

Tom's Story

When I was in high school, I played a lot of sports and was a good athlete. When I wasn't playing sports or working out, I enjoyed partying with my friends. One weekend before graduation, I had been drinking at a party and crashed my car into a telephone pole. The accident caused a brain injury that has led to problems walking, talking, and remembering things.

I've lived with my mom since the injury; she's my main support, and I appreciate all that she does. However, I have a lot of frustration due to her constant worrying about my safety, my lack of social options outside of her and my older brother, and the fact that I can't do what I used to do. I end up taking my frustration out on her. I used to take great pride in my appearance and my many friends, but now I have little control over my appearance and barely any contact with my friends. I miss playing sports and all the physical things I used to be able to do. Since I can't drink alcohol anymore, I try to get a buzz from drinking lots of caffeinated drinks like soda or coffee.

My health has not been good recently. I am incontinent, which is embarrassing and causes skin problems. I have been in and out of the hospital four times in the last year; once for a seizure and three times for falls. I still see my pediatrician, who doesn't really know what to do with me or how to get me the help I need to get back some of the things I miss about my life before the accident.

Care Coordination

My mom and I knew that we needed to make a change in my care. On the recommendation from my care coordinator, we met with a nurse social worker who did an assessment in my home. I felt she understood my frustrations and didn't just focus on my brain injury. She explained there were people who could work with me so I might feel less angry and help me build skills so that I could get back to more of the things I miss. I also learned there are other support options and social outlets that can help me be more self-reliant and not as dependent on my mom.

What is Important to Tom:

- Independence, especially concerning personal care
- Building relationships and overcoming physical limitations that lead to social isolation

The care coordinator and social worker helped me with getting a home assessment for safety, hiring a personal care assistant (PCA) to help with my care, and linking me to an independent living skills specialist to help me learn new ways to access the community and meet new people. My care coordinator and I also found a new primary care doctor serving adults who better understands my issues and is at a clinic that is physically accessible. I have met with specialists in neurology, urology, psychiatry, and physical medicine and rehabilitation, and communicate with these providers based on our communication plan.

The Impact of Care Coordination on Tom's Life

My care coordinator and nurse social worker helped me to realize that I could have more control of my life. They understood my need for independence and aversion to living in a nursing home. Working with rehabilitation therapists has given me more independence and allowed me to be less reliant on my mother. I have learned safe transferring skills and can now bathe independently with a bath transfer bench and grab bars. I have been able to work out at the YMCA with my PCA, which helps me feel better about my own physical appearance. I also hang out with friends now at a local spot several days a week and feel much less isolated.

Disclaimer: Names and identifying details have been changed to protect the privacy of individuals.

You can find additional resources regarding the Disability-Competent Care Model [here](#).