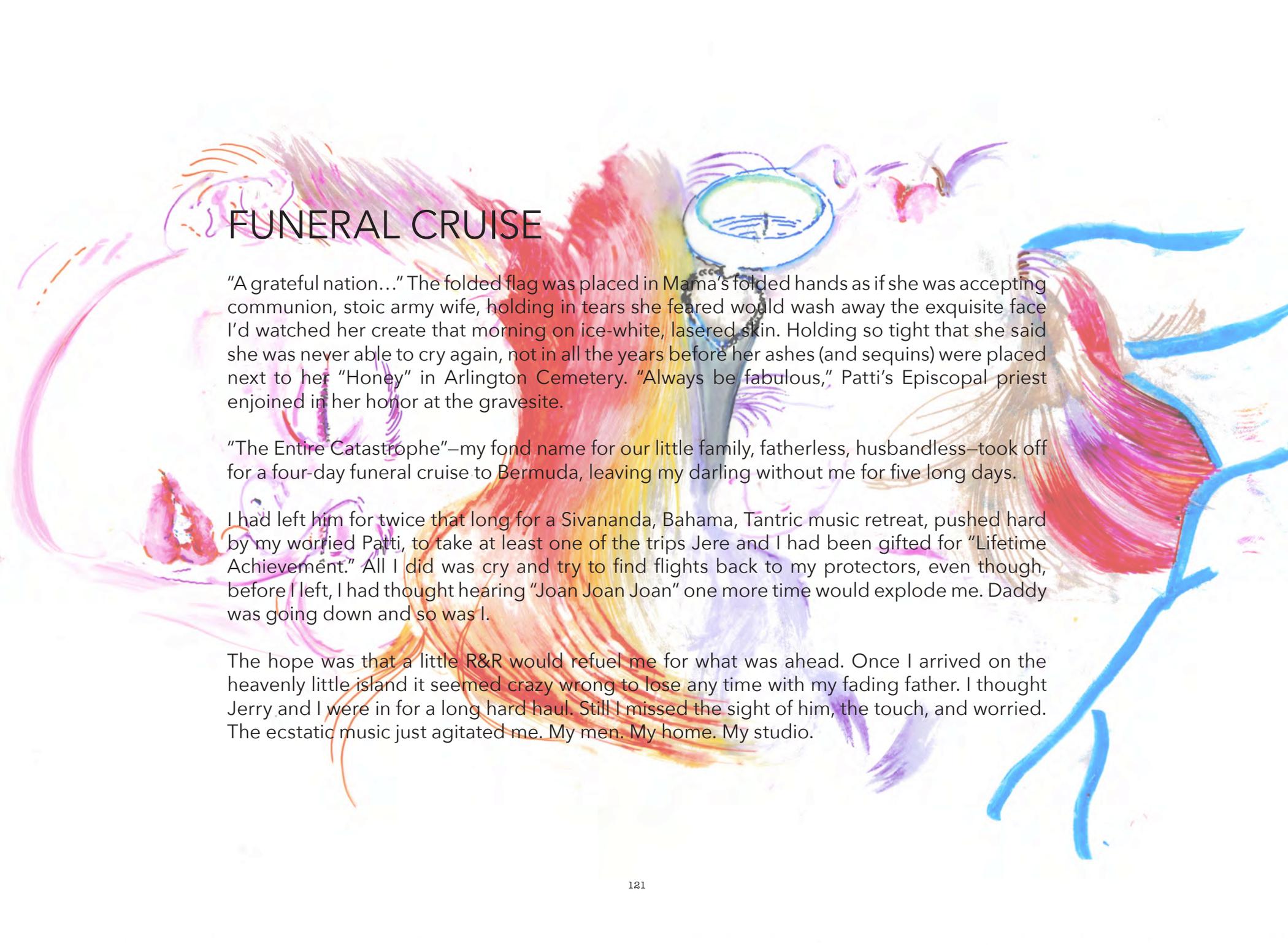
There are moments that bring us so intensely into the present that the big scary picture dissolves into the here and now.

Our last New Year's Eve together—the first: fireworks in Frankfurt, where you came for me almost forty years ago—I was sitting in your lap as we looked out into the snowing night at a red cardinal on the birdfeeder I brought for our Memory Care courtyard.

'Do you know who I am?' I ask.  
"My marry," you answer.

Then the gift of a new moon, a Mr. Man smile in the sky.

'Make a wish!' I say.  
"You," you say.



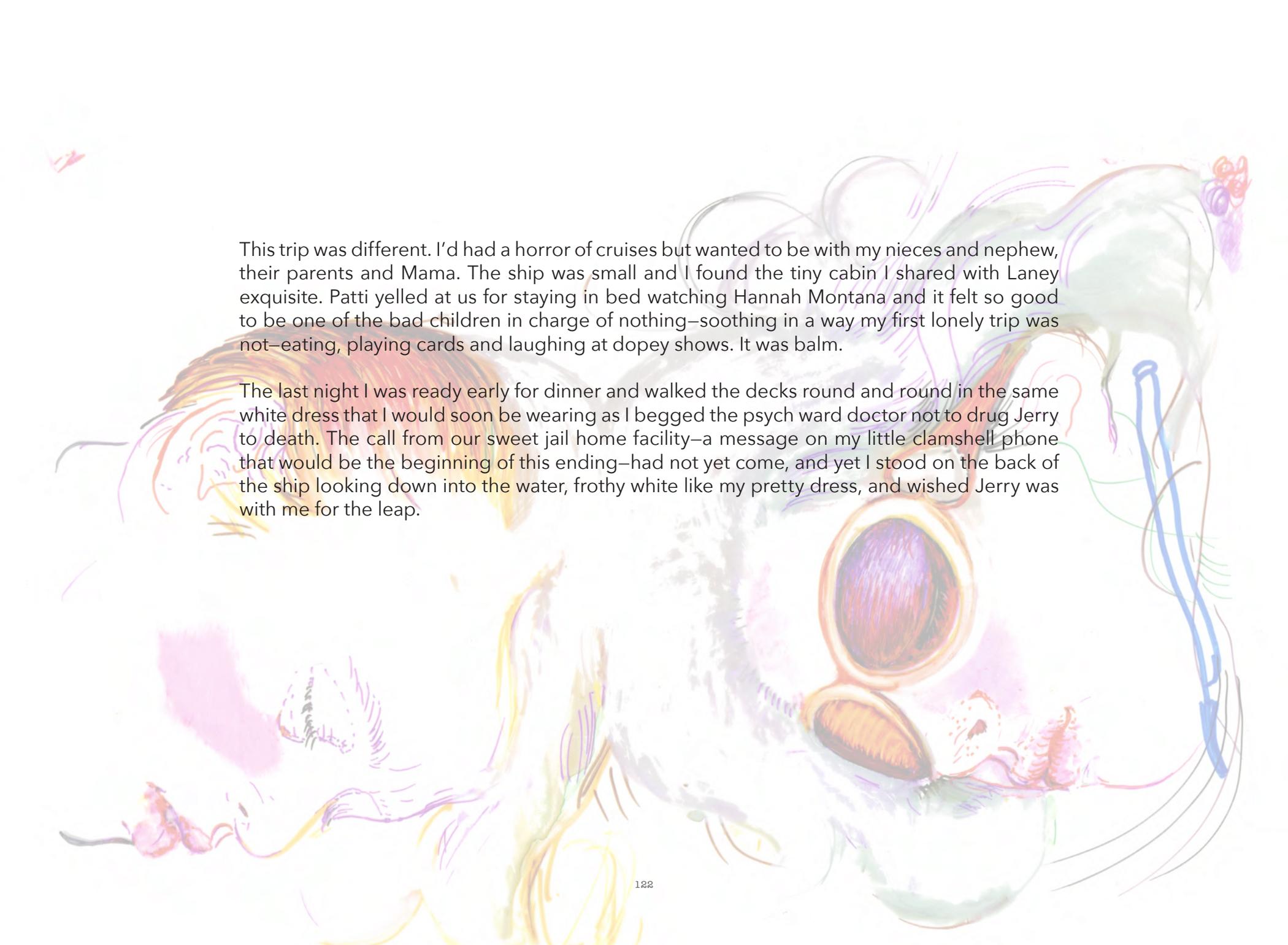
## FUNERAL CRUISE

"A grateful nation..." The folded flag was placed in Mama's folded hands as if she was accepting communion, stoic army wife, holding in tears she feared would wash away the exquisite face I'd watched her create that morning on ice-white, lasered skin. Holding so tight that she said she was never able to cry again, not in all the years before her ashes (and sequins) were placed next to her "Honey" in Arlington Cemetery. "Always be fabulous," Patti's Episcopal priest enjoined in her honor at the gravesite.

