

## Growing Up: Care for the Woman with Rett syndrome

### Age Has its Rewards:

GROWING OLDER WITH RS has some rewards. The regression is over, school days are complete, yet the woman with RS continues to learn and enjoy life. She is more engaged with those around her and her ability to communicate improves. She can draw on her experience and wisdom to help her better understand things. 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 less intense.

In spite of the tendency to develop deformities, many older girls and women with RS continue to walk for decades. Those who lose ambulation remain alert and still keep a close watch on what's going on around them and stay connected to those they love. It is important to keep her in the mainstream of life, allowing important long-term relationships to continue and flourish. While she may slow down, it is important to include her in activities and events she loves.

Most of us find it hard to see our daughters as grown-ups; they still look like small children and still need us for so much of their daily existence. Yet, it is true. They are women with RS.

*In many ways, I have found that dealing with Ashley at twenty-five years is much easier than when she was younger. She now seems so peaceful. There is a calmness about her that was never present when she was younger. Ashley smiles now from the moment she wakes up until her eyes close in the evening, unless she is having a problem. She is quite healthy so that is a blessing. Ashley is now out of school so her weekdays are spent at home. Consequently, I rarely have to worry about what might be happening to her, which also gives me peace of mind. Ashley loves people, loves to travel, loves hotels, loves to go out into the community to restaurants and movies, loves festivals and music. We call her our party girl because she is always up for a party! Ashley is absolutely delightful and a real joy to live with.*

*Lyndie is eighteen years old. She walks very well in familiar territory, but needs to feel a hand of support when venturing in an unfamiliar environment. She goes up and down one step with little to no assistance, but the more the steps, the more the level of difficulty she has. Although Lyndie walks well, she is lousy at transitions. She needs quite a bit of help getting into and out of most chairs, bed, etc., though once her feet are both on the ground, she's off and walking. Although Lyndie's walking has always been fairly good Rett-wise, it actually improved after having her scoliosis surgery done three years ago. That was certainly a bonus of a blessing we were not anticipating!*

### Life Expectancy

Due to the rarity of RS, very little is known about long term prognosis and life expectancy. Most of those who have been identified are under eighteen years of age. It is often difficult to identify older girls and women due to

the frequent lack of complete infant and childhood developmental records. However, studies have determined that a girl with RS has a 95% chance of surviving to age 20-25 years. This compares to a 98 percent survival probability for the general U.S. female population. Between the ages of 25-40, the survival rate drops to 69 percent in RS, compared to 97 percent in the general US female population. The average life expectancy of a girl given the diagnosis of RS may exceed 47 years. While there are probably many women in their forties and fifties with RS, there have been too few women identified and studied to make reliable estimates beyond age 40. While these statistics show that life expectancy is less in RS, it is not nearly as low as other similar neurological disorders. While sudden death in sleep does occur, most women with RS can continue to live well into their forties and fifties with good medical care, nutrition and therapy.

*I feel so blessed that my daughter has lived thirty-three years. She grows more precious and beautiful as the years go by and with each additional day I feel blessed with her presence.*

### **Quality of Life**

WHEN SCHOOL IS NO LONGER a daily activity, maintaining friendships can be harder than in the past. Having graduated from the school routine, more emphasis must be placed on finding ways to keep her busy and comfortable.

*The wonders of current medical technology have given Jenn a quality of life, and an extension of life, that we didn't think she would ever have. Jenn was so medically fragile in her youth we didn't think she'd make it to her sixteenth birthday. And here she just celebrated her twenty-third!*

### **Keeping Busy**

DEPENDING ON HER STATE OF HEALTH and local resources, there are many ways to keep her active such as park programs, swimming at the YMCA, trips to the zoo, walking, bowling, craft shows, movies, plays, concerts, visits to the pet shop or animal shelter, shopping, lunch at a restaurant... the list is as long as your imagination and energy.

*Jenn remains pretty healthy, gets hydrotherapy three times a week, and volunteers twice a week during the school year listening to students practice their verbal reading skills. She works with a special needs dog in-training to assist individuals in wheelchairs. She helped out in two music classes the year before. We're aiming to start private music therapy and PT. If time, energy and, financial resources are available; we may finally get into augmentative communication.*

*Shelley does what we do. She goes for walks and has her bird and squirrel watch outside the kitchen window. She prefers to walk in the neighborhood or walk in town for short trips. We have learned that too much stimulation does not make for a happy Shelley. We do not overdo. If we eat in a restaurant, we always tell the waitress to be prepared to box everything up in case Shelley does not want to sit.*

*Project Sunshine is a wonderful organization of university volunteers. They have monthly parties and each participant has at least one 1:1 volunteer who spends at least one hour each week with Ashley. The students come over weekly and they spend about four hours together. She loves this time with her friends.*

