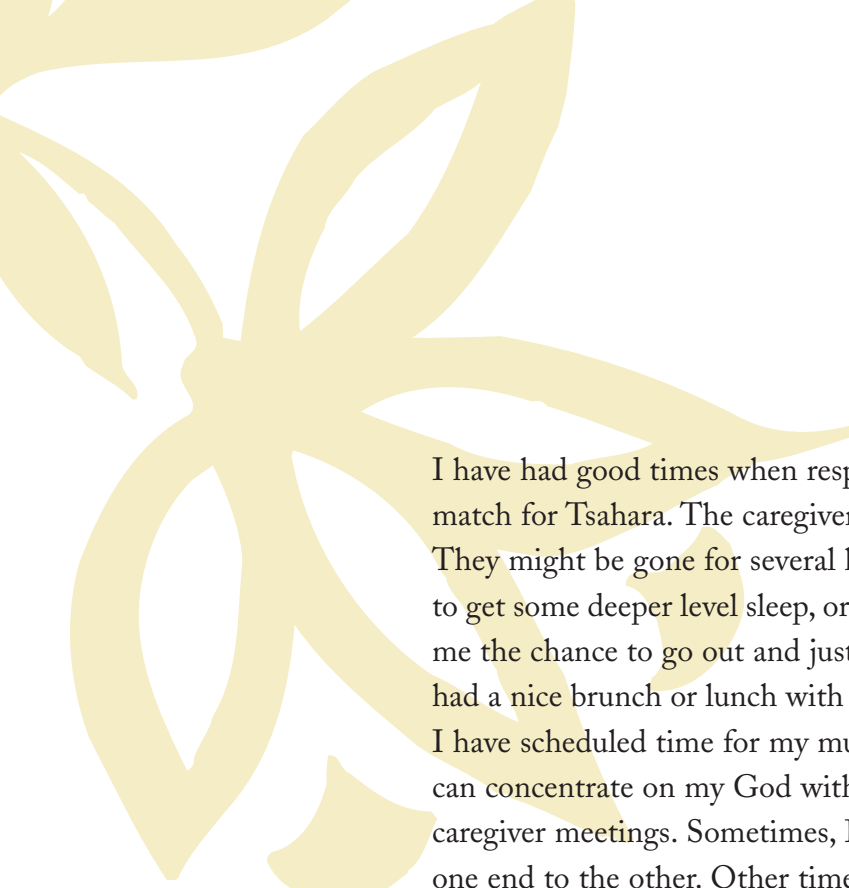


Respite: A Quest for Rest

I AM A SINGLE PARENT AND SOLE CAREGIVER OF A teenager with mild cerebral palsy and cognitive challenges complicated by oppositional defiant disorder. I often find myself hearing Hamlet's words in my mind, "to sleep, perchance to dream: ay there's the rub". Now don't get me wrong, I love life and unlike the prince of Denmark, I don't wish to "shuffle off this mortal coil" to sleep. I find myself often desiring just the option of being able to sleep, perchance to dream without having to worry about what damage Tsahara is doing to herself or the house or our belongings in her impulsive efforts to have fun at inappropriate times.