"The Entire Catastrophe"—my fond name for our little family, fatherless, husbandless—took off for a four-day funeral cruise to Bermuda, leaving my darling without me for five long days.

I had left him for twice that long for a Sivananda, Bahama, Tantric music retreat, pushed hard by my worried Patti, to take at least one of the trips Jere and I had been gifted for "Lifetime Achievement." All I did was cry and try to find flights back to my protectors, even though, before I left, I had thought hearing "Joan Joan Joan" one more time would explode me. Daddy was going down and so was I.

The hope was that a little R&R would refuel me for what was ahead. Once I arrived on the heavenly little island it seemed crazy wrong to lose any time with my fading father. I thought Jerry and I were in for a long hard haul. Still I missed the sight of him, the touch, and worried. The ecstatic music just agitated me. My men. My home. My studio.



This trip was different. I'd had a horror of cruises but wanted to be with my nieces and nephew, their parents and Mama. The ship was small and I found the tiny cabin I shared with Laney exquisite. Patti yelled at us for staying in bed watching Hannah Montana and it felt so good to be one of the bad children in charge of nothing—soothing in a way my first lonely trip was not—eating, playing cards and laughing at dopey shows. It was balm.

The last night I was ready early for dinner and walked the decks round and round in the same white dress that I would soon be wearing as I begged the psych ward doctor not to drug Jerry to death. The call from our sweet jail home facility—a message on my little clamshell phone that would be the beginning of this ending—had not yet come, and yet I stood on the back of the ship looking down into the water, frothy white like my pretty dress, and wished Jerry was with me for the leap.



poorefield

Gerald Donato: Reinventing the Game

VCUarts Anderson Gallery



## F.E.A.R.

As one by one all of the many things I thought were my reasons for loving Jerry were lost to us, my feelings for him, my awe of him, only grew more intense.

My most treasured image of his face at its most beautiful was when he picked up the tips of my tailbone-touching hair, ratty long from neglect, and held them to his lips—the sweetest smile and eyes that looked into mine with complete connection.

We were behind Windsor, the walk we always took—always new to Jerry—laughing as always at our distorted reflections in the huge car warning mirror on a chain-link fence separating us from the highway below.

This day was the beginning of the end and I knew it.  
F.E.A.R. “False Evidence Appearing Real.”  
The most bullshit aphorism ever.

Jerry had socked his aide again and we were out.  
Back to the psych ward and this time I could find no “upside,” just as Joan Didion told her doctor she failed to see in the sudden death of her husband, and that my counselor repeatedly failed to convince me was not always to be found.

That evening, waiting for a bed to free up at 9 North, I took my sorry self to a champagne celebration, toasting the acquisition of the Donato thirteen-foot masterpiece *Beach* (or *Butt*, as Jerry always called his painting of a giant fleshy dune) by our local art collector royalty, newly engaged, she so tall and lovely in all white. The ring, he said, was “not ostentatious, but to scale.”

“Joan, do you want to say anything?”  
Shaking my head ‘No,’ I savored the expressions of admiration and pleasure this artist and art still had the power to give.

From this sparkling dream, a dark descent.

We got the call to come but no transport. Sally took that grim duty and brought us to the ward where she had slipped the *Artforum* through locked doors a year and a half before. It had changed from the place where a therapy Parti poodle cruised halls full of people. The “activity” room was inactivated, the aquarium empty, the piano shoved into a corner, no books or games.

The room Jerry was given had wire mesh covering the windows, dimming the sky. The top of the bathroom door was sliced at an angle to prevent suicide by hanging, I was told.



Truption  
sunday 30 august in the my

35th week  
242-123

This is a major struggle & confusion. W/ Jerry at MCV early found him "out" & out in the hall w/ his head on the bed. Back in the room we got him cleaned up and I was able to get some liquid & food into him - yogurt & an apple. We can see the shyness now I curled up w/ him & rested. it was sweet. I said "It is late August, we are on a boat drifting. I could get few words from him (he did call "Jean") when the nurse turned him). I said "Jerry what can I do for you? Please tell me." He tried to pull my shirt up so I untucked it & he put his hands tenderly & hungrily - I loved it. Love him - as I was leaving to meet John & Chris B to move out of W. I thought as I looked across the room at Jerry "With all my heart I love you" - So I went to him & said it and he delighted - so I said it again & again -

AUGUST 2009

M	Tu	W	Th	F	Sa	S
		3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

u my head feels like it is going to  
Monday 31 August  
turned red in <sup>DB</sup> 100A

SEPTEMBER 2009

M	Tu	W	Th	F	Sa	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

36th week  
243-122  
Up early & out to MCV to meet Lakhan's team. When they came in I was putting a cool cloth on Jerry's head. He was having his first headache in my memory. I tried to talk to the Sultan (Dr L.) about side effects he blew up. "We agreed on this from day one!" I don't think there any way else we could try - "No! there is not enough brain left to work with!" Brutal. Lynmore accepted us maybe there w/ Dr Boley we can adjust - I swept on Jerry's chest & when he was out. He put his hands gently on my head "Poor poor poor" and when I said "With all my heart I love you" "Thank you"

AUGUST

AM migration - rough 1 trip  
tuesday 1 september

36th week

244-121

My face just  
hung from my skull  
in pain + exhaustion  
Seeing my beauty in the  
ambulance makes me smile

SEPTEMBER 2009

M	Tu	W	Th	F	Sa	S
31	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

be sure to buy your 2010 daily desk refill

even now - The room is as sweet  
as I remember - the view &  
location by couches of ladies  
grooming - I just like home.

Jerry + I just pierced (SPT)  
into each others eyes  
& delighted in each others  
tears - "We are addicted to  
each other".

I fed him melon + choc  
ice cream - and felt free  
about him + Lynnmoore -  
all the long drive home  
but I called before dinner  
or heard about his -

1/2 a hot dog.

He slapped my  
hands away -

I felt guilty about  
my nice market fair  
although he would  
not have cared  
much for it -

My JERRY

wednesday 2 september

OCTOBER 2009

M	Tu	W	Th	F	Sa	S
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

36th week

245-120

My prayers  
Please let me do the  
right thing - I am speaking  
to me + hoping my sub-conscious  
knows what the right thing is.  
And please let Jerry know  
peace - that to the universe  
which I do not trust to be  
compassionate.

It was sweet w/ Jerry  
to day for the short while  
that he was eating but he  
slept deeply most of the  
three & a half hours I was  
there. Met w/ the Bon Secour  
Hospice + have confidence  
in them + the Lynnmoore  
staff - felt ok til I  
called - he was

awake + I wondered -  
"What is he thinking"  
SO FAR AWAY

Lynnmoore is lovely  
and yet  
final - facility

wednesday 30 december

53rd week

364-1

DECEMBER 2009

M	Tu	W	Th	F	Sa	S
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	1	2	3

Jerry -

cant - 31 - movie, I'll feed you -  
 I told path I was afraid I would  
 jump on him "He is so adorable" -  
 She said "I read with benefits"  
 We laughed & I would like it I  
 think but want to put what's  
 left of my heart & soul in to art  
 for 2 months - I feel great  
 longing for a love - of the  
 same time as being truly endearing  
 in love with Jerry - but I also  
 do not feel strong enough in  
 my body but I plan to be  
 super strong & joy our  
 in Jodo & for ever more -  
 I accept that I cannot  
 be perfect - I just want to  
 be kind - peaceful &  
 make art that connects -

U.S

thursday 31 december

JANUARY 2010

M	Tu	W	Th	F	Sa	S
			1	2	3	
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

Last day & I chose to 53rd week  
not go with my friends  
New Year's Eve 365-0

I wanted to stay with  
 my feelings about Daddy & Jerry  
 & just now I opened the book  
 to the day after Daddy left his  
 little body - So blessed - I am  
 so glad I had two great loves -  
 how heartened I feel to have  
 not been more able to spare  
 them suffering & now - I know  
 Jerry must be better when I  
 am w/ him - & yet I am not so  
 much now -

I prayed to night - just felt  
 compelled to get on my knees  
 Not much came - just a  
 sense of let me be at peace  
 w/ what is. I do wish (but  
 don't pray for) Jerry's release from  
 his body (they can't even  
 break his teeth - and get  
 his nerves are sweet & he  
 blows into my mouth or  
 breathes me in.)