*We have a garden that we planted to attract hummingbirds. I bought those interlocking rubber mats, so Carol is able to w-sit and get her hands in the dirt and help. We also made bird feeders out of pie pans or paper cups covered in peanut butter and rolled in bird seed. We're doing a scrapbook of all her adventures from last year. We make hats, which is great fun, and we go fishing. At home, we pile all the blankets in the middle of the floor, pile in and eat popcorn. Carol has this whole other social thing she does with her dad. He took her to dinner last week, without me!*

*I take one day off each week in the winter and we go skiing. Jocelyn has a used bi-ski and we modified it so that she is more comfortable. We have a regular ski date and friends at the mountain an hour away. We also volunteer at the theater in town and usher together and take tickets to about twenty shows each year. After we finish with the tickets, we see the shows. Jocelyn joined a social club and meets a few times a month for dinner, movies, etc., whatever we can figure out how to include her and fit in our schedule. I am starting to work on developing a network of people who would be comfortable supporting her in mutual interest activities. Jocelyn goes to the beach and loves the water. She can even ride on the jet ski. We bike on her adapted bike. She goes to as many of her brother's' hockey and baseball games as she can; she loves sports.*

## **Age Appropriate Activities**

IT IS TEMPTING TO KEEP HER HAIR in ponytails with ribbons and dress her in cute overalls. After all, she still looks like a child, and the selection of clothing which fits is generally limited to the children's department. But dressing her in age-appropriate clothing, similar to what ladies her age might choose, will help her assimilate into her adult peer group, whether typical or special needs. Give her some choice in how her hair is styled and the clothing she wears. You may be surprised at what she likes!

Some of the items used in therapy are actually cause and effect toys, because they are easy to adapt and easier for her to manipulate. But those same switches can be adapted to do other things, such as the hair dryer or the mixer, radio or computer. Provide her with age-appropriate books and magazines. If she is like the typical RS female, she will love posters and magazines of handsome guys.

There are many age-appropriate activities which your daughter may enjoy. How about the movies, shopping, or visiting friends? The list is endless.

With all this said, sometimes too much importance is placed on making sure everything is age-appropriate. Is a Barbie doll an inappropriate gift for a woman with RS? What about the collector? How about a Beanie Baby or stuffed animal? Many typical adults buy toys, bears, and dollhouses and entertain themselves for hours with them. Many adults love cartoons. It's important not to get carried away with the idea that everything must be age-appropriate.

## **Finding Respite**

ONCE YOUR DAUGHTER HAS AGED OUT of the school system, adult programs should be sought out. Too often, there are too few available programs to fill the gap. This calls for more caregiving at home, and more stress on families. It is important to find respite programs to help. After all, parents are aging too, and the burdens of lifting, bathing, feeding and dressing take greater toll.

*We just admitted Sara to a nursing home for an eleven-day stay. She has a bath daily, goes on outings and has a private room. I call her daily and sing to her just to hear her giggle. When we admitted her, I asked if I could bring her home if I felt she was in distress. I thought she might try to tell me by moaning or her eyes would tell us that she was unhappy. It was just the opposite. Her eyes just sparkled and when the familiar faces would come to greet her she would belly laugh so hard. I do this yearly so that we can function as a normal family and go on outings, just a little break from doing everything that has to be done for Sara. For the adult, funding respite care is often the easy part. Funds are generally available through Medicaid, Community Supported Living Arrangements (CSLA) or other adult services. However, finding a suitable caregiver may be another story. It may take some persistence and resourcefulness to find the right person.*

## Health Care

### Pediatrician or Adult Physician?

AS YOUR CHILD GROWS INTO ADULTHOOD, you may be faced with the decision to change her primary care from the pediatrician to an adult primary care physician. In some cases, insurance requires the switch. Often, pediatricians are willing to keep those over eighteen on their caseload. However, when illness or surgery requires hospitalization, the pediatrician may only be able to admit patients to a children's hospital.

### Age Has Its Problems Too

THE WOMAN WITH RS FACES THE SAME ISSUES of aging as the typical population. It is important to follow up with routine health checkups and screenings, including colonoscopy, mammography, and pelvic examinations as well as screening for heart disease and diabetes.

### Muscle Tone and Contractures

THE WOMAN WITH RS MAY CONTINUE TO W A L K 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) when they are children become the most rigid or spastic (hypertonic) in adulthood. Elbow contractures may prevent her from doing the stereotyped hand movements so common in childhood. Ankle and foot contractures may limit her ability to bear weight.

### Scoliosis

SHE MAY HAVE INCREASED KYPHOSIS OR SCOLIOSIS and intermittent muscle spasms. If her scoliosis has not been surgically corrected, she may experience back pain and will need to be repositioned often. Good seating and positioning is important, not only for comfort but to allow her to breathe as well as possible.

