

The Mature Rett Woman

If you're the parent, relative, friend or caregiver of an adult Rett woman, you face special challenges. You will worry about her care, her health and her future.

Should you arrange for her trusteeship at 18 (yes!)? What care options are open to you? What health issues will she face?

And, sadly, what about the end of life? For more information, [click here](#).

As you deal with RTT through the years, IRSF can assist you with information and support.

The IRSF has a network for the Mature Rett Woman, which you can join. The RettNet ([LINK TO INFO ON THIS](#)) is also an ideal place to get feedback or advice.

Here are some recent comments from the parents of mature Rett women- the real experts:

"We are 67 and 68, Our Rett daughter Shelley has always lived with us. We are going to try to keep her with one of us, and or her brother and sisters. At this time Shelley's siblings are against having Shelley in any institution. But we always live with that fear. We pray we outlive her or we all go together. But we know the realities of life and like many other parents we have not found the perfect solution. One cannot depend on their children even though we hope."

"All Rett girls do not qualify for group home placement. If they are not mobile at all and must be diaper changed and fed, in most states that means a nursing home type of environment. And some are very fragile in health and require lots of medical intervention on a daily basis. If you live in one of the "good" states that provide more money for this type of care, then you are lucky. Also, I do realize that some families have the finances to be able to provide 24-hour care on their own, but in reality, most of us do not. Our Rett daughter is 24, and in our area, we have been told that Kimberly does not qualify for any of our area group homes. She wears diapers, must be fed, is not mobile at all and weighs 103 lbs, she requires a minimum of two breathing treatments a day on good days, and the list goes on. She would be placed in a nursing home situation if something happened to both of us. Needless to say, she is not going anywhere. Kimberly goes to a fabulous day program five days per week, and it took us 1 1/2 years to get her into that program after high school. When she got transferred to the waiver that paid for her day program, they took away all respite that I had. I only got eight hours per week anyway, but poof, it was gone. We have had trusts setup for many years and just revised them last year. While, it is far from the ideal, our oldest daughter has basically told me that she would never forgive me unless we made her Kimberly's guardian if something happened to her dad and myself. She is a wonderful daughter and mother herself, but she has her own family, and it makes me sad to think of her taking on the care of her sister. However, we did this last year when we updated our will's/trusts. We have the same dream as I'm sure all of you do, that all 3 of us die on the same day, but I know that is just a fantasy. It breaks my heart to think that our oldest daughter might someday be Kimberly's main caregiver, however, the scarier thought is Kimberly being placed in a nursing home. So, as of today and hopefully and for the long time in the future, she is home with us."

"My daughter Carol (31) an active member of our family of three. By

Rett standards, I'd say she had just about everything Rett could throw at her. A few things we threw back and more stuck around. By Medicaid and the state method of scoring, she's total care. At 65 lbs, I can lift and carry without to many snaps and crackles on my 56 y/o body. That weight lifting class 25 year ago has paid off big time. Her best form of transportation is her wheelchair and adapted golf cart. As long as I've got a full spoon on stand by, she's a great eater and loves her 48 oz of water everyday. Carol attends a Day Treatment program 4 days a week and hangs out with her dad or me....depending on who's doing what. She ramp bowls on a league on Saturday's and we volunteer at an animal shelter. We have a 40-foot motor home that we've put to good use. She enjoys the adventure and the food. She has a

pen pal and friends in all the places we've visited. She's fearless and brave. But tender and loving. We have a will and trust in place for Carol. Plus we have three different options if something should happen to both of us. One option is a dear friend who's a Rett Mom as well. In turn, we will do the same for her Rett relations. I don't worry about aging or that Carol won't be taken care of.....because I know she will be. Rett is to damn hard in the early years, at 31, we're looking for the next big adventures waiting for the three of us. We're not waiting for Rett to come pounding on our door againWe're to busy living!"

"I have been in a very bleak place in my life recently after realizing I wasn't coping with my beautiful girls, Asha and Bree living in the family home. They turned 25 this year. There is such a stigma attached to the topic of not being able to or not wanting to provide lifetime care for a child with a disability that when the time came to make that decision in my case I felt as though I was committing some dreadful sin and my soul will be sent to hell for doing so. Why has society done this to parents of children/adults with special needs? And especially why do other parents of children with special needs do this to each other? It has taken me months to sift through my thoughts and feelings about not being able to and not wanting to be a fulltime caregiver any longer and justifying to myself all the reasons behind my decision. I have answered most of my own questions and finally justified my decision to myself and I have also come to the conclusion the one thing that has messed me up the most is the huge guilt thing I carry around that has been slowly but surely imprinted in my conscience over the years of " a good mother will never give her child up" and " they should live at home with us" and the tsk tsk by others when I went against these beliefs."

"I would like to offer hope to other families who are feeling the stress, that there are options to explore, many good ones, and not necessarily mine. I am a control freak when it comes to Angie, but have learned over the years to let go a little bit at a time. It begins with hiring sitters when the kids are young, and can graduate up to whatever you feel you can live with as they grow older. Could it be better? Of course. There is never going to be the perfect solution, as our emotions are so tied to our kids, and our emotions are never perfect. Those who are more medically fragile than Angie, may have to have a plan tailored to their more specific needs."