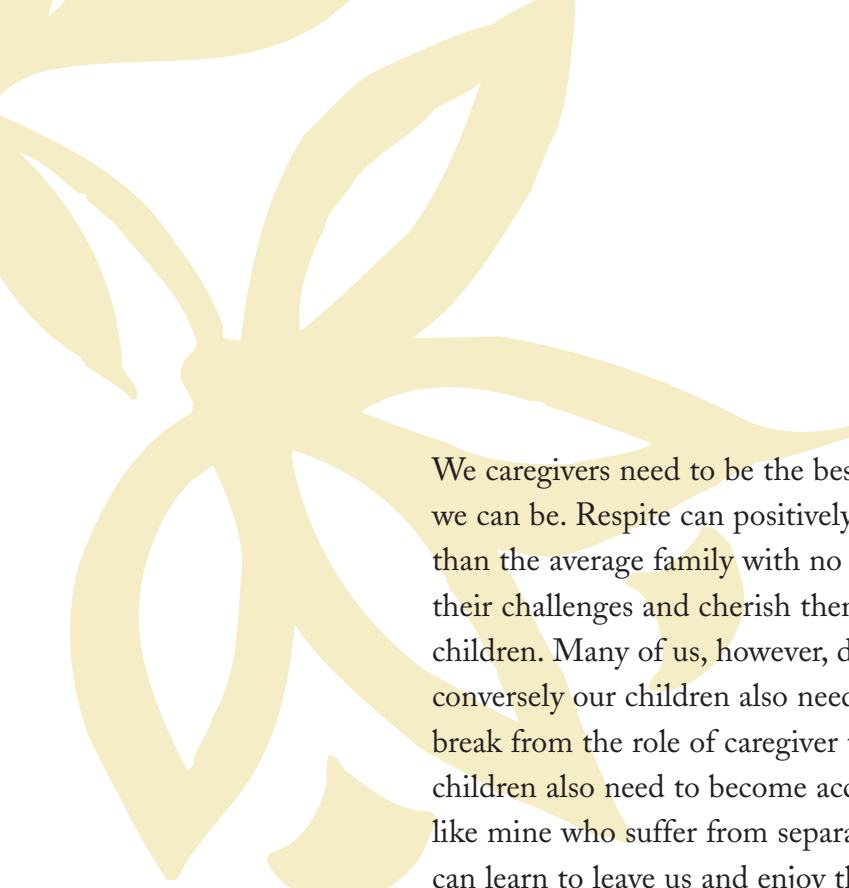
It is the extremely rare occasion that I can go to sleep and sleep deeply enough to have a dream. One might say everyone dreams, but most people forget their dreams as soon as they wake up. I have never been one of those. I have always remembered and explored my dreams. I have often revisited them, changing the outcomes and consciously manipulating circumstances that I have found disturbing in them. My dream state has been something of an alternate reality for me; a place to escape the stresses and dramas of waking life. Without respite, I can almost guarantee that dream level of sleep will not be reached. I have to hear every sound that might be made in order to circumvent Tsahara's impulses to do inappropriate things at night. Life has become a series of long, awake and conscious, stress-filled events joined by mostly cat-naps and some home-based respite sponsored hours of deep sleep. I have spoken to many families with special needs members, and I have found that respite is the most underused benefit offered to caregivers. Caregivers admit to being burned out and tired all the time, but have either not considered or just haven't taken the time to try respite. I have seen both sides of the respite coin, and in my humble opinion, the good outweighs the bad hands down. I urge any caregiver to utilize this benefit even if you have help from family members in caring for your child.



I have had good times when respite has been in place and the provider was a great match for Tsahara. The caregiver might take Tsahara out to the park or to an activity. They might be gone for several hours which would give me the option of being able to get some deeper level sleep, or some extra time to work, if needed. Respite has given me the chance to go out and just do something for myself. I have visited with friends, had a nice brunch or lunch with them, caught a free concert, or I have gone shopping. I have scheduled time for my much needed Bible study during respite hours when I can concentrate on my God without interruption. I often used my respite to attend caregiver meetings. Sometimes, I would get on the cross-town bus and just ride from one end to the other. Other times I would just stay in and watch a movie that had no precocious children, talking animals, or animated characters in its cast.

Admittedly, getting to that good place can sometimes be trying. I have lived that experience as well. Companies can send people out who are not equipped to properly handle your child. Or as soon as you start to become comfortable that a caregiver is the right fit for you and your child and you plan to go out for your respite hours, they send a new person. For me, the most infuriatingly stressful thing is when they just keep sending someone new every week for several months at a time. I understand that the nature of the agency means that there is a high turnover and people will go where they have the best pay, hours, workload, etc. As non-employees the respite caregivers can decide if they want to work and what assignments they choose to accept. However, with persistence and good screening, home based respite can work really well.

If you just really can't wrap your brain, time and effort in acquiring home-based respite, there are other options for respite available as well. Some facilities such as The HSC Pediatric Center offer in-house respite to certain populations. Social groups for special needs children and youth give the caregiver time to do a few things for themselves or for other typically developing siblings. If you need a break from the associated drama of typical siblings as well, Sibshops offers a respite alternative for them, too. Regular activities such as K.E.E.N. (Kids Enjoy Exercise Now) can also provide respite time. Play dates can also be a viable alternative to home-based respite. Networking with other parents of special needs children is the key to making this option work.



We caregivers need to be the best person we can be in order to be the best caregivers we can be. Respite can positively impact our quality of life, which is inherently less than the average family with no special needs members. We accept our children and their challenges and cherish them. Most of us would not willingly give up our children. Many of us, however, do need a break from them from time to time, and conversely our children also need that break time from us. We need an occasional break from the role of caregiver to keep us from losing the person we are. Our children also need to become accustomed to us having that time away. For children like mine who suffer from separation anxiety, respite can even be therapeutic. They can learn to leave us and enjoy their own activities, reporting back to us about what they did. It allows them to miss us for a little while when we leave and understand that they weren't abandoned when we return.

In my household, respite is like the Holy Grail, something known to exist, searched for and possibly found, but never quite really permanently recovered. Like the knights of old and the archaeologists of later times, I never give up the hope of finding it and holding on to it. It is an elixir of life, and a key to my sanity.