### Breathing

APNEA AND HYPERVENTILATION SEEN IN THE EARLIER YEARS may no longer be an issue, but if her scoliosis is severe or has not been surgically corrected, her breathing and lung capacity may be compromised. Internal organs may be compressed due to displacement from the spinal curve, and scarring in the lung from previous episodes of pneumonia may lead to shallow breathing. Each episode of pneumonia weakens the lungs and leaves her vulnerable for the next episode.

### Foot Deformities

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, and may advance and worsen with movement. Decreased blood flow to her legs and feet may cause the feet to be cold, reddish-blue, and swollen. 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.

## Dystonia

DYSTONIA CAN BEGIN AT ANY AGE, but is more common in older girls and women. The cramps caused by dystonia can be very painful. Treatment commonly consists of using medications, such as Klonopin/Clonazepam, which is very effective. Dystonia can range from mild to very severe and debilitating.

## Long Q-T Syndrome

AS DISCUSSED IN THE DAY TO DAY LIFE chapter, Long Q-T syndrome is a disruption of the heart's rhythm. Long Q-T often first appears or worsens with age. If abnormalities are seen in the electrocardiogram indicating the presence of Long Q-T, the cardiologist may prescribe medications such as beta blockers (propranolol, Inderal). One contraindication for use of propranolol is asthma, but there are other medications that the cardiologist may choose to treat Long Q-T syndrome.

## Appetite and Weight

IF HER WEIGHT IS WELL BELOW what it should be 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-button may be necessary. If loss of appetite is sudden, it is advised to have her checked for gastroesophageal reflux, a very common cause for refusal to eat and discomfort.

Despite being very thin as children, many women gain sufficient weight in late adolescence or early adulthood, even without intervention. Some women become overweight, which poses a challenge to her when it comes to walking, moving, and transitioning.

## Fatigue

AS SHE GROWS OLDER, SHE MAY TIRE MORE EASILY than as a youngster. Her body size and weight put more challenges on her central nervous system. She may not have the stamina she once had, and may need to rest more often. L-Carnitine can be helpful as a daily supplement.

## Sleep

IN GENERAL, SLEEP IMPROVES WITH AGE. She may require several short naps during the day. Research studies show that as they age, women with RS have less nighttime sleep and more daytime sleep.

## Seizures

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 antiseizure medications. This should always be done very slowly, and only with a doctor's permission.

## Breathing

AS SHE GETS OLDER, the disorganized breathing patterns 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 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.

## Crying

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, 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.

However, it is most important to consider physical causes for crying and to take them seriously. Gall bladder disease in RS is a recent finding, and can cause a great deal of discomfort. Thyroid disease can cause depression and crying. Dystonia can cause severe muscle cramps. Urinary tract and vaginal infections can be very distressing. Don't give up until you identify the cause of her distress.

*Carol had always been a gentle silent soul, taking RS in stride, until she turned twenty. For the next two years, she became this person I didn't know. The episodes seemed to have no precursors and were a sudden burst of violent behaviors that included self-abuse serious enough to draw her own blood and screaming spells, kicking, pinching, food throwing. However, there were periods of hours (not days) where Carol would reappear and be her normal, gentle self. We did every possible test from EEG, CT, MRI, gastro, ortho and all other points in between, including dental. We made changes in seizures meds ... things got worse. Changed diet ...no change. We looked for environmental problems, like allergies. The closest we came to an explanation was dystonia, which I still believe played a role, however it didn't explain everything. This period was the first time I ever considered a group home placement. It was a frightening and difficult period, because she had made so many improvements to her skill sets. Then, almost magically, the episodes stopped. Literally one day, I realized we had slept through a night and then another. The school wasn't calling. Her hair started to grow back from where she had pulled it out. She started to regain weight. The smiles came back to her little face and then happiness. To this day, I've never completely understood what happened. I just know it was an awful period.*

*Lisa screamed a lot for several years, we knew we'd have to leave any place we took her or take turns going. Her screaming slowed down when she was in her mid-twenties. Now she doesn't scream at all.*

## Adult Resources

Elderly/Disabled Waiver (E & DWaiver)

Consumer-Directed Personal Assistance Services Waiver (CD-PAS)

WHEN QUALIFYING FOR THESE WAIVERS, one can receive attendant and respite care plus Medicaid benefits (co-pays on prescriptions, medical equipment and therapies paid, co-pays on hospital and doctor bills paid, incontinence supplies paid, insurance premium paid for your whole family, etc).

