

Intro to Adult Years

There are advantages for the woman with Rett Syndrome. Her mental state is essentially stable and she continues to learn; her motivation and skill for hand use may increase; her potential for walking continues in spite of the tendency to develop deformities; and her ability to communicate improves. We can help this communication by protecting her long term relationships with the people who matter most to her, by making time for undemanding face-to-face interaction, and by learning to use non-speech vocalization and music as a personal means of communication. ~ Dr. Alison Kerr

When the school bus doesn't come anymore, the woman with RS needs an appropriate adult program that meets her own special needs. A number of different programs may be found in the community, which should be explored for the one best suited to her. Often, these programs are a carry-over of the developmental approach used in the public schools. However, while the structure of the program is important, the most crucial aspect is finding caregivers who understand her and are knowledgeable about RS. They will make the biggest difference in her life. She needs to continue therapies that will help her remain as mobile as possible, and a communication system that allows her to relate her wants and needs and to make choices. She should have good medical care by professionals who are aware of the changes which take place as she advances in age and stage of RS. She should have opportunities to participate in community activities and experiences that enrich her social life. Her parents are getting older, too, and may not be able to continue to provide the same quantity and quality of care as in earlier years. It is wise to seek help so that she is allowed the continuity of good care.

Many families tell us that in many ways, the older girl and woman with RS is more settled and mellow, better than she has been her whole life. She makes better eye contact, is less irritable and has fewer panic attacks, seizures and breathing problems. She may sleep better. The sweeping mood changes that characterized her early years are gone and she enjoys activities that once frustrated or angered her. Her hand movements may become less complicated and intense.

Se may continue to walk well into adulthood, but as she gets older she may face other problems. Her muscle tone may increase, causing contractures of her joints that limit mobility. Girls with RS who have the least muscle tone (hypotonia) as children become the most rigid or spastic (hypertonic) in adulthood. When tight muscles pull her joints into abnormal positions, she may develop foot deformities which make it more difficult to walk and even to find shoes that fit. Dystonia may begin with the foot turning in and over time, may advance and worsen with movement. She may have increased kyphosis or scoliosis and intermittent muscle spasms. All of these factors can lead to decreased mobility.

To minimize deformities:

Promote good standing and sitting posture

Encourage active movement through walking and exercise

Use hydrotherapy

Do passive range of motion exercises

Use hand, elbow and/or foot splints

Treat rapidly progressing scoliosis with bracing or surgery

Correct foot deformities before they cause discomfort

Many women gain sufficient weight in early adulthood, and some even become overweight. However, if she weighs well below what she should for her height, measures should be taken to increase her weight. If this cannot be accomplished by adding calories through extra meals and snacks in her diet, inserting a G-tube may be necessary.

Seizures often come less frequently or even disappear in adulthood. In women who continue to have seizures, they are usually well-controlled with medication. If she has not had seizures for a considerable period of time, it may be possible to reduce or gradually stop anti-seizure medications. This should always be done very slowly, and only with a doctor's permission.

As she gets older, the disorganized breathing patterns which she had as a child may decrease. Hyperventilation usually decreases, although she may continue to have breath holding episodes. While sometimes difficult to watch, these episodes do not seem to cause pain or distress. They may occur rarely at night, but they do not seem to contribute to a severe drop in blood oxygen supply. If you notice long breath holding at night or breath holding that produces a color change, it may be important to see an Ear, Nose and Throat specialist to rule out a simple obstruction caused by enlarged tonsils and/or adenoids. In rare cases, surgery is necessary and helpful.

While we do not understand why, some women return to the crying and irritability which characterized their early years. This is frustrating for everyone concerned. Sometimes the source can be traced to a toothache, constipation, heartburn, headache, menstrual pain, gall bladder disease or muscle aches. Sometimes it can be identified as anger, frustration or boredom. Unfortunately, at other times these crying spells cannot be understood. It is very important to rule out obvious physical causes for pain, such as mentioned above. Some of the remedies which worked in childhood may work again. If not, sometimes giving her comforting words and some quiet space to recover is what she needs most.

While sudden death in sleep does occur, most women with RS can continue to live well into their 40's and 50's with good medical care, nutrition and therapy.

What kinds of programs are available when her school years are over?

In most cases, education in the public schools can continue until age 21. After this time, the availability of programs varies vastly from one area to another. Programs range from respite and in-home care to sheltered workshops and day centers. Residential programs present another option. More recently, some girls with RS have been able to attend college classes with assistance or work at community jobs with a job coach.

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