The friends were at Mary's  
 tonight but it has been  
 too exhausting to act like an  
 not greedy - I just could  
 not.

Dear Emil said come  
 drink wine, well watch a

DECEMBER



# THE SIMULATED DEMENTIA WORKSHOP

Why is this so hard to write about? It wasn't even real. Reality was brutal but it was my real and this was theirs.

Jerry and I seemed to be and actually were deep into the endgame when I signed up, still I longed to see from the other side. I arrived early at Lynmore to claim a seat then went up through the coded doors to the locked-down floor, finding my darling sitting dark and dejected near the nurse's station. He had been combative, they said, and was inconsolable.

Do I leave him to go to this workshop? Did I need to better understand how things were for him or be with him?

I went, already in tears. We were seated in an arc—families, nurses, aides, social workers, even the cleaning crew, around a rolling plywood floor. There were packets on each chair containing distorting glasses, latex gloves with random fingers taped together and sand filling the tips. A raw voice on the loudspeaker demanded "Put them on! Quick! Quick! There isn't much time!" The room went dark, cacophonous chatter and music blared. Strobing lights flashed.

The voice began to bark orders: "Go to table one!" "Find the form!" "Fill it out with a pen you find on table two!" The words were difficult to discern through the blasting sounds, the tables hard to find in the shots of light, the floor unsteady, writing with hobbled hands impossible. The rapid-fire voice gunned us down. "Put the form in the envelope you find on table three!" "Stamps on table five!"

What about table four? By then we were disoriented, anxious and alone, the glasses inhibiting eye contact and the sense of "We are all in this together. It's not really real."

By the end, I was far from the only person in tears. Even the DON from our first facility, who let Jerry escape after one week and wanted to charge us for the time he was held in the psych ward, came over and said, "I'm so sorry, I didn't understand." None of us did. None of us could. And yet now, remembering Daddy and Jerry—their separate and similar terrors—"I'm in Hell!" they'd howl—I did. I did.



FRIDAY

January

1

AR · AT · AU · BE · BR · CA · CH · CN · CZ · DE · DK · EE · EL · ES · FI · FR · HK · HR · HU · IE · IS · IT  
\* JP · KR · LT · LU · LV · MX · NL · NO · NZ · PL · PT · RU · SE · SG · SI · SK · TR · TW · UK · US · ZA

BE

BE

BE

AT PEACE

WITH

WHAT

IS

BE

AT

PEACE

WITH WHAT

IS

Forward SATURDAY

January

2

\* NZ · RU · SI

LOOKING →

GO!

ANYTHING IS

MANY THINGS

gave

⇒ POSSIBLE

GREAT →

→ ART

GOOD → FRIENDS

FAMILY FUN

STRONGER & STRONGER

BODY  
HEART

↓  
SOUL

JOYS

\* RU

8 all my animal friends -  
 9 Moussey, Podchini - the  
 10 wildy cats - Momm, Paw Paw,  
 11 Skittles & Fuzzywunkee - birds &  
 12 squirrels -

13 Trees - berries, flowers  
 14 family - my girls -  
 15 friends - so many  
 16 moving, getting stronger  
 17 many images -  
 18 books -

\* RU

8 This is a lovely book - and on all  
 9 ways I feel the way I did 18 - on  
 10 the balcony in Bangkok at dawn  
 11 just arrived and wondering where  
 12 life will take me - feelings full of  
 13 possibility & hope - so much to  
 14 love. The hospice social worker  
 15 Jen advised me to stay in our  
 16 phone conversation and on home  
 17 "under the weather" and away from  
 18 for days now to not sleep  
 19 looking back & holding on to  
 20 what we have been through -  
 the brutal or endearing - &  
 especially to relinquish the  
 crippling guilt, to know Jerry's  
 sense of time unmediated by  
 memory is protecting him from  
 knowing how long I am away.  
 Being laid a bit low these  
 2 days I feel happy to just be  
 with my little animals & to  
 read The Museum of Innocence  
 (gift from B.R.) but frustrated in the  
 attempts to begin the 3rd pic  
 of Joe which could be the  
 "Lionel" -

Jerry fears mice

he lifted my  
shirt & I had nothing  
on under - he held  
my little breasts  
with a look of long  
I took a long for  
life -

I must decide what I  
can do to make his  
part of life as sweet  
as it can be for  
him -

Andy helped me  
in so many ways  
Daddy =

I painted - or more  
unpainted - by pulling  
vibrant red on the  
offending hand &  
rubbing it away

YOGA - MTRT

grate in forehead -

but first - little doggo was undeniably  
unwell & I took him to 2 bags of pop to  
the vet - (probably Sal's delicious chicken  
I go to the people vet tomorrow)  
I also noticed a dent over my left  
brow - the vet thought it odd -

Long my "Jerry's"

my pictures of him  
& my Jerry

We lay in each other's arms & when  
I pointed to the beautiful darby  
she he perceived it & delighted  
This was amazing because  
most often his eyes wander  
not always to gaze there -

He laughed at his brother  
Pruver's remembrance &  
said a whole rant once -  
(something like "what was that?")

in response to a lady voice -  
I had been to see Ellen & told  
her of my sobbing trip home &  
she said it is adaptive behavior &  
she would worry about me  
if I weren't reacting to the  
massive grief - but I cannot  
continue this way - I must  
pray - but more as the  
sage - "for strength" because  
being at peace w/ what  
is not possible

WEDNESDAY

January

27

Jerry

study - a bit of  
a gift

on the wrapped  
hands

drove in the evening sky  
why was back lit like a  
piece of mylar -  
such a lovely pink gold  
gone by the time I  
watch w/ jere  
from his bed.

Joann responded  
so beautifully  
to my  
- Jerry's  
the hand -  
she liked &  
I want even  
wren't  
read