Medicaid Home and Community Based Services Waiver (HCBW)

THE HCB SERVICES WAIVER PROVIDES IN-HOME SERVICES to people who, without in-home care, would have to go to nursing homes. The program can be used to access a broad range of home and community services and supports for people of all ages with disabilities, and to promote consumer satisfaction and control. These Home and Community Based Waiver (HCBW) programs can be used to fund services not otherwise authorized by the federal Medicaid statute such as respite care, home modifications, and

nonmedical transportation. Waivers can also be used to provide optional Medicaid services for waiver participants not offered to other adult Medicaid beneficiaries, such as case-management and personal assistance services. HCBW programs allow states to waive three specific Medicaid requirements: state-wideness, comparability of services, and community income and resource rules. Through these waivers, states can elect to cover a limited number of individuals, offer different groups different sets of services, offer the services in only certain geographic locations, or waive deeming requirements to allow more individuals to be Medicaid eligible. HCBW programs provide states the flexibility to design a waiver program offering a mix of waiver services that meet the needs of the group the state wishes to serve. Federal regulations permit HCBW programs to serve the elderly, and persons with physical disabilities, developmental disabilities, mental retardation, or mental illness. States may also target programs by specific illness or conditions, such as technology-assisted children or individuals with AIDS. States can also make home and community-based services available to individuals who would otherwise only qualify for Medicaid if they were in an institutional setting. States may limit the number of Medicaid beneficiaries who may participate in a HCBW program. Currently, 240 HCBW programs operate across the country.

### Community Supported Living Arrangements (CSLA)

ONE FUNDING STREAM FOR SUPPORTED LIVING is the Community Supported Living Arrangements (CSLA) program, an initiative to provide supported living services to Medicaid-eligible adults with developmental disabilities in eight states. CSLA provides individuals with the support necessary to enable them to live in their own homes, apartments, family homes, or rental units with no more than two other nonrelated recipients of these services; or members of the same family regardless of the family size. Covered services include assistive technology, adaptive equipment, environmental modifications, case management services and respite care.

- The person/ guardian, through a person-centered planning process, identifies the supports and services which best meet his or her needs. If provider agency staff and the person receiving the services have a parting of ways, it is the agency that must be replaced, not the person.
- The person must live in his or her own home (including an apartment, condominium or house, owned or rented) where the setting is controlled by the person/ guardian and not a service provider. Control may be shared with other people who live in the home. No more than three unrelated people excluding live-in care givers may reside in the home for it to qualify as an allowed living arrangement for CSLA. Participants may also reside with their families or with a relative.

### Supplemental Security Income

WHEN YOUR DAUGHTER REACHES HER EIGHTEENTH BIRTHDAY, she becomes eligible for Supplemental Security Income (SSI) automatically. There is no financial formula, and the parents' income is not counted. She can probably qualify for the highest amount of benefits. It is best to apply a month or so before she turns eighteen so that her benefits will not have to be retroactive. If you do not apply, she does not receive the benefits. These funds are to be used to pay for her lodging, food, clothing, recreation and other needs. The Social Security Administration uses a mathematical formula to calculate her benefits. If she lives at home, you should assign an amount for her to pay "rent" to access the higher benefits. If she lives away from home, her SSI check is sent to her residential placement to help pay for her needs. You should expect a six-month wait for the bureaucracy to get all the paperwork approved. They will still back-date payments.

*Jane just purchased her first accessible van. She is able to pay for this with money from her SSI check that she became eligible for at age eighteen. So she and friends have transportation to get where they need to go. Hopefully by the time she needs to worry about paying for housing, her van will be all paid up!*

## Day Habilitation Programs

### Transition to Adult Services

AROUND THE AGE OF FOURTEEN the public school system begins the process of transition to adult life and adult services with a transition IEP. The options available when the school years are over will depend in large part where you live. Adult programs are not mandated and therefore, availability is tied to local funding. Programs may not be available in rural areas. Your state Developmental Disabilities Agency should be able to assist you with identifying appropriate programs.

### When the School Bus Doesn't Come Anymore

IN MOST CASES, EDUCATION IN THE PUBLIC SCHOOLS can continue until at least age twenty-one. 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.

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 she needs 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.

*When Shelley finished school it was a day of celebration for us. At first I wondered what she would do, but it worked out fine. My other children moved into their own lives and Shelley became our main focus. She adjusted to her siblings being gone and loved knowing she didn't have to go anywhere. She was happy to be done with school and the pressure was off her. She doesn't get sick as much, less colds. She loves just being home and feels very secure with Mom and Dad. We bought a motor home and off we go into the wide blue yonder whenever we want.*

### Starting Your Own Program

IF A DAY PROGRAM DOES NOT EXIST IN YOUR AREA, it may be possible for you to start a local program, pooling the energy of other families of adults and accessing local resources. Four families started talking with our school district about this "idea." We spent two years working out the details and one week following graduation, the Partners in Adult Living (PAL) program started. We were fortunate to get a state grant to help purchase a bus, van and other equipment. The families hold an annual fundraiser each year to raise funds for any shortfall we have in the budget and purchase the extra items we need for the program. We have monthly partnership meetings to review standards, and purchasing of equipment and work on all other issues. Our ongoing challenge is to have the program fully staffed all the time. For those interested in starting their own programs, here are some ways to start:

- Begin planning two years in advance.
- Find three or four committed parents who are strong advocates and have common goals.
- Try to get services for all of the attendees coordinated by one agency.

