

A BRIEF TIMELINE SINCE CARRIE'S STROKE IN 2020

The following timeline was added later for clarification. A significant portion of emails beginning with June 24, 2021 were included in the copy of the email attachment (see user.xmission.com/~mkeener/family/toxicfamily), though the timeline below is more detailed and also refers to other emails that were not included. The other emails have not been added because as a caregiver, I really don't have the time for this. The other emails can be made available if needed for a good reason. -- Matt

CARRIE'S STROKE, DEMENTIA, AND OTHER CHALLENGES

March 12, 2020. Carrie was given a CAT scan because she appeared impaired or distracted. The scan showed significant damage to her right frontal lobe and lesser damage to the left temporal lobe and basal ganglia in a manner consistent with a stroke. Her first neuropsychological evaluation was not done for two months because of COVID and scheduling limitations. She did not drive during this time because of her impaired condition. Carrie remembered later that she felt confused about what was happening to her.

May 13, 2020. Carrie was given a neuropsych evaluation and the neuropsychologist provided feedback on May 22. She was diagnosed with vascular dementia and these were the recommendations (PDF). Impulsivity was one of the most serious issues, especially with food. It was also clear that she would not drive again. Carrie remembered later that she felt overwhelmed but she wanted to deal with it.

September 7 to October 4, 2020. Carrie was hospitalized because she was having a hard time speaking. This turned out to be caused by a subdural hematoma. She was also prescribed hydrocortisone due to low cortisol levels.

After being discharged, Carrie had more serious issues with memory, impulse control, and strength/stamina, as well as minor issues with verbalization. Constant supervision was encouraged for purposes of safety. Her condition appeared to improve for about a week.

October 10 to October 12, 2020. Carrie was hospitalized because her difficulties with speaking returned. There had been another subdural hematoma.

After being discharged, Carrie regained verbal skills fairly quickly. Her strength/stamina appeared to improve for several months though it never recovered completely. She was not supposed to shower without supervision because she could lose track of time, get tired, and fall down. She also demonstrated a great deal of effort in the following months practicing the keyboard in order to regain some of her piano skills because she had lost most of them.

October 25, 2020. Basic boundaries were reviewed in an email with Carrie's immediate family. Mainly, Carrie should be supervised with food and drink, when taking showers, whenever leaving the apartment, and that there should be no unsupervised phone calls except with family.

April 3, 2021. Carrie passed out briefly while cooking and burned her arm badly on a hot stove element. As a result, she needed to have the burns cleaned and bandaged every few days for a few months. She was no longer supposed to cook without supervision and this was communicated with Carrie's immediate family.

MISTAKES HAPPEN: CLARIFYING BOUNDARIES

June 24, 2021. Corey sent an email to Carrie with tips taken from Facebook that might normally be helpful, however, given Carrie's psychological and physical challenges, some tips were potentially harmful. For example, encouraging Carrie to cook something, take a long shower or go outside and take a walk unsupervised could cause serious problems. Encouraging the playing of loud music could lead to eviction because of Carrie's clinical impulsivity combined with big speakers. For more details, this email is found at the beginning of the copy of the email attachment (PDF) posted above on December 10, 2023. Most of these boundaries had been established months ago and some (like loud music) should be common sense. All in-person visitations were temporarily suspended.

July 2, 2021. This email was intended to establish clear boundaries with the hope that family interactions might improve while allowing me to take proper care of Carrie under very difficult circumstances. For the time being, I would supervise all visits. The email mentioned the importance of positive role models rather than negative ones and it made clear that Carrie struggles with an addictive tendency toward food and screens. Therefore, it would be most helpful to avoid suggesting activities that always involve food, and screens were a potential rabbit hole. Social media in particular was to be avoided because it is the rabbit hole of rabbit holes. I acknowledged that I disagreed with Carrie's immediate family regarding the dangers of food and social media who did not feel that they posed such a serious threat. I summarized my agreement with Carrie that I will do my best to take care of her if she can trust me to do this and she does. Otherwise, I cannot take proper care of her. As her caregiver, I must do what I feel is necessary to take care of her. Finally, I suggested setting up more visits provided that others could commit to respecting these boundaries.

July 6, 2021. John sent an email that reviewed the boundaries and I responded with an email on July 7 that clarified some points.

July 7, 2021. Judy emailed a list of activities that Carrie might enjoy during visits that the immediate family had brainstormed. There were many good ideas and most of them were cheap. I appreciated the work that Carrie's family was doing and nothing was upsetting.