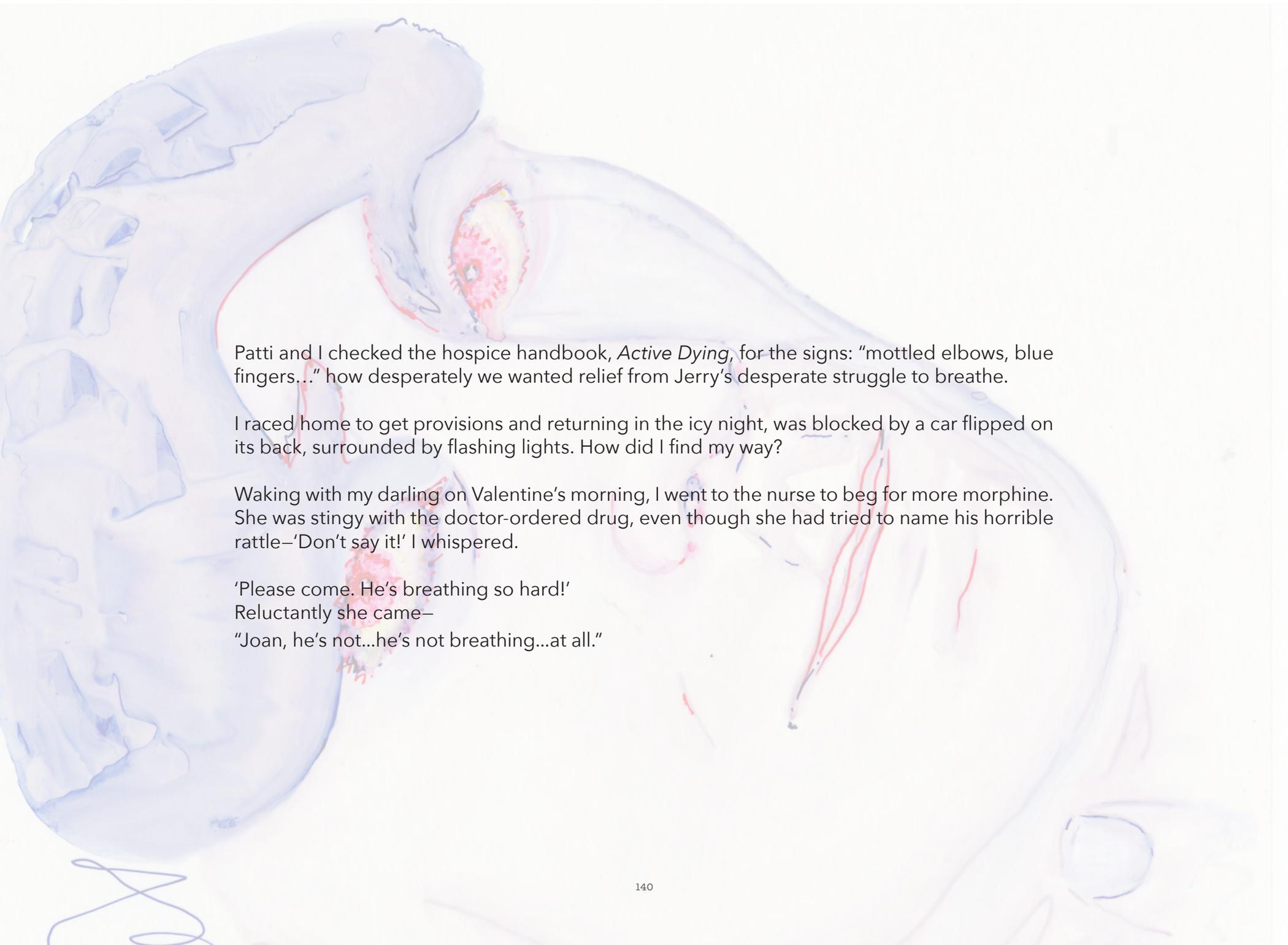
## SHATTERED

Stopping at the gas station in a frantic rush to catch Jerry's hospice nurse, the gearshift knob shatters in my hand. How could this happen? I had already shattered the passenger side window when, seeing a cypress branch frozen to it, I pushed the down button knowing, as I did it, that it was a disastrous thing to do. Maybe I wanted to hear the shattering sound that matched my mood and my heart.

I call Shiva, a new friend, former sweetheart of my helper Cat. He comes in his Chevy truck to take me by highway, no faster and no less scary than the windy, treacherous, beautiful roads I know by heart. A young social worker tells me that the nurse is gone, and asks with a look of concern, "Joan, you are a beautiful woman—are you taking care of yourself?" Oh dear. How many weeks has it been since I washed my hair? And these raggy sweatpants, "quitters," Macon called them.

Jere sleeps through and when Shiva picks me up he asks if I would like to take a walk. Yes—always—and tromping through bright snow would be balm. He takes me to Belle Isle. How could I have never been? And now, think I will never go again, not wanting to blur the image of an ice palace we have to ourselves. Another brief shimmering dream in these dark dying days.





Patti and I checked the hospice handbook, *Active Dying*, for the signs: "mottled elbows, blue fingers..." how desperately we wanted relief from Jerry's desperate struggle to breathe.

I raced home to get provisions and returning in the icy night, was blocked by a car flipped on its back, surrounded by flashing lights. How did I find my way?

Waking with my darling on Valentine's morning, I went to the nurse to beg for more morphine. She was stingy with the doctor-ordered drug, even though she had tried to name his horrible rattle—'Don't say it!' I whispered.

'Please come. He's breathing so hard!'  
Reluctantly she came—  
"Joan, he's not...he's not breathing...at all."



And then with all a lovers grace  
He stoopes and kisses her sweet face

SPECIAL ATTENTION

*The relief, the peace, the elation as I closed the door and crawled in with your still-warm body.  
I swooned and smiled as you floated above the bed.*

*“Joan, why did you put me in this pink T-shirt?”*

*‘How did I know you would choose Valentine’s Day, my Jerry?’*

*But of course, to keep it ours always.*

And then and then all through the friends, the families, the food, the flowers, the Jerry celebration—which truly was a celebration for me—*Jerry, we did it!*—I blocked the memory that I could not live with. Until, in the dentist’s waiting room—exactly fourteen days, two weeks after, the longest we’d ever been apart—I checked my cell: “You-have-one-new-message: The cremated remains of your husband are ready for pick up.” *We did what? You’re dead!*

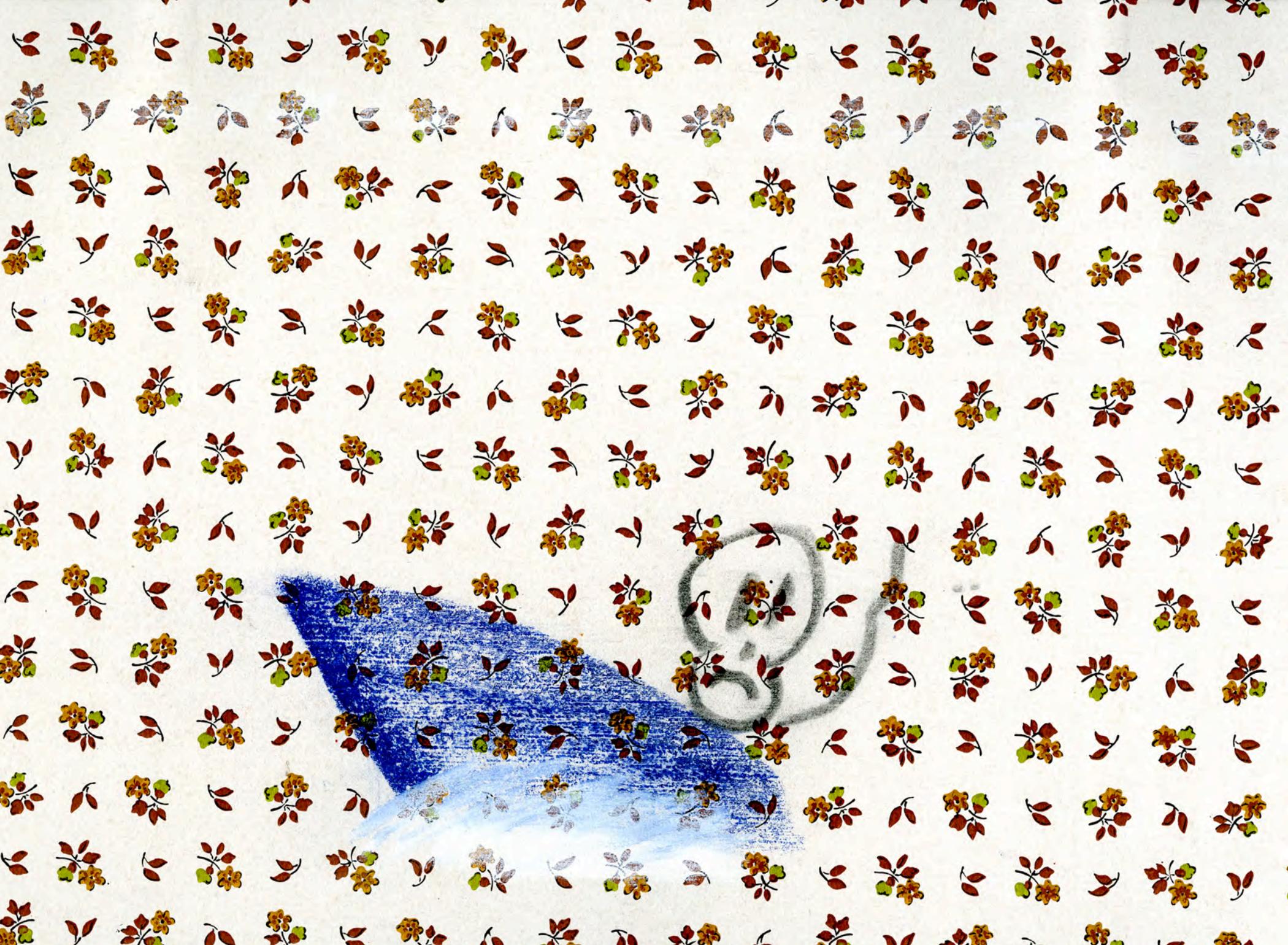
It all came back. It had been a Sunday, low staff. Our wonderful hospice nurse was away and I told her chirpy, “How did you two meet?” replacement, ‘I can’t have this conversation now. I have calls to make.’ The aides had come in to offer condolences, “We know how much you loved him” and finding us in bed together, did not return.