- Do a fundraiser prior to the startup date to demonstrate your commitment to the project.
- Encourage parents to donate personal money to the program.
- Apply for Medicaid waivers at least one to two years in advance.
- Get a local legislator to advocate for you.
- Ask people in the Office of Special Education to help identify possible grants.

## Alternatives to Day Programs

EVEN IF THERE ARE FORMAL DAY PROGRAMS in your area, you may choose not to use them, instead utilizing help from a home health agency to take advantage of community resources.

*My daughter has been out of school for seven years now and we have not yet utilized any type of adult program. She has a support person through a home health agency who comes to our home weekdays from 8-4. Together, they cook, play games, go out for walks and to the pool, sit and swing in the sun, read, have lots of discussion about stuff going on in their lives, the newspaper etc. They work on projects, have friends over, have pampering "girlie days" with manicures, bubble baths etc. She also does regular bathing and hygiene duties, feeds her, and does range of motion stretches. The particular agency we work with does not allow their employees to transport clients, so they keep busy at home and have friends over. The previous agency had made an exception and she was able to get out regularly to go shopping, find volunteer employment, utilize the rehab pool in town, go to movies, take classes, go to the beach, mountains, etc. She still gets out a lot but mostly I take her out and support her in her involvement in the community.*

*Lynn took part in Community Supported Living Arrangements (CSLA) for a number of years, but nobody told me that I could have the money to do her program myself. Basically, it is the sum of money that's given to the placement for her education/placement at a day facility. So, after finding out, I got the sum of money myself (thru a payroll) and I administer her day activities myself. I hire aides to do it with her at ten dollars an hour, six hours a day, five days a week, which comes out of the sum allotted for her for the year. That way she does what she can do, instead of the day center taking all the money and giving her what it wants, which in my experience has not met Lynn's needs. It was a struggle at first trying to arrange activities and plan her day, but now three years later, it runs quite smoothly. I have no problem finding help. It is a good alternative to what is available in adult workshops and day centers.*

## Community-Based Resources

MONEY IS AVAILABLE TO YOUR DAUGHTER for programs when she is over twenty-one. All you have to do is submit a plan for the program. Workshop facilities have persons who will write up a plan for you (but beware it comes with a cost, which comes out of her total money for the year and quite frankly, you can do quite easily yourself).

## Finding a Job

WHILE THERE ARE A LIMITED NUMBER OF JOBS available, some girls do have supported employment, either through a workshop or other habilitation program.

*I have been working on developing a job with junior high age kids in an alternative school placement. These kids are "troublemakers" in school so are in a different environment, working on skills they need to develop to succeed in life. Hopefully she will "work" with them on projects one afternoon a week, by giving them opportunities to think of ways of helping her to help them. This calls for problem-solving skills, positive attitudes, compassion, and understanding. I think these are things she can help to teach them very effectively.*

## Home Away from Home

SOMETIMES A FAMILY FEELS THEY CAN NO LONGER CARE FOR their daughter at home full-time. Parents may be getting older or have health problems that limit their ability to provide the quality care their daughter needs. The physical and emotional strain on the family may be too much to cope with, especially for the single parent. There may not be adequate support or respite care from the extended family or through the community. In some cases, the family feels that she will do better in a residential setting which can provide twenty-four hour care. Whatever the reason, making a decision to find an alternative living arrangement can be painful and difficult. Finding the right home is often hard, and sometimes impossible. The family must choose to either remain in the same situation and feel drained, or place their daughter somewhere else and feel guilty. There is often no choice that is good for everyone. Parents may face criticism and judgment from others, and they will probably always feel some sadness.

*It is easy to say that you would never do this or never do that, but when the choices are out of your control for any number of reasons, for health, income, or safety, you may just find yourself looking at an alternative placement for your child.*

*I don't have family, so the caregiver role falls squarely on my back and it gets heavier every passing year. I have started realizing that my dreams are gone and it all becomes a snowball rolling downhill at breakneck speed. It's comforting to know that there are people out there who do care, even in nursing homes and hospitals. We are not alone, there is help, and sometimes we need to reach out for it. It is not easy for families who have found other options. Many times there is a great deal of contemplation over the decision and self-guilt. My support goes out to those who work hard to keep their children at home as well as those who have had the courage to know that they are unable to give the level of care that their child needs and have found alternative placements.*

*I thought Heather would never have to go anywhere after something happens to me, but that isn't the way life goes. When my two nieces were younger, they said they would take her and now they have families of their own, and don't visit any more. I have made an application to a very nice group home but I'm not ready yet. Heather needs twenty-four hour care. I wish I could live and care for her as long as she is on this earth but as she ages, so do we and we have no one that comes in to care for her.*

