



What's Working?

List past experiences where taking a break was successful or helpful

Taking a break is helpful when I'm feeling exhausted, burnt out or overwhelmed by providing 24/7 care for my child. Respite is also a great preventative tool for me; when I intentionally plan and build in breaks, it rejuvenates me and allows me to provide better care for my daughter in the long run.

List Past experiences where taking a break didn't work out well

We have had inconsistent care from private duty nurses. In the past, nurses were "checked out", on their devices or not providing safe and sufficient care for our child.

What Would It Take?

List current or future life experiences or goals that will continue to support your good life vision

My goal is to plan intentional, regular breaks where I can spend time with my spouse, one-on-one time with my other children and self-care time alone. Currently, I plan one small break each month but am working towards scheduling shorter weekly breaks to allow myself time to focus on other tasks while my child is being cared for by loved ones.

List what might make it hard to take a break from caregiving

Nursing shortages make it difficult to plan regular respite breaks, due to inconsistent scheduling and staffing. Our child has a very busy therapy and appointment schedule; I'm not willing to miss any of her appointments, so it limits the times available for me to schedule breaks.

Vision for a Good Life

For the care recipient

Our goal for Ella has always been to provide her with the best, happiest life possible. We strive to enhance her life with a significant number of therapies and interventions to allow her to develop independence and confidence. She is constantly defying the odds (and proving medical professionals wrong) so we typically get 2-3 opinions from different physicians before proceeding with a medical decision. Our girl is determined and continuously challenging the status quo, so our plan for her is always changing and adapting to follow her lead.

For the caregiver

I envision a healthy caregiver-wife-mom balance where I can provide the highest level of care for my medically complex child, while also being intentional with my time with my other children. I want to create a consistent, reliable respite team for her so that I can care for myself, as well as continue developing relationships with my other children that give them a break from the every day demands of being a sibling to a child with medical complexities.

Vision for good respite

We see good respite as having a consistent, reliable team of loved ones that can care for Ella with the same level of love that our family does. We expect respite providers to meet her medical and health needs while also interacting with her. Our respite providers are trained in understanding Ella's robust communication methods, ASL, seizure protocols and preferred toys/activities. We encourage respite providers to incorporate fun, novel experiences to enhance their time together.

What We Don't Want

For the care recipient

We don't want our daughter to be ignored, neglected or left alone while being cared for.

We don't want her to lose out on opportunity to interact, be active, and communicated with, while she is in the care of a respite provider

For the caregiver

We don't want a caregiver that is passive, negative, or distracted while caring for our daughter.

We expect our caregiver to be consistent, loving, active, and positive during their time with our child.

Not good respite

Respite providers that are distracted (ex. on their phones), inattentive or inconsistent in their care are not ones that we welcome onto Ella's team.