July 21, 2021. As a caregiver, the challenges for Carrie become clearer over time. I emailed an update because it needed to be shared with anyone who was going to be visiting, and it included these instructions: "(1) No caffeinated coffee. The last time Carrie had some, her blood pressure spiked and her verbal abilities became more erratic. (2) Frugal spending. It's my fault for not realizing this one. I've mentioned that Carrie has struggled with spending, although she has not had the opportunity to indulge herself lately. And even if you're spending the money, that makes you the role model. And most of the ideas from everyone do not involve much money, so that's modeling good behavior. However, Carrie and I both agree that deposits in a savings/trust account would mean more than a pedicure. Kristen, that was a very generous offer and you weren't breaking any of the prior boundaries. ... And to clarify, I'm not saying that people can never buy Carrie anything (or that you must buy her stuff). ...Cheaper gifts for birthdays and holidays are sufficient (though not necessary). Otherwise, if she receives an expensive gift from anyone, she knows well enough that she may need that money later more than a gift. Please be aware of this."

MISTAKES ARE THE GIFTS THAT KEEP ON GIVING

September 13, 2021. The email mentioned that Bran died a few days earlier. Also, during a visit in the park on the day that Bran died, Corey and Judy invited Carrie to make applesauce without my supervision. I had not mentioned this during the visit a few days earlier because I was doing my best to be polite and flexible. But I pointed out in this email that their actions violated two boundaries with respect to food activities and supervision.

September 26, 2021. I emailed the immediate family to postpone a Zoom meeting that had been arranged until there had been some acknowledgment of the applesauce incident. John responded, "Regarding the food boundaries, we didn't respond because we didn't know what to say. Partly because we don't seem to understand the boundaries exactly. As far as the applesauce is concerned, that was a plan to harvest apples from our trees, chop them up and make applesauce to freeze for use later in winter. None of us seem to understand how that project crossed the boundaries." On September 27, Corey responded, "I am sorry if by offering to include you in a food-related activity, I disregarded the established boundaries. I am not trying to do that."

October 30, 2021. Judy had emailed some suggested activities for Carrie's birthday and I needed to point out two issues: (1) that the activities would need to be supervised by me and (2) that her suggestion of cupcakes ignored the food boundary.

November 4, 2021. I suggested a Zoom meeting to celebrate Carrie's 50th birthday on November 8. The Zoom meeting occurred without incident.

November 10, 2021. John emailed me to thank us for the recent Zoom meeting and to invite us to Thanksgiving dinner -- as well as to describe the feast, though he acknowledged that he only sent me the email because he knew he was suggesting a food activity. We did not attend.

April 1, 2022. I emailed Carrie's immediate family with an update. Carrie had recently gained ten pounds in a short period of time with an increase in urinary incontinence because she was eating and drinking more than usual. Her doctor was concerned enough about the weight gain that she ordered additional lab tests. In fact, Carrie was having more difficulty with impulsivity in general. I reminded everyone that she should remain in the apartment during visits that did not involve my supervision. No food, alcohol or social media. I also pointed out that during a recent visit from Judy, Judy invited Carrie to an activity that did not involve my supervision while I was in the other room. In the email, I asked them to respect boundaries because their visits were having an effect that was not entirely positive. Corey responded to my email, "I think we are aligned on your objectives, Matt, and we support you and Carrie always."

April 2, 2022. Carrie sent an email because Corey's recent response was confusing. Carrie wanted to be sure that everyone would respect the stated boundaries. Corey responded, "Of course, Carrie. I respect the boundaries and want you to do the same."

April 3, 2022. John sent an email to revisit the same subject. He stated, "I'm starting a new email because I was getting confused. I can state that Judy and I will observe and support the boundaries you have stated for Carrie

(food, alcohol, social media)... Now, it would help me if I could get some more specifics on the boundaries you stated. Social media: what's off limit? Email seems to be ok. I know Facebook is definitely out. But what else? ... Food: this is a tricky one. We have been very casual in the past but I pledge to change! Let us help you monitor Carrie's food intake." This prompted Carrie to become confused and send an email asking, "Why are you asking about food?" John responded, "Ok. Didn't mean to confuse anyone. I understand. Only visit at the apartment, short walks if physical condition allows, no food, alcohol, social media period! Please forgive me for trying to expand my understanding of the boundaries." Carrie and I both felt confused by John's focus on his "understanding of the boundaries." Carrie responded, "The boundaries are clear, I understand them and I agree with them. Your responses seem to avoid the boundaries." There was a visit scheduled for the next day but we postponed it.

