

Detour Ahead: Planning for Contingencies on Your Caregiving Journey

ACT I.

Case Study:

Chloe was born deaf and exhibited signs of developmental delays in early childhood. Now 17, her parents, Trey and Tina, both active duty, want and need to start planning for what comes next in Chloe's life. They enjoy their posting, especially because Chloe is so well-cared for and content. Recently Chloe has grown restless and started acting out at school. Tina thinks that she isn't stimulated enough during the day and needs to start some type of skills training. Trey worries that "his little girl" isn't ready for any additional stress or pressure.

Alicia: Trey, it always brightens my day when I see your name on my calendar.

Andy: We've been in and out of this office so much I feel like I should have a chair named after me or something.

AL: All the chairs in this office are named after your Uncle Sam so good luck. In my notes for today it says that you and Tina have some concerns about Chloe starting some technical training through the local program.

AN: Yeah, Tina is hot to trot about this but I'm not so sure. Chloe is so fragile sometimes and I worry she's not ready. Which is to say, I worry that I'm not ready, I guess. I want what's best for her. And I realize Tina does, too. But how the hell do you know what's best? And it's really causing a lot of heartache around the house.

AL: Like the heartache when you two were first discussing putting Chloe into public school?

AN: Different. Well, maybe not so different. It was easier then. She goes to school. The end. She has a teacher, she has classmates, she does her schoolwork, eats her lunch, does some more schoolwork and then comes home. We had time to figure out what comes next.

AL: That was 10 years ago. What comes next is now. So if you close your eyes and imagine the next 5-10-15 years of Chloe's life, what does it look like? From your perspective, of course. Chloe may have different ideas.

AN: Oh man does she have ideas. I guess I want her to be happy. Content. Like she is now. I want her to know that her mom and I would do anything in the world with her and for her to keep her happy and content. And safe. And I want her to be okay one day when we're not here.

AL: Hopefully that day is a long way off. The report I have from the school says that she is strongly task-oriented and shows real aptitude with organization and processes. But that her attention sometimes wanders.

AN: Tina thinks the wandering is that she's bored. She's great when you make a list of what needs to be done and she can follow it. She's not so great when things get out of whack but we try to structure her tasks so we minimize things that can go wrong. Do you know the other day she made a cake after Tina rewrote the recipe in more of a stepwise format?

AL: How was it?

AN: What?

AL: The cake.

AN: Delicious. And I think you can probably still see her beaming.

AL: The local training program has a culinary track, you know?

AN: I didn't. I've been so caught up in safety and contentment that I haven't even looked at what they offered.

AL: So maybe a good first step for you is to take a look at what they offer. They have this thing now called the internet and you can find just about anything you want And a good first step for you all might be to arrange a visit.

AN: But what if she hates it?

AL: What if she doesn't? It's a first step. There's no pressure, no rush, no commitment. It's a field trip – you go, you look around, you go back home and have a piece of cake. But it's just like all the other times we've talked about Chloe over the years – try it and see what sticks. Revisit, revise, reward, retreat as needed. You and Tina have worked so hard for a long time to pivot and adapt to the next iteration of Chloe's life. It's time to start considering "what comes next" next.