

Ellyn



We define ourselves in the roles we have. I am a wife, mom, grandma, sister and a psychotherapist. I live in Madison, Wisconsin with my husband, Jim. We have been married for 32 years. We met in Boulder, Colorado when we were both students at the university there. I was completing a degree in psychology and he was finishing his Ph.D. in literature. I was 25 then.

It was shortly after we met that I got a diagnosis of retinitis pigmentosa. I was a single mom with a small child. It was a devastating time for me, but I was determined to remain independent. My brother had vision loss and serious medical issues, and I had grown up seeing how few options seemed open to him. My parents coddled him rather than pushing him to be more independent. I was determined to adapt and not have the same restrictions.

We have learned over the years that siblings with BBS may not have the same symptoms, and this is the case in my family. Of the three of us who were affected by BBS, one died before the age of one, and my brother died ten years ago. I did not develop the more serious medical problems that they had. Carrier genes for my three remaining siblings have not been ruled out.

My daughter's family lives close by and my granddaughter, now 14, is very much part of our household. My family of origin was often secretive about the problems that the three affected siblings had, and I have made sure that my own family talks openly about BBS and vision loss and that it is not seen as something that limits choices. We do things differently, and differences are accepted and encouraged.

Adapting to vision loss is an ongoing lifestyle challenge. I am a licensed marriage and family therapist in private practice. I earned my master's degree in 1987 before we left Boulder. I went back to school over the next few years for postgraduate coursework needed for my license. I found that even working in a clinic was challenging, and for many years I was not very upfront about my disappearing vision. Seven years ago I left group practice and am now a solo practitioner, sharing an office with another professional. I have a mixed practice of both men and women, seen individually or as couples. I see clients three days a week, and the other days are set aside for phone calls to clients, dealing with insurance companies or typing up clinic notes.

There is a lot of documenting in this field, but technology makes it all possible for someone with very little vision. WindowEyes and an iPhone keep my practice up and running. I communicate with my clients by voice text and email. Siri makes it easy to set up appointments and enter phone numbers. I'm still an avid reader through audiobooks, and as needed I make book referrals to my clients. I have office staff, just like any other practice. Jim is my silent business partner with HIPAA clearance. He is the "eyes". We work around each other's schedules so that I do not have to take many cabs to work. Besides my practice as a psychotherapist, I am now facilitating support groups for adults with BBS, and a book discussion group is also starting. I have worked as a psychotherapist for the last 25 years and I have no plans of retiring any time soon.

-Ellyn Hunter