April 4, 2022. Kristen sent an email suggesting that an in-person meeting might be arranged to discuss the subject of boundaries. Carrie and I both felt like we were not getting a clear answer about boundaries in writing and that a verbal exchange would be worse. Evasive language is harmful to someone with dementia. I sent an email to decline the suggestion and I responded, "I am asking everyone one more time: for the record, who will clearly agree to respect the boundaries ... as stated, no ifs, ands, or buts, and no further discussion needed?" Corey responded that she had discussed it with the family, and that "no one will encourage Carrie to leave the apartment without your permission and supervision. No activities will include or encourage food, alcohol, or social media." I let Corey's change in wording pass despite the significant change in meaning because I was thoroughly exhausted by this point. And Carrie's impulsivity continued to worsen.

July 21, 2022. Judy sent an email inviting us to a family dinner that we did not attend.

August 4, 2022. These were the recommendations (PDF) from Carrie's second neuropsych evaluation. Carrie was given a second evaluation because her impulsivity had continued to worsen since April. (There have only been two evaluations so far.)

August 11, 2022. I sent an email letting everyone know about Carrie's recent evaluation and that her impulsivity had worsened.

August 15, 2022. Judy sent an email asking how everyone could help. I replied to everyone with an email thanking Judy for her recent visits and welcoming any other visits (implied: from anyone else).

November 9, 2022. Carrie emailed everyone and asked to postpone visits for a while, partly because she had recently started attending Elderhaus during most weekdays. She stated, "Matt and I are having a tough time and Elderhaus is not leaving us much time to invest in our relationship and deal with ordinary stuff. Also, Elderhaus takes a lot of my social ability." She recommended that monthly visits or Zoom meetings would be better. Judy responded, "Whatever works for you Carrie. I'll work my schedule around yours. Also, everyone is invited here for Thanksgiving dinner if you'd like to come." We did not attend the Thanksgiving dinner.

November 11, 2022. I sent an email with an update about Carrie and other emails were exchanged. Carrie bent over to put a weight scale on the floor, stood up and passed out early in the morning when trying to weigh herself. She had tested positive for COVID the night before and she was more tired than usual. She hit the floor with her face (ouch!) and her nose was bleeding. She laid down and her bed and her nosebleed stopped while

we contacted her doctor who told us to go to the ER. I was going to drive her there but Carrie did not get far from the bed before her nose started bleeding again. She laid back down and was taken to the ER by ambulance. Her nosebleed eventually stopped at the ER but she suffered serious bruising that got a lot worse as the day progressed. We were both glad that it was not worse. I mentioned in the email that we were worried about the bills for the ambulance and the ER. John and Judy offered a donation that we gratefully accepted.

December 18, 2022. Carrie and I attended a Zoom meeting with Carrie's family without incident. Then after the meeting, Judy sent an email inviting us to a Christmas dinner that we did not attend.

December 25, 2022. John and Judy drove to our apartment for a Christmas visit in the afternoon. They stayed in the car in the parking lot because John was having trouble with his back. We visited in the car for a while. It was a relatively pleasant visit.

Financially, the next few months were much more difficult than usual. I had resigned from a job because of caregiving responsibilities and complications. I was still looking for work. Carrie and I were facing the possibility of eventual homelessness, which was only a slim possibility but that's enough to cause some serious stress for both of us. That point is important in order to understand what follows.

March 21, 2023. I emailed my sister Naomi, telling her that I was still looking for work. I also mentioned Carrie's family, "... they have consistently invited us to special dinners despite my requests not to do so, and food continues to be a regular topic in conversations. And when talking to Carrie, there's the occasional comment like, 'So-and-so posted some cool photos on Facebook,' or 'It's too bad you're not on Facebook or Instant Messenger.' And a common saying among family members is: 'I do what I want.' Their behavior has a bad effect on Carrie, and it definitely has a bad effect on me. They are driving me crazy."

THE LAST STRAW

April 2, 2023. Corey sent an email to arrange a Zoom meeting among family for a pleasant visit.

April 5, 2023. I emailed, "It's been a very stressful week here. We need to renew our lease soon and they've increased the rent by almost \$200 a month. I'm still looking for work and I already did not know how we were going to cover the existing bills. We may need to move to a smaller place (and moving is expensive). At this point, financial donations would be accepted, but that's not why I'm writing. Carrie is excited to hear more about her being a great aunt. However, we're both stressed right now. I hope you can understand that discussions of the latest trips that people have taken, or new jobs, or home remodeling in-progress, etc. would only make Carrie's emotional state worse. It wouldn't help me either, but I'm focused on taking care of her. She's looking forward to the Zoom meeting. Please, please, please avoid burdening her with extra stress. And I really hope you can understand why I need to ask this." Corey responded, "Hi Matt, I'm sorry to hear it's been hard lately. We're all sending our love. Absolutely, we can honor that request to talk about things that won't trigger Carrie's sadness/stress. I'm glad we get the chance to be together as a family in any form. I'll send that zoom link today."