*If I've learned one lesson in life with Carol, it is that nothing ever stays the same. There will come a day when her needs are going to outwit my body. The emotional stress takes its toll. Carol lives at home only because I took an early retirement from my career. I spend every day trying to make her life meaningful. I am forced to re-evaluate my ability to physically care for Carol. In the big picture of life, I would rather emotionally connect longer than to burn out physically.*

*I know there are many of you who cannot fathom having your child cared for by anyone but you. At the moment that is how we feel, too, but I have learned through the years to never say "never." I have two older daughters and their welfare to consider, so while Tori does get the bulk of our attention, they deserve to have a life as well. My husband and I are also getting to an age where our parents are getting older and we may need to help shoulder some of that responsibility as well, so we really don't know what our future holds. We plan to keep Tori at home, but we can't rule out other options for the future. You just never know what curve balls life is going to throw you or for sure how you will be able to deal with them when the time comes.*

*To those of you who have had to make the gut wrenching decision to have your child cared for by someone other than yourself don't let other people add to your guilt by criticizing your decision. I believe a lot of soul searching goes into each decision that is made and that the welfare of the child is of utmost priority.*

*Mary was placed in an institution, and then later moved to a group home. As a single parent, I had to rely on babysitters, and Mary's behavior had become so bad that I could not keep a sitter and she was kicked out of every school, including the one that took the worst of the worst. My guilt sent me into therapy until I accepted that none of us can be everything to our children. Mary moved into a group home and I have never been out of her life. I go to every treatment planning session. I fight all the battles all of us do, and bring Mary home for weekends. She never lost me. She just has me in a more loving capacity because I am not doing the hard*

*work of training her. We can enjoy each other much more. Mary is thirty-seven and I'd say I've done a darn good job of hanging in there with her.*

*How easy it is to judge others. I think we are trained to be cautious and are primed to defend our situations and our daughters. When the majority of us hear the word "institution" we envision the cold, heartless, horrible places of years past. Every family is different and I feel does the best it can and makes the right choices for the individual situation. I can see it from both sides of that fence as I am the parent of a girl with RS and the foster parent of a young lady with cerebral palsy. She was "placed" with me when she was six. People always ask me that nasty question, "Why?" I answer them with the truth. The parents knew that to allow her to live with my family and me was the best for Melissa. It broke their hearts to let her go and to not be a part of her everyday life. But they did it purely out of love for their daughter and her needs.*

## The Right Time

SOME FAMILIES KEEP THEIR DAUGHTERS AT HOME for all of their lives. If sufficient resources allow for good support and respite services, this can work well. However, the life expectancy in RS is well into the forties. When parents are in their sixties and seventies, it is difficult for them to maintain the level of physical care and attention she requires. They also must face the fact that their daughter may survive them. Parents should plan ahead for when they can no longer care for her at home.

*As time goes on and your life patterns change you will make different decisions. I am also faced with very fragile aging parents who need a lot of support and help. I haven't had a vacation in eighteen years that hasn't been to care for someone else. I am not complaining. I feel blessed that I have the skills to give comfort to others. But I am tired. And on the days that we feel less than perfect we should be able to say so.*

*Amy is in a group home and has been for eight years. She went there when she was nineteen. I share her care. Amy gets tremendous support and love at her other home. It was the best decision we ever made. You have to protect your family unit and marriage and learn to let go at some point and trust that all of this is somewhere in God's plan. I remain Amy's guardian and she is home every weekend and holiday. I attend all doctor's appointments and take her to the Rett Clinic every year for evaluation.*

*We have a contingency intervention program and Carla was "placed" at a nearby regional center. Carla had a number one priority because I was a single parent and not getting any younger! If I said "No," there was no guarantee of placement in the near future. Furthermore, since this was her last year at school, there was no guarantee that there would be a day program available if she were still living at home. So, after many restless nights, I decided to give it a try, especially since I was told I could change my mind at any time during the transition I made my list of pros and cons. The pros included the following: it was a small facility with six beds to a unit and four units to a building designed with two units on each level; it was two miles from home, which was a big plus; the staff were warm and caring people who had worked there several years; and another girl with RS who was twenty-five years old would be Carla's roommate. All the cons were Mom related: I didn't want her to go; I wasn't ready; and maybe I should do this next year. I spoke to family, friends, Carla's teachers, therapists, and clergy. I had to do it! So the transition began. For two months, I brought Carla to the center after school for visits. The visits got easier and then we had our first overnight. I stayed until she was asleep and then cried all the way home and most of the night. I was there when she woke up the next morning. She seemed a little confused, but happy. The overnights became more frequent, but not easier—for me, anyway. Then, she moved in. I*

*tried to think of it as going to camp. She spent Monday through Thursday nights there, attended summer school at her regular school, and was home from two to seven each day. Then, she was officially admitted. I was devastated. I heard myself talking at the meeting, but what I said was not what I felt. I knew what I had to do, but it wasn't what I wanted to do. I had to believe it was best for Carla, but I wasn't convinced. I felt I was giving her away. I had never experienced such pain even though I had gone through a divorce and lost a parent. Those events didn't even come close to the pain I experienced that day. I was awake and up all that night. I cried and cried, a full-box-of-tissue cry. Morning arrived and zombielike, I went about my chores. Carla*