Tender telling to our nears and dears, ‘I’m with Jerry but he’s not with us anymore.’ (“Do you mean he’s dead?” Myron asked. I was not ready to say it then or believe it ever.) Then more and more alone. Hours went by. No one told me that the cherished body I had held close all my adult life could turn cold and foul the room so obscenely. Windows wide open to snow-washed air only made us colder. Finally two young men came with a pretty quilt.

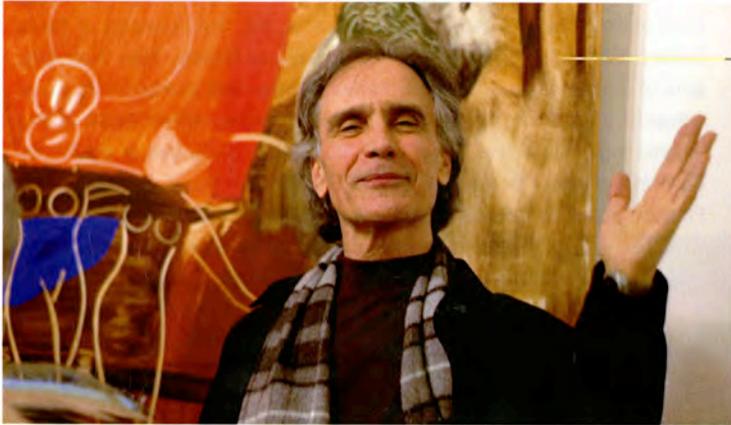
“Do you want to say a last ‘Goodbye’?”

My Jerry was already gone.

Patti called. “I’m coming with the girls to help you move Jerry’s things.” She would not take, ‘Please, no.’, so I found an aide to help me drag the tainted mattress out. By the time they arrived I was high on denial. The memory of driving the icy road last night and the car flipped on its back, blocking my way to Jerry—and the hours this morning, more alone than I ever knew possible—were shoved deep into a dark pocket of my heart.



(doh-nan'toh) vt, bestowed  
**DONATO**



Many thanks to our master of ceremonies  
Richard Roth, our musician J. Plunky Branch,  
and to all of you who join us in celebrating Jerry



Photos courtesy of Richmond Times-Dispatch, VCUarts Anderson Gallery, Richmond Magazine, Style Weekly, BrickWeekly

(doh-nan'toh) vt, bestowed  
**DONATO**



## GERALD DONATO

1941 - 2010

A CELEBRATION OF DONATO  
21 FEBRUARY 2010, 3:00PM  
PLANT ZERO ARTS CENTER  
RICHMOND, VIRGINIA

"TU TE TORNAS ETERNAMENTE RESPONSÁVEL POR AQUILO QUE CATIVAS"  
TRANSLATION—YOU ARE FOREVER RESPONSIBLE FOR THOSE YOU CAPTIVATE  
FERNANDO ANTÓNIO NOGUEIRA DE SEABRA PESSOA, LISBON 1888-1935



## CELEBRATION

It was such a rush—I wanted to wait so more people could hear and come from far but it was good—a rush of love—the flowers—anemones from the Dean’s office, your favorites—how did they know? The only time I cried.

You were so present in this flood of families from Chicago and Gloucester and so many friends, and your students present and past—the stories, the remembered craziness, the joy.



# ELIZABETH SPEAKS

Like the romantic that he was, Jerry stuck around until Valentine's Day.

From now on, Valentine's Day will be the annual celebration of the most famous marriage in Richmond.

Two days later, Joan opened their house as she and Jerry had done for more years than any of us can count, to welcome a visiting artist to VCU for the Sculpture Department and make a grand occasion of it. Students, teachers, friends, food from Eddie and Manny. Art on every wall, in every room. In the Gaustad-Donato world, art and the celebration of it go hand-in-hand with life, with death.

Valentine's Day this year was a new moon. So two days later, the moon was just coming back, a perfect crescent in the southwest sky. I got a great view of it from the downtown expressway on my way to that party. My first thought was, "Mr. Man's smile!"

That smile! Dreamy, archaic, goofy... Everything in his painting orbits around that grin. Mr. Man, but everybody else too, all the angels and fools in the Donato cosmos. Smiling to themselves, or winking at us, pulling the curtain aside, thumbing our nose.

We love the carnival of Jerry's paintings, and we love something else in them too: what Richard Carlyon called the "delay." You think you've got the story, and then you see something else. He was brilliant at painting watery things—waves, rivers, whirlpools, floods. He painted them with all the fluid states of paint itself, this master of liquid things. Aswirl in the deluge you discover a boat...a ghost...a halo... and it pulls the ground out from under you. Look again, and another Mr. Man in his bow tie has been there all along, waiting for you. We fell in love with this delay, with the way everything changes when we look again. We are still looking, and everything is still changing.

He left us these paintings!

One night at dinner Jerry and I got into a contest about how many bodily fluids we could name. All the standards—blood, sweat, tears, and so on—but then we kept thinking of more, amazed at the number of them. “Amniotic fluid!” I said. “Toe jam!” he said. “That’s not a fluid,” I said. Then he jumped up and yelled at the top of his lungs, “we forgot pus!!” [joy and triumph] All other conversation at the table fell silent.

Carlton told me yesterday that Jerry was the most unapologetically vulgar person he knew, and that when they first met, he worried about being seen with him. Then he noticed how even the most proper old-fashioned elderly ladies howled at Jerry’s X-rated wisecracks. How did he do it?

We’ve all asked ourselves this. How did he do it? Is it because he was so handsome? Always dressed elegantly. Perfect manners, a courtly man. He had charisma. He was gallant. He said one thing, but did another. And in his paintings the same thing: what the painting says and what it does are two different things. This is their greatness.

And then there was his joy. All by itself. The carnal sublime.

He left us these paintings!



## NEVER MISSING

After Patti had people in tears and before Elena left them laughing, I spoke. I had never been comfortable in front of large groups—interviewing my students rather than lecturing them—and I did not know whether it was appropriate for a widow to speak. Still, there was something I had to say to those who thought Jerry had been lost long ago.

'It is often said that memory makes us human. I was happy to read recently in the *New York Times* Science section that what makes us unique as human beings is our ability to project, not only into the past and future, but into each other. To see Jerry look at a child, a tree, a fellow patient or me, was to be awed by the infinite capacity for empathy we all have, and to know he was more Jerry than ever.'

Jesse funeral Celebration ①

Always stayed Jerry.  
There is a notion that <sup>it is</sup> memory  
makes us human so I  
was happy to read that <sup>recently</sup>  
it makes us unique as  
humans in the ability to  
project into the past &  
future but most of all into  
each other & that always  
stayed w/ Jesse along w/  
his humor his increasing  
inappropriate <sup>ness</sup>, his <sup>meek</sup>  
he was so <sup>amazing</sup>  
His bro would <sup>always</sup> <sup>said</sup>  
was another <sup>bro</sup>

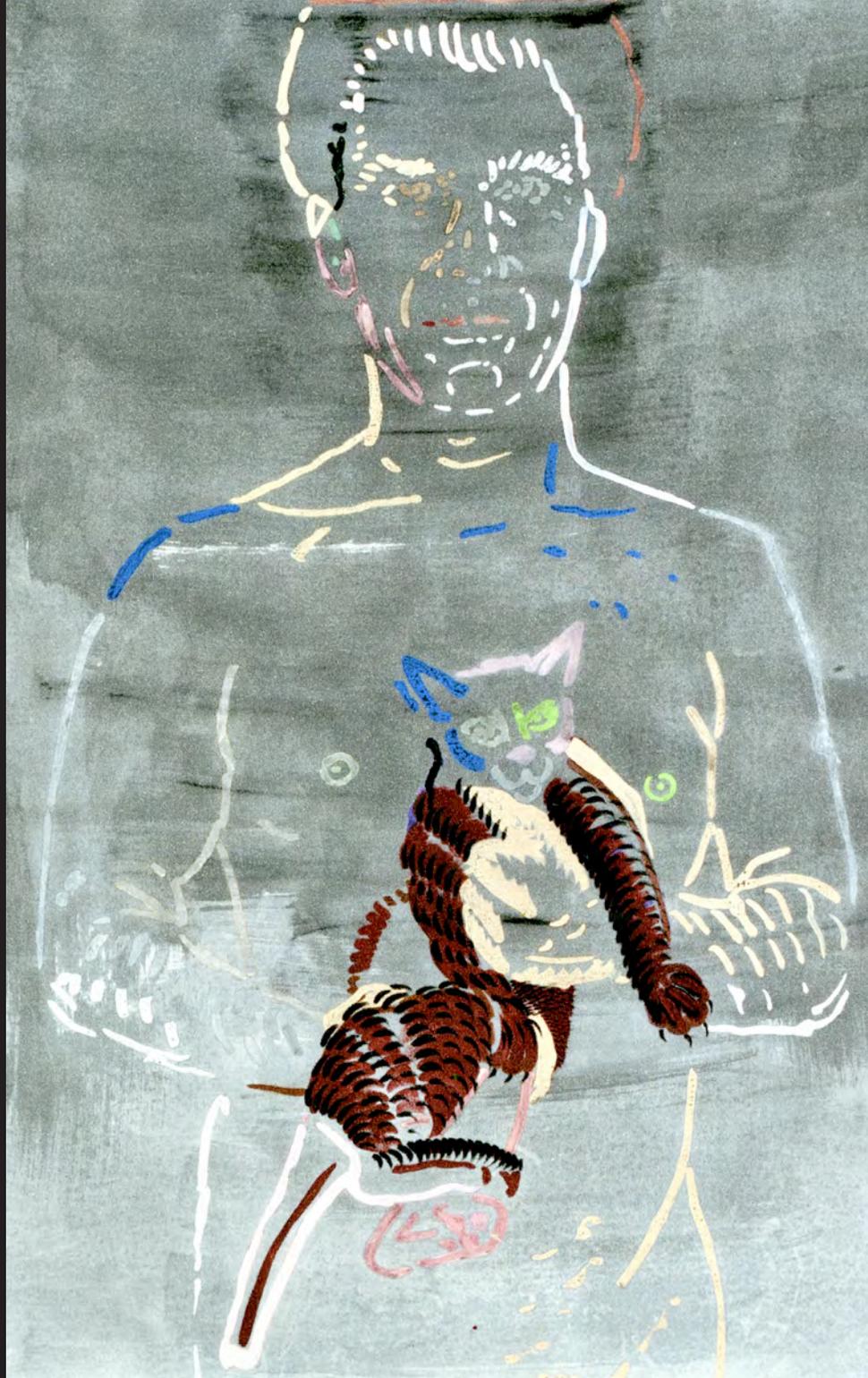
certainly was to his <sup>bro</sup> ②③  
students but when his  
venue was radically changed  
he was a mother hen w/ the  
little ladies & he brushed the  
crumbs off the old men's laps  
There was this big polar bear  
who would grab <sup>Nurse - It's in his eyes</sup>  
I'd stayed so long  
on the words of

Donato is <sup>over</sup>

336 918 3668

the way he  
looks at you

Jobs never threw anything away. In the beginning he had few clothes and I had his uniform. Fisher's knit sweater re-woven and the elbow patched and repatched many times. The one bedroom apartment a love one's studio held little but when we moved to a too big house two blocks away, a room began to fill with



things store finds and hand-me-downs. As he was getting new nice things he did enjoy them but would let go of nothing and in the odd manifest a hoard of brain illness, the piling on of layers of clothes, he was well supplied. It was sort of the style at the time, multiple shirt and jackets, and he was a stylin' guy but the hats on hats was pushing it even for Mr. MAN

## CLOTHES

I knew what I would do with Jerry's cherished things when he would no longer have earthly use for them. Our Sunday morning walks had always taken us through Monroe Park where people in need lined up for hot breakfast. They loved our dancing dog and Jerry loved joking with them. When a hawk swooped down and grabbed a squirrel, a gray-froed fellow with a plate full of scrambled eggs looked up laughing, "We're having breakfast and he's having breakfast!"

One spring Sunday, Sally and I piled Jerry's last best coats, jackets, pants and shirts in her car, worrying that we might be too late. Breakfast was over but we saw a few people around the fountain and walked towards them with arms full. Rushing to meet us as if we were expected, each selected what seemed to be meant especially for them. "That's mine," the first woman said as she took the down vest. It was almost mystical. 'Jerryman, you are with your people!'

(I laughed at my surprise that there were no takers for the black crepe Mani jacket that had been the hardest for me to part with.)

This began as a horizon on the when I was  
driving the windy roads to be with  
you in the last days.  
— transcribed sound — and after  
it righted itself —



— the body became the yellow  
candle used as a stopper in  
the blue clay pitcher holding your  
ashes. and my belly. it boiled  
like the ocean we poured  
you into

## BACKGROUND MUSIC

In your room, the aides were good about keeping the music going, as you did for me always—in our always adjoining studios—Sidney Bechet, Son House, Howlin' Wolf—an education. I never took it for granted.

And Marvin Gaye, the singing card sent by your family—*Mercy mercy me, life ain't what it used to be*. What were they thinking?

You did understand, *It takes two baby, me and you*—yes, to make a dream come true, but not the way I understood—an illness, that takes two lives.

Driving the wooded, scarily winding roads between us, with Van Morrison's aching voice—*I know you're dying and I know you know it too*—sobbing with—*gotta stop gotta stop gotta stop breaking down*—and still I could not stop playing the soundtrack to my sorrow.

In your last three days, while I lay in a plank-hard roll-away and with you in your barred bed, Billie Holiday—*just say you'll remain*—played nonstop. And then constantly for three months after your body went cold—in my long hot baths and then with long hot yogic lust. I was appalled by my cold hard heart—before I realized that it was not in spite of, but because this was the background music of our three-day last embrace, that I wanted her voice with the heat I hoped would stop the hemorrhage of my heart.

*In this right?*

*In this true?*

UN 4256449  
TURN GARMENT  
INSIDE OUT  
MACHINE WASH  
COLD WITH  
LICE COLDS  
GENTLE CYCLE  
ONLY RINSE  
CHILDREN BLEACH  
WHEN NEEDED  
TUMBLE DRY LOW  
REMOVE PROMPTLY

PREPARE  
TO  
SCARE

FUCK ART.



LET'S DANCE.

# FUCKING

"Jerry wasn't Jerry anymore." It still makes me crazy when people say this. He wasn't the life of their party but they should have seen him leading the octogenarian Dixieland Band at Windsor, and giving the ten-year-old daughter of the activity director giggle fits. She trailed after him loving the teasing and high silliness that his five-word limit did not inhibit.

"Donato has lost his soul," a long-time professor told me she had told a long-ago student. *'Jerry couldn't lose his soul if he were dead!'* I shot back, in my head.

And that was true. Is true.

But what about Joan?

"You survived." Patti said.

No. My amputated heart still beat but where was the person I thought myself to be? I could bring back nothing from my piles of Buddhist books and notebooks filled with years of religious studies—Zen, Tibetan logic and debate, Thomas Merton. Of the desire to be "easeful peaceful useful," all that was left was desire.