April 9, 2023. The Zoom meeting went relatively well until the end of the conversation when Judy inquired about what [names redacted] were going to do with their extra property in Hawaii. Were they going to rent or sell? Perhaps a Bed and Breakfast? Given our situation and my polite request, this was incredibly insensitive. At this point, more than enough damage had been done and I disconnected the Zoom call.

April 10, 2023. John texted from his phone, "Matt I'm sorry about yesterday's zoom call going into vacation and trips. I should have thought and tried to change the subject but my back was hurting and I wasn't thinking clearly. Muscle spasms in my back were distracting me during the call. I can usually calm things down by reading, listening to music and relaxing in my recliner. But yesterday the spasms were too frequent and intense. I'll remind Corey and Kristen and we'll try to do better, especially in reminding Carrie that she will always have a safe place. Again, sorry about yesterday."

April 11, 2023. I responded, "John, I appreciate your apology; however, I don't blame you specifically. Corey, Kristen, and Judy were part of this conversation. Your explanation does not explain why Corey and Kristen failed to change the subject, or why Judy did this in the first place. As stated more than once, we are under immense stress and this simple Zoom call made it even worse. I hope you can understand that I need to cancel future Zoom meetings, and that phone and email conversations will be strictly monitored. I will take it upon myself to protect Carrie's mental health because I have to do so. Any phone conversations that venture into the area of all the cool things Carrie's family is doing with their money, or their new sources of income will be ended with a hangup. And any emails that go there will be deleted. At this point, unfortunately, that's my job."

It should be noted that no one else emailed to apologize.

April 17, 2023. John sent an email that walked back his apology. He stated, "It has taken me several days to gather my thoughts so that I can share them with you. And I do so with understanding and good will and hope you can accept these thoughts in the same way. First, when you are angry with, criticize, or are rude toward Judy, Corey, and Kristen, you need to realize that I love them very much! I love them as much as I love Carrie! They are just as much a part of my family as if they or Carrie were attached to my arm. So it hurts just as much as if you criticized me or Carrie." I emailed the following response, "I have given your email serious thought and I've discussed it with Carrie. We have no intention of hurting you or anyone else. Nevertheless, there appears to have a case of irreconcilable differences here with respect to our values. I could speak much more on this subject in another email if you wish to read it. I have also been reviewing emails from the past two years and they demonstrate a pattern. I'll be happy to gather these emails into a PDF and send you a copy if you wish. First, I alone have the responsibility to take care of Carrie (regardless of whether you disagree) while you and other family members disagree about how this should be done. I am responsible for my own mental health and I am responsible for Carrie's mental health because I'm her husband and she suffers from dementia. I am in no way responsible for your mental health or anyone else's. Second, regarding topics included in social conversation, I recommend Googling 'is it impolite to talk about money' in order to get a sense that there are people who consider this rude. Of course, some people do it and this relates to irreconcilable differences. You are going to do what you're going to do, and the same goes for Judy, Corey and Kristen. However, when this has a negative effect on Carrie's mental health, then I have a responsibility to take care of her. Carrie and I have discussed this and we agree that we should limit communication at this time to texts, email or mail. (Meaning: no visits, phone calls, or Zoom.) Again, we are not doing this to intentionally hurt anyone, but it is clear that you,

Judy, Corey and Kristen are going to do what you're going to do. This boundary is necessary to protect Carrie's mental health. John, you are Carrie's father, therefore, I hope you can appreciate the effort that I am making to take care of her. Please respect this boundary that Carrie has approved. And if you wish to communicate this boundary to other family members, let me know and I'll leave that to you. Otherwise, I can send out another email."