*was fine, though, and I got one of her "Don't bother me" looks when I visited her. That same day, I was involved in an auto accident. When they say that God works in mysterious ways, I believe it. I had been praying for guidance and this accident was an answer to my doubts in a way. It made me realize that if I had been seriously injured or killed, there was a place for Carla with people she knew and with those who knew how to care for her. For the first time in four months, I felt OK with the decision. I had mourned my loss and now it was time to celebrate Carla's new life. If I said everything was wonderful now, I'd be lying. It still hurts bringing her there Sunday nights. It's wonderful bringing her home weekends. We share only quality time together now. I'm beginning to enjoy my new freedom. For the first time in twenty-one years I can do things like making appointments without making arrangements for a sitter or like working my daily events around Carla. I visit her daily; they asked if I wanted a part-time job since I spend so much time there. She enjoys the constant activity and attention.*

*What is my advice to parents who might be in this stage? Do it! Do it while your daughter is still in her regular school program, if possible. It's easier for you and for her too. Don't let her see that you're upset. Be happy for her and her new "independence." Don't get upset with friends who say it's just as if she were away at college. They could never understand the pain of letting go of a child who is still so dependent on you. Kids choose to go to college and choose the college as well. They can tell you what's happening. In our case, we're making all the decisions and hoping and praying that they are the right ones. Carla has a new family now, and I have, too. I keep thinking that if I won the lottery, I'd bring Carla home, and have live-in help. But would Carla like that arrangement? Finally, pat yourself on the back for being such super parents. You've won all the awards for best parents and now it's time to enjoy life. Let others do the daily caregiving. Be there to love her, have fun with her, and keep an eye out for her. There's no place like home, but your daughter can have two homes. Try to view the new setting through your daughter's eyes. She is blind to situations that may not be pleasing to you. Isn't it better to be the one in charge of finding your daughter a new home and family than waiting until it is too late and letting strangers make the decisions?*

## Finding the Right Place

IT IS PROBABLY BEST TO CONTACT YOUR STATE Developmental Disabilities Administration (DDA). Today, children are not placed into state facilities (institutions). All of the agencies participate in a review of each case. If she is over eighteen, she automatically qualifies for Medicaid, which provides assistance in the home at crucial hours, foster care in a family especially trained to deal with her problems or a group home.

## How to Start the Process

THE PROCESS FOR PLACEMENT IS DIFFERENT from state to state but a cry definitely needs to go out to the social worker or caseworker. Talk to other parents who are in your area. The local ARC is a good starting point.

## Foster Care

People should not discount foster care when they are looking for placements. I know the feeling is sometimes that "if our family can't do it anymore, then how can another family?" Well, the other family hasn't been doing it all these years. They also may have different family situations than your family that may make providing care a possibility for them. I've met some pretty amazing foster families who have done marvelous things for some people with some severe disabilities. Every situation is different, just as every person is an individual.

## How to Evaluate a Residential Setting

DESPITE THE BEST REVIEWS by state case managers, you will never "trust" the quality of the residential setting without making a personal visit and speaking with the staff. There is no other way. And probably the bottom line will be an instinct, a gut feeling, that this is a good place. Certainly, ask the tough questions such

as: Are your staff trained? Is the facility licensed? How often is it inspected by government agencies? Can I see your last report? Would it be OK for my family or my daughter's advocate to visit her and take her out occasionally? And, of course, the big questions. How much and what do we receive for this amount?

Whether she lives at home or away from home, those who care for her must be given adequate support and respite in order to meet her many needs. Caregivers need regular time off and some holidays without responsibility for the woman with RS. Caregivers should be provided with ample information about the woman with RS, and any problems, aids or adaptations that are necessary for her success. If she lives away from home, the caregiver should be contacted regularly by family members, who will always be her foremost guardians and advocates.

### Adjustment to a New Lifestyle

MANY PEOPLE THINK THAT MOVING THEIR DAUGHTER to a residential placement solves all of the problems. It does not. While the physical stress of caring for her at home is eliminated, it is often replaced with emotional stress over making sure she gets the same kind of care away from home. Parents find themselves helping to raise money, volunteering, and cheerfully spending more time than they had planned at the "new home." The sadness which follows placement tugs at the heart. Adjustment to a new and less demanding lifestyle that once was so overburdened by her care can take time. But eventually, as she convinces you that she is doing well, you can begin to adapt. There will always be a yearning for the way things might have been. You will always want to remain vigilant about her care, and in close touch with her new caregivers.