I listened, speechless in the sculpture grad candidacy critique as the students contemplated a thing on the floor—"It should be bigger"..."It should be...whatever..."

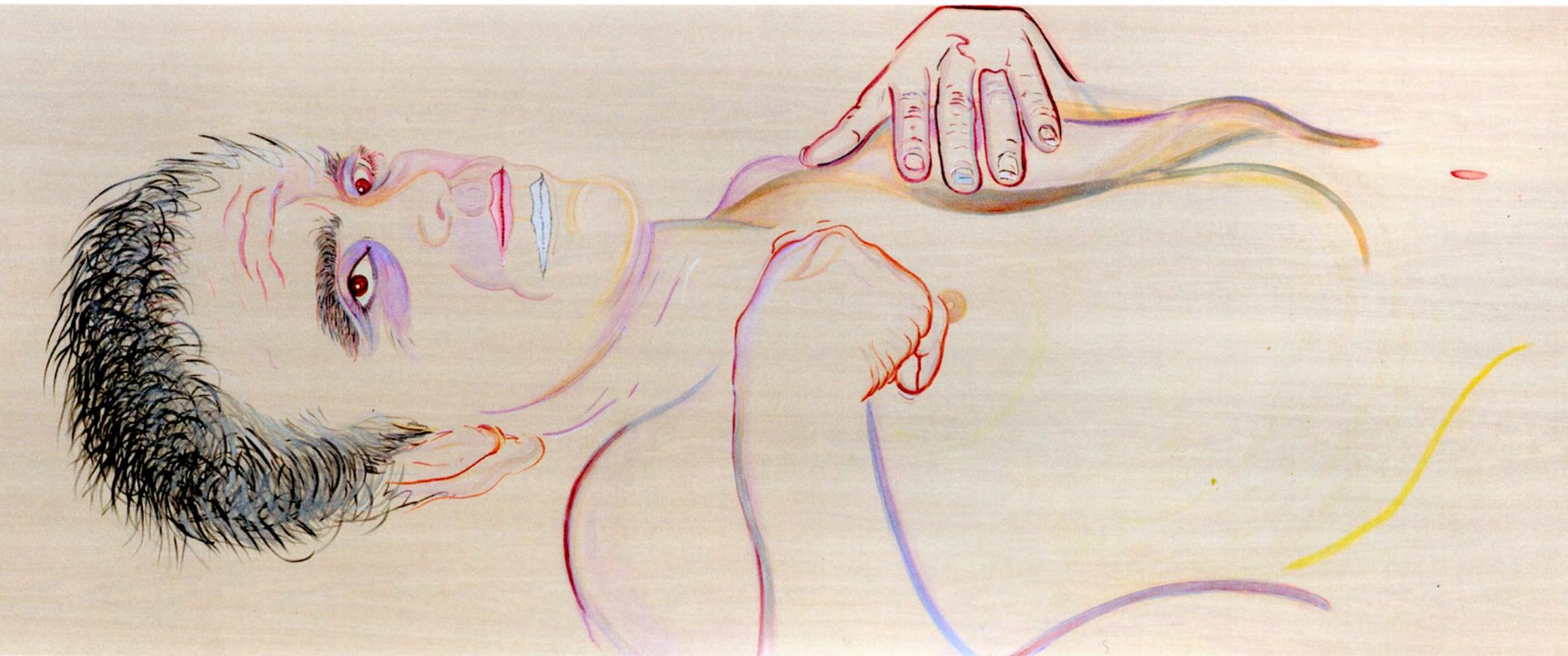
'What difference does it make?!' I wanted to scream.

'You should all be out rolling in the grass. You should all be fucking!'

I looked at people in the streets, and even in movies, and couldn't comprehend why anyone was doing anything else.

Totally tempted to tumble into bad behavior again—the hammock, the river—I went to my baby Byrd House art kids. They hurled themselves into me like little comets of love, filling the black hole I had become.

No need—for now—to fall in.



# ASHES

Elizabeth and her Carlton take me, newly widowed, to Philadelphia to join a parade created by “healer” artist George Ferrandi. We stop in DC to see a show of carved Christ figures at the National Gallery. A larger-than-life Mary, her back to the wall, looks down in stunning sorrow at a crucifix in her hand. I slip behind her to see the body on the cross. The ribs, the hollow pelvis, the arched agony bring back your last suffering.

George’s procession of white lanterns and illuminated figures, silently wending its way through Little Italy, is balm—the funeral I long for, for my Jerry.



A  
XXVI  
540  
844

Ernst Dornat

What to do with your ashes—silvery sand, now my treasure, slipping through fingers, caressed into skin and lips, and the fur of our precious pets and into the trunks of all our treasured trees. Still so much, so heavy in the ugly wine jug you had happily rescued from a trash pile in our alley.

Patti says we can go with her girls to the Cape Hatteras timeshare she had loaned us for many honeymoon anniversaries. Three months to the day it will be, from the last time I saw the face imprinted on my heart, body on my body. A lovely plan but I worry—walking Poochini down to school in the dark, a sliver moon above the cathedral dome—about how to make it worthy.

'Jerry, please, what do you want?'

The response is clear. "Joan, just have fun with the girls."

Ah!

Wonderful.

'And while we're talking—what do you think—about me dating?'

Silence.

Oh.

*And you never speak to me again.*



I pack your Mr. Man suitcase with the jug of ashes, a bundle of scented sage, the crystals you used to put in a sock to dip in the ocean, and your family's silhouette photo that had been magically projected above you on your last breathing night.

In Nags Head the four of us go to memory-filled Tortugas' Lie for dinner. The girls giggle wildly saying that I'm saying something lewd about "Jerry juice." On the way back I mention, for the third or fourth time, that you had always loved to climb to the top of the highest dune to watch the sunset and for the fifth time as we pass it, Patti barks back, "We are not doing that!" as she makes a sharp U-turn into the parking lot across from where the Wright Brothers first flew. Racing up the hill, feet sinking in sand, the girls pulling and pushing their crawling little Mama, we collapse in laughter at the top just in time to see liquid sky melt into the sea.

Back to the beach I wheel the Jerry bag down to the ocean's edge and make a circle in the sand with the crystals and daisies we find washed up by a tide that had taken them from a long row, seemingly planted just for us. We stick the sage bundle in the center and light it. Elena, Jere Bear's goddaughter, takes the earthen pitcher to pour his ashes in the lines of the "Mr. Mans" I draw in the sand as Jerry used to do, so Patti and I—running at sunrise—could find him, chasing the ever-bigger, wilder alter egos before they were lapped up by waves.

Laney playfully lays you close to the water and lets your ashes wash into the sea. Patti calls to me "Look!" I turn to see her pointing at the moon—new like it was on your last earthly morning—now joined by a star, and the flames illuminating the flowers and faces of our beautiful nieces. "Jerry would so love this!" she beams.

Sitting around the smoldering sage, we tie colored strips of cloth around our wrists as mementos, promising to wear them forever. 'Jere Bear, you are in us as us' I say—'and the part of you, the swearing part that's in me, please take back now.'

As the girls pack your bag and pull it away from the chilling, suddenly dark beach, I walk towards the ocean to talk to you. The profanity that seems to have become my every other word and thought ("Joan, you have to stop!" Patti says of my trauma-induced Tourette's), does not come. 'Thank you darling.'

Sitting on the balcony of the bedroom where we had watched the sun rise many  
May mornings—beyond crying, beyond thinking, my future as unfathomable as the star struck sky—  
Elena comes and puts her music in my ears, a song of loss that she loves, and I lose it.

“You have always been Joan and Jerry,”  
the sixteen-year-old tells me.

“Now you have to learn to be Joan.”





No -  
HIND

# STORIES, SECTIONS, & ATTRIBUTIONS

## **BEGINNING PAPER**

“Tangle Mask” My drawing on wallpaper from Jerry’s collection.

## **LETTERS (p. 2)**

### **NOT/ERN LOVE (p. 3-6)**

“DONATO Mask” (p.5) Created by Victor Kord.  
“Jere & Jimmy” (p.6)

### **MET (p. 7-14)**

“Super Jere” (p.7) My painting of Jerry at our beginning overlaid with a sketch for the painting at our ending –

“Bangkok” (p.9) In a dress designed by MaJoRee (Mama).

“Airport” (p.10) Jerry took me to fly home to Germany right after we spent our first Christmas night together. I made this print.

“Joan & Jerry” (p.11) Hooked rug portrait (even our cats) by Sherry Urquart.

“Kiss” (p.13) Jerry’s note on my note.

“Beaux Arts Ball” (p.14)

### **HUMOR (p. 15-20)**

“A Mad Tea Party” (p.15) by Sir John Tenniel with drawing by DONATO.

“Untitled” (p.17) Painting on wallpaper by DONATO.

### **PRIVACY (p. 21-22)**

“Beanie Babies” (p.21) Photo on wallpaper from Jerry’s collection.

### **SIGNS (p. 23-24)**

Wedding photo and still from “Breathless” (1983) (p.23)

### **LIES (p. 25-30)**

“DOUBT” (p.27) Jerry’s license plate – based on Carter Radcliff’s comment about his paintings.

“Banana Split” (p.29) One of Jerry’s plaster ice cream parlor displays.

### **RAPUNZEL (p. 31-38)**

“Self Portrait” (p.31) My sketch.

“Waterbaby” (p.33) Painting by me – of me.

“Girls” (p.35) Painting on pink Formica – by me at the time I knew I would have to work fast.

“Note to self” (p.37)

Elena’s scrapbook (p.38)

### **THE WIDOW (p. 39-40)**

“Living Wholeness” (p.39) My sketch for a painting over D.H Lawrence quote.

### **ADVICE (p. 41-52)**

“Shrinky-Dink Jere” (p.41) On Jerry’s wallpaper.

“Ain’t We Got Fun” (p.46) Donato family; grandparents and their sons on arrival in America.

### **“HIS WIFE HOWEVER” (p. 53-60)**

“Doctor’s Notes” (p.53)

“Interactive journal” (p.55-60)

### **META (p. 61-62)**

“META” (p.62) My license plate – meant to be “METTA” – Pali for loving kindness.

### **EASTER (p. 63-64)**

“Egg” (p.63) Plaster egg by Virginia Samsel.

### **MEMORY—MINE (p. 65-66)**

### **PINK DIARY (p. 67-70)**

### **MEXICO (p. 71-72)**

“Untitled” (p.71) Pastel by DONATO from his Avon bodies of work.

### **THE VIOLENCE (p. 73-74)**

“My Friend Jerry, Here and There” (p.74) Etching by David Freed

**THE BRAIN (p. 75-76)**

“Stolen clipboard” (p.75) I wanted it. I wanted a brain.  
I wanted to understand.

**TORN PHOTOS (p. 77-78)****EARLY ONSET SUPPORT GROUP (p. 79-80)**

“Jerry” (p.79) Oil painting by Tom Papa.

**FIRE (p. 81-82)**

“Poochini Paws” (p.81)

**THE CRIME (p. 83-88)**

“A Women Responds to a Bite on the Neck” (p.88) Postcard  
of painting by Leonard Dufresne.

**ESCAPE (p. 89-96)**

“Untitled” (p.96) Mr. Man Post-it drawing by DONATO.

**9 NORTH (p. 97-100)**

“Mr. Man” (p.98) Photograph by Myron Helfgott.

“Cake” (p.99) By Phyllis Di Maurizi and Kim Tetlow.

**DANCING (p. 101-104)**

“Elena’s Scrapbook” (p.104)

**DOCTORS (p. 105-106)****INAUGURATION DAY (p. 107-108)****BLOOD (p. 109-112)**

“Slipping Away” (p.110) Sketch by me over Jerry’s  
wallpaper.

“Untitled” (p.111) Painting and snapshot of painting in  
progress by DONATO.

**FUCKING TREE (p. 113-114)**

“Fucking Tree” (p.113) Photograph by Myron Helfgott.

**HAVE YOU EVER WONDERED (p. 115-116)**

“Beloved” (p.115) Sketch by me over Jerry’s wallpaper.

**SHOOT (p. 117-118)****MOMENTS (p. 119-120)**

“Untitled”(SNOW) (p.119) Painting by DONATO.

**FUNERAL CRUISE (p. 121-122)**

“Funeral Cruise” (p.121-122) My drawings of my nieces.

**F.E.A.R. (p. 123-130)**

“Beach” (p.123) Donato catalogue cover.

“Untitled” (p.126) Painting on pallet paper by DONATO.

**THE SIMULATED DEMENTIA WORKSHOP (p. 131-132)**

“Untitled” (p.132) DONATO drawing on wallpaper.

**SHATTERED (p. 137-144)**

“Love” (p.137-138) My painting.

“Blue” (p.139-140) My painting and the sketch for it.

“Valentine” (p.141) By DONATO.

“Untitled” (p.144) Drawing by DONATO on his wallpaper.

**CELEBRATION (p. 145-146)**

“Program” (p.145) Designed by Phyllis Di Maurizi.

**ELIZABETH SPEAKS (p. 147-150)**

“Untitled” (Dancing With My Mr. Man) (p.150) by DONATO.

**NEVER MISSING (p. 151-152)****CLOTHES (p. 153-154)**

“Darling” (p.153) My painting of Jerry and the cat he  
named Darling after a grade school crush.

**BACKGROUND MUSIC (p. 155-156)**

“Slipping” (p.155) My painting in our last days.

**FUCKING (p. 157-158)**

“Tea Shirt” (p.157) By George Ferandi.

**ASHES (p. 159-166)**

“Looking Back” (p.159) My painting of Jerry on woodgrain  
Formica. (37” x 96”)

“Avon” (p.161) Pastel by Donato.

“Untitled” (p.166) Charcoal by DONATO made in Avon – our  
little white-washed house – blown away by a hurricane.

**END PAPER (p. 167-168)**

“Touch” (p.167) My painting with wallpaper from Jerry’s  
collection.

# ACKNOWLEDGEMENTS

## **To my millennial-artist co-conspirators, I offer heartfelt gratitude:**

Hillary Waters, you so got that our approach was like a film being shot on a cell phone and ran with it. Thank you for making “*Someone’s missing...*” an actual book in my hands before slipping off to Sicily.

Megan Goldfarb, experienced beyond your few years, you allowed, in your strict editing, for what you came to see as my voice. Your amazing new book — *135-56 229th St.* — makes me realize — even more — how lucky I am to have your creative vision and you in my life.

Eli Gray, no one knows Donato’s artwork more intimately than you do — you archived it all. Now, you give your artist’s touch and warm heart to wrapping this book up — and the zine transcriptions — all your recreation!

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Sista, Sara Monroe, my “First Reader,” you went through the manuscript by your Blue Mountain Lake, commenting and advising on birchbark Post-Its; your tough-love honesty, deep intelligence and imagination touched every page.

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## **The stories in this book came easily; the writing, unlike the solitude of painting, became collaborative:**

Writing teacher, Amy Richie Johnson and her “repeat offenders,” especially Sara, Tim, Sandy and Cory taught me to “clip tail feathers” and so much more. The camaraderie and laughter as we share our writing lives is a great joy in my life.

# KINDNESSES

Bless all of you who came to Jerry's wallpapered residences, again and again:

Myron, most loyal — every week — and Robin, singing a capella when the Christmas musicians failed to show up. (You two fell back in love meeting there.)

Sally-girl — I know it was hard for you but you did it — even to the psych ward — with your Tim.

La Richard — “That guy!” Jerry joyfully said on seeing you — his boss, his best buddy.

The ROMEOS — David and Chuck — thank you, loyal old friends.

Chris B. — sharing your magic — right up to the end.

Rick and your Phyllis who made that wonderful DONATO book for Jerry.

Jim — you loved your twin and came to him with your Anne and Uncle Dirty's Lisa and Danny.

Joannie — coming all the way from C'ville with Santa hats and Christmas stockings, Halloween costumes and treats, the Billie Holiday CDs in our last days — your golden hair hanging over your teacher, your friend — two beauties.

Finally — nurses and med-techs — you are the hidden heroes.