June 5, 2023. John emailed, "I have a favor to ask. Judy's arthritis has taken a serious flare up and she is in some pain. That has also caused her to be a little despondent. I think that a call from Carrie would raise her spirits and help her forget about the pain for a few minutes. It wouldn't need to be long just a quick hello. But I think it would help. If you don't think it's a good idea, I understand. Thanks for giving it consideration." I responded, "I've been giving this a lot of thought. And I was not offended by your question. For Carrie's sake, I would like for her to be able to talk to you, or Judy, Corey, or Kristen, whether by phone, Zoom, or in-person. Therefore, if everyone can respect current boundaries until December (texts, email and mail), then we can discuss opening up communication for the holidays. I need to know that everyone can do this. In the meantime, John, I am not comfortable accepting donations, though I sincerely appreciate the thought. Thanks to you and Judy for the prior support."

July 21, 2023. John emailed, "I don't want to cross any boundaries but I do want you to know. And if you think it's appropriate, tell Carrie... [names redacted] will be here Tuesday morning for a very brief visit while they are on their way east to their new posting. I don't know what time exactly, just that it won't be very long. They will be in Maryland for 3 years and then they could be sent to a number of places including overseas. If you want to discuss it with me, give me, give me a call." I had already stated that we needed to see if boundaries could be respected and I was exhausted. I did not respond to this email.

July 23, 2023. John emailed, "Just a quick update on the arrival of [names redacted]. They plan to be here around 8-9 am. And they won't stay long as they are trying to make it to Omaha Tuesday night. If that's too tight of a turn around for you. No problem. Or if you didn't plan to do anything, I understand. I would appreciate some sort of a response, so I know you're getting my emails. Thanks." I hope it is apparent to the reader that John's emails ignored my prior email. I responded, "I have been getting your emails. We will not be there on Tuesday for what should be obvious reasons. In other words, you really should not be asking. To clarify: at this point, Carrie and I will not be available for any Zoom calls, phone calls, or in-person visits, including hospitalizations and funerals, between now and December. If more respect is shown to boundaries between now and December, I will consider making exceptions to this boundary to some degree. So far, I have already had multiple requests from different people ignoring this boundary. If this does not improve by December, communication will be severed. And I am not willing to discuss this further. (Note: if you cannot remember the boundary issues that go back a little over two years, then I will agree to compile these emails and send them to you, though it would take some time.) Carrie has approved this email, and she hopes very much that you'll be willing to respect this boundary."

After reviewing prior emails, I decided that there was no more hope for constructive dialogue. There comes a time when lines must be drawn. I could not continue to place Carrie or myself in this position. Communications during the proceeding months were limited to texts, mail and email. These communications were not toxic but trust had been severely damaged. In addition,

in October 2023, our car was destroyed in a fire when a neighbor's car was set on fire for reasons we do not know (and that car was also destroyed). Given the amount of the insurance settlement and the price of cars, our best option was to buy a car with serious problems because other options in the same price range had even more serious problems. This involved adding thousands of dollars to a great deal of existing credit card debt just to make the car drivable. Even then, I would not risk driving it out of town.

December 10, 2023. For Carrie's health and mine, I emailed, "John, Judy, Kristen, and Corey, I hereby acknowledge that communication between each of you and Carrie using texts, mail and email in the past few months has not been toxic. As a result, these forms of communication will remain open unless they become toxic in the future. Unfortunately, other family interactions in the past two years have been repeatedly toxic (see attached PDF). Since 2021, boundaries have been repeatedly ignored and promises have been broken to the point of insult. I have reflected a great deal on these last two years and there is no reason to expect anything will change. For the sake of Carrie's mental health and mine, communication with Carrie will be limited to texts, mail and email. To be clear: None of you are allowed to supervise Carrie and none of you are allowed in our apartment. I am done. Do not contact me."

Update added on February 12, 2025: In the time since communication was restricted between Carrie and her immediate family, I was working a part time job. I eventually resigned and accepted a part time job with slightly better hours and pay. More recently I've been working two part time jobs. However, our financial situation has not improved because of unexpected car repairs and minimum credit card payments that have grown.

Despite our challenges, Carrie and I have been more stable emotionally than we were prior to restricting communication with her family; in comparison, if I had not done that, I might have committed suicide by now. I am being very honest. After restricting communication, I haven't been as stressed. Carrie's struggle with impulsivity improved a little at first and has stabilized and we are hoping that she may not need another neuropsychological evaluation for some time (crossing fingers). [When reviewing the timeline, Carrie added: "All my fingers are crossed. But not my toes. Or my eyes."]

In any case, I hope this timeline helps to clarify why this restriction is in place and to show that it has been helpful. [Carrie added: "I really miss my family. But the damage they're doing to Matt and me is terrible. It is better this way." And speaking to me, she said, "Thank you."]

I hereby added: Happy Valentine's Day! I love you very much.

[Carrie added: "I love you very much as well."]