

Dear Family and Friends of Mark Petchey,

This year I have big, surprising news for you.

Mark moved out from home to start a new own life of independence! He now lives with a sleep-in help in a two-bedroom apartment in Santa Rosa about 10 miles to the east in West Sonoma County. So, nearly 39 years of my motherhood has ended.

The story started about 5 years ago. Since Mark is disabled and receives all financial supports for medical and other benefits, his case managers and social workers from the local governments annually examine his condition. During one of these occasions his social worker asked me if I was ever interested in having Mark live by himself with 24/7 care. I have never thought of it. I was so totally involved in his affair for the 20 years of his disability. When this question came up and before I opened my mouth, Mark who was quietly sitting next to me, suddenly raised his head up toward the social worker and clearly expressed his will by squeezing his voice from his throat with a sound like “Wooh.” That was an obvious YES. Not only me but the social worker was quite pleased and satisfied by his affirming response.

Mark had always displayed a streak of independence since his babyhood. He was always able to express what he thought and felt. I learned early that my job was to follow his wishes so that we may establish peaceful co-existence. He was easy to read and get along with throughout childhood. That was my Mark.

Since that discussion with the case workers years ago, one more thing got added to our lives. We went to register him to apply for low-income housing in the area. We went through a typical bureaucratic procedure. The rumor then was that it could take up to 7-8 years for a housing availability. About 2 years ago, one complex called us about an opening but it did not work out. The vetting process was complicated and lengthy. For the need of the second bedroom for overnight caregiver that individual must be processed via background check for criminal record and must sign a residential contract to occupy the place. Otherwise, Mark would only be granted a one-bedroom apartment and that would obviously not work. Government controlled low-income housing has very strict rules on background check, especially relative to care of disabled persons. An agency specialized for 24/7 care was introduced, but the idea of them providing nightly available personnel was not workable. Back to square one.

Then in April this year, the same housing complex again contacted us with news that a two-bedroom apartment became available. This time I pull out all efforts and even placed ads. Finally, Mark’s former caregiver, Tashi Yangzom, now a fully licensed nurse who works in a hospital, brought her good friend into the rescue. Tenzin Yangdon is her name – she is a fully licensed acupuncture doctor as well as a Tibetan medicine woman and a devout Buddhist practitioner.



They finally offered Mark a place after the thorough criminal check – they ascertained that he was not a sex offenders record or had committed financial mismanagement and they did accept the fact that he did not own a credit card nor a credit rating. Roommate Tenzin Yangdon also subsequently passed her check, Mark moved into this apartment during the last weekend of September. Everything he uses daily at home went together with him - from his two trash cans, and his spoons and forks. His apartment is just about 15 minutes away by car and he is quite content in this new phase of his life. His primary daytime caregiver, Kafoune, is now in charge of his daily program. I cover some evenings and most weekends so that we are still frequently together. But I am slowly discharging myself from Mark’s affairs. He is in charge and I will always be available to support him when needed.

Mark has been in good spirit since the move. He could not attend his day school due to Covid but his care providers fill his activity and go beyond. Kafoune brings her energy to brighten up his daily life. Penpa provides her Indian-inspired dinner so that I am no longer the only one responsible for his food. His routine exercise is more disciplinary and improved. Mark’s former tutor, Parris Mazer, is still in touch and recently took him and

other clients to the San Francisco Zoo. Mark's outdoor activities often involve a weekly drive to the beach with Dylan Greene for fish and chips. Our North Bay coastline is friendly for activities in all seasons.

I have housemates, a young Thai couple, Fah and Jett who rescue me in covering for Mark's care on occasional Saturday evening dance. Our whole team is growing more diverse in Mark's care community. His life, though limited in mobility and conversation, has blossoming into a positive, more independent lifestyle in which he appears content and well-adjusted. We shall see what comes next...

I am also going through some life transition as Mark goes through his. I am no longer working. My hospice volunteer has been ongoing for over 5 years though there were interruption because of Covid. I will be helping a local Zen temple as volunteer bookkeeper just for a few hours a month beginning in the spring. I also serve on the board of our local dance organization.

This year I planted many shrubs and trees in my garden with the help of my special friend, John. He is Chinese and a retired museum curator, historian of Asia, and arts administrator. He also helped Mark's move but his love for gardening has resulted in many additional plants and fruit trees to my backyard. Some are too early to harvest but my quince and pineapple guava gave plenty of fruits which pleased my family and friends. Earlier in October, one of the old birches fell over due to a severe storm. There was fortunately no harm to persons nor property. It went down towards the front lawn. The main trunk was happily accepted by local woodturners through a good friend. My latest addition to the garden is a Japanese flowering quince. Quince is my favorite for the colorful orangish blossoms in early Spring, around here in February. Covid is less overwhelming to our lives now and we are slowly return to normalcy. My dance affairs will soon start in person with a good dance partner, John.



Thank you for your thoughts of Mark and best wishes to all of you

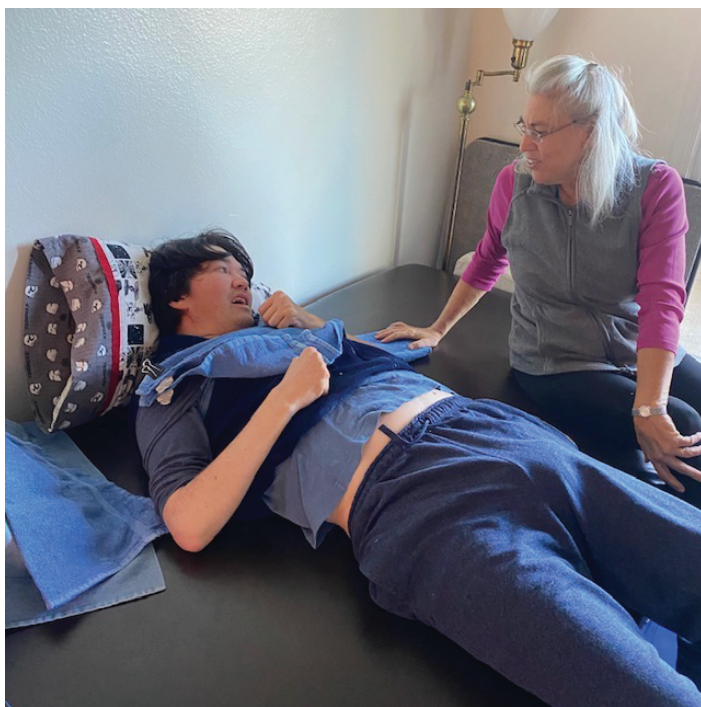
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PS - The next page is a therapeutic report from Letha who again helped Mark throughout this year. Mark loves spending time with her, and they have their own special communicative language.





In occupational therapy, we've focused on increasing Mark's functional abilities. Mark is relearning balance. At 6' 3" tall, the challenge is significant. Here's Mark kneeling next to his plinth, finding his center and regaining control of his core. He is now able to get himself into this position, climb on and off the plinth, and maintain his balance for ~ 20 seconds. We are all very proud of him. Functionally, his gain is significant. In November, we installed a floor to ceiling pole next to his bed. With help to get his right hand around the pole, Mark is now able to move from his wheelchair to his bed, and back by himself.

What a great boost for him, his new apartment and more independence! He remains good natured, hard-working, and happy. Letha