

## LOVE LETTER NUMBER #2 – April

Dear Mom:

It has been so great to see you come out of the fog you've been in for the last months, over the past week. Seeing you arrange flowers, take control of your closet today, dress up, interact with your friends, get out to a show, give me crap, and (to some extent) enjoy my cooking has been a gas!

I have been here since late november. Steve has helicoptered in for a weekend every three weeks. Carol has never been here. Nat was here twice, Hailey not at all. You have hallucinated that. It has been just me, 24/7 for 4 months, with totally inadequate financial support from steve, and constant backbiting from your HPP friends.

In all the chaos and noise and opinions from others I chose to prioritize **rest** for you based on the doctors advice for your back (2-3 months to heal, 12-16 before you could see a chiropractor again), and for your mind – 3-6 months since the operation.

It is april 8<sup>th</sup> today. Another month and your back will be healed enough for another x-ray and further suggestions for treatment. By June, we hope, the side effects from the brain surgery will subside, and then you will be back to whatever other problems you may have. Everyone else (especially steve) thinks I have been doing a bad job in some respect or another – but I had a low bar for success – get your mind operational again and not let you fall again. SUCCESS!

I had intended to stay here in the apt through august, with a couple short breaks. Steve on the other hand, is fed up with me, and is helicoptering in on the 12<sup>th</sup>, kicking me out, and does not even want a smooth handoff. His intent is to find you a cheap live-in CNA and drop the 24/7 service we presently have taking care of you, where I feel another 2 months of this sort of relief is required. He also has other ideas towards more aggressive care than I. But he mostly wants to drop the 24/7service...

... because it is too expensive. I got a double dose of the art gene from you, mom, him the miser gene. Most of your expenses to date (like medicab, except for pleasure jaunts) have been covered by medicare, the 24/7 care is not. The amazon bill is pretty big, too!

I certainly need a break, and I intend to spend a week on a beach, ASAP. But I am feeling terribly, terribly protective of you and want to make sure steve does not screw you over. I am fiercely willing to make it possible for you to die at home, if that is what you still want – and also make it a more pleasant place to make music and art. I am very sorry I have not been in your life much these past 20 years, and yet I would like to be in it for the next 14. Honestly I could use some help too - I have been rather blasé about things you care about – like personal appearances, dental, and some needed surgeries – thinking for the past decade was going to die from MS – which I think (now) is more of an auto-immune disorder from my busted back.

Things are so bad between Steve and I that I have been thinking of lawyering up to advocate for your rights, but in a fight like that I would lose. He has made multiple offers – offering to pay to fix up my boat as one example – not within his remit - to try and get me out of the way ... and while I am delighted that finally he is taking time off from work to attend to your care, I have developed major trust issues in him and his ability to closely follow your instructions and wishes.

6 weeks back - Steve made me your primary caregiver without giving me the means to do the job right or to support myself, and I have lost a lot of sleep and a lot of money caring for you as best as I could on what I had. I have learned a lot about being a CNA and about your ways and needs (he did give me free run of your credit card, for food, supplies and racking up a large amazon bill for various items including re-habbing your office, but only 1600 dollars in cash to cover my own life, and stuff I pay cash for, like tips and massage therapy. I have fired 5 lousy CNAs. Note: there has been a lot of inflation in the last few years and 20 bucks is what I give your drivers). I have a really bad back, and threw it out again last night. But with Francesca being such a tiny thing, I felt that carrying you to your chair was the best thing to do. Now I have a string of massage appointments I cannot afford to pay for to put me back together.

I loved the concert last night. I am NOT embarrassed about being swept away by music as you are, but perhaps next time I will seek another seat.

Anyway, Steve has consistently opted for the cheapest, most robotic bargain basement sort of care, and caregivers for you, where me, I have been trying to develop relationships with the best people I can find to take care of you. Your staff is getting better and better. I have a few other people that I think are worthwhile, like the piano tuner guy you met last night.

**The smartest thing I think you can do to get your life back under your control is to take back your power of attorney, work out exactly how you want to run and enjoy your life, financially, given 6 months, 5 years, and 14 years projections for how long you will live. I and my family would like to be part of it.**

After Steve's arrival on the 12<sup>th</sup>, I will not be able to protect you. I may give up. I may collapse. But you are my rose, and I want to see you flower again.

Love,

Mike (I really do prefer being dave!)

PS I do not actually really want to live with you long term. I like making noise. :) But I am willing to move to the ft myers area for a few years at least. There is an apartment for rent on the 24<sup>th</sup> floor here that the family (including steve and I if we can reconcile) could use to "be there" for you when you need us. (it is 4k/month)

PPS There's also this cool boat I hope to show you to today.

PPPS And perhaps a really nice new gf...

Love Letter #3

Dear Mom:

In terms of your rad treatment. In the past 2 weeks you have also skipped some prescribed medications that I feel are no longer necessary. And got way better! I do not understand your "theory" but I did give you a book on advanced differential equations that might help you express what you mean.

You are otherwise as healthy as a horse. I think it is ok you discontinue your treatments, as the thereapy does also kill otherwise healthy brain cells, your resection, might have been perfect, and with close monitoring of the tumors recurrence, I think the odds are really good for you. I hate the american medical system with a passion for what it did to me, so I am biased.