### Residential Options

OPTIONS FOR RESIDENTIAL PLACEMENT will differ according to where you live. There are various types of residential living arrangements whose housing and/or supports are funded in full or part or are provided by the Division of Mental Retardation and Developmental Disabilities (DMRDD). The DMRDD contracts directly with the person or family providing direct support to the individual, rather than contracting with an agency.

Large institutional settings are no longer an option for people with disabilities. Small group homes are a least restrictive alternative, providing a homelike atmosphere in the community. Some families prefer to combine resources and benefits to provide her own house or apartment close by with full-time caregivers.

Some options include:

#### Group Homes

The DMRDD contracts for residential habilitation services with agencies that may provide live-in and/or shift staff arrangements. A single base rate is established for the support of each resident. Regular group homes have four to eight residents. Residential Care Centers are group homes with more than eight beds.

#### Semi-Independent Apartment Living

The DMRDD licenses and contracts for semi-independent apartments. Each resident has his or her own apartment and support staff live in close proximity.

#### Home Ownership

For information on the Home of Your Own program (sometimes referred to as HOYO), contact: Michael Renner, Missouri Planning Council on Developmental Disabilities, 59th & Arsenal, Suite IB, St. Louis, MO 63139, (314) 877-0068, or e-mail at [mjrenner@aol.com](mailto:mjrenner@aol.com).

#### Habilitation Centers

The DMRDD operates various habilitation centers, ranging from small (forty bed) to large (three hundred fifty bed) campuses. Residents primarily have significant and multiple disabilities.

### Division of Aging Licensed Facilities

These include Residential Care Facilities (RCF I and RCF II), Intermediate Care Facilities (ICF) and Skilled Nursing Facilities (SNF). A program license from the DMRDD is also required if 50 percent or more of the residents have a diagnosis of mental illness or if one person has a diagnosis of mental retardation. Rates for these facilities are set by the Division of Aging, not the DMRDD.

### Supported Living

THE OPTION OF SUPPORTED LIVING ALLOWS A PERSON with a disability to live in and become integrated into the local community. It provides the ongoing supports necessary for an individual to live in her own home, allowing control and personal choices. It occurs in your own home and community and gives you the chance to choose where, how and with whom your daughter will live. This service is offered around the country, with some differences from state to state. General eligibility requirements are: 1) eighteen years or older; 2) client of the Developmental Service Program; 3) desire to live in your own home; and 4) the need for ongoing supports and services to do so. An eligible person requesting supported living is not expected to demonstrate total independence or attain a predetermined level of skills. Even individuals with the most severe or complex disabilities can live in their own homes, if adequate support is provided. Supported living tailors supports and services to the needs of the individuals instead of making them fit into the system. It transfers control from the service providers to you. Supported living is different for everyone, just as every person is different. Individuals in supported living can live all over the community, in rented/leased homes and apartments, or in homes they own.

Supported living separates housing from support. A person does not have to live in a particular area to get needed supports and services. The intensity of the supports and services provided are designed to meet the individual's requirements. If an arrangement doesn't work, another is tried.

A supported living coach is provided through the Developmental Disabilities Program, Home and Community Based (Medicaid) Waiver. The coach enables your loved one to live in her own home or apartment by providing the help and training necessary. Help that a coach may give includes:

- finding an affordable house or apartment
- setting up and maintaining a household
- planning and preparing meals
- shopping for groceries, clothing and household necessities
- taking part in leisure and recreational activities and other life skills

Functions of a supported living coach are teaching new skills in the context of everyday life, helping with tasks and doing things with or for your loved one. Some people in supported living may need help with certain activities or need things done for them. A coach may also help by locating community resources and natural supports for your loved one.

Your support coordinator is your family's main contact with the developmental services system. It is the responsibility of your support coordinator to be sure you understand all available residential options and possibilities that can be created for you. If you choose supported living, your support coordinator is responsible for:

- assisting your loved one in the process of selecting a supported living coach or provider
- coordinating all the supports and services your loved one needs, both paid and unpaid
- facilitating communications among various providers of supports and services
- advocating for your loved one by helping communicate likes, dislikes, hopes, and dreams
- monitoring your loved one's ongoing health and safety in the supported living arrangement

Just as every person's life circumstances are unique, her supported living arrangement will be unique also. Some people need only the assistance of a supported living coach. Others need the kind of intensive help with daily tasks that can only be provided by a personal care assistant or a homemaker. Still others have more complex needs that involve several service providers along with the coach. The support plan that will specify and authorize those services that your loved one needs will be as unique as that individual.

### Individualized Supported Living (ISL)

ISL IS A COORDINATED SYSTEM OF SUPPORTS centering on the individual which is designed to facilitate each person's choices to live, work, learn, and actively participate in their community. Supports may include training, protective oversight, her own personal assistant services or environmental adaptations. It could be a person living alone with little support or a person living with several roommates, with or without disabilities, with a lot of support. This is NOT independent living, but supported living, based on the individual's needs. Supported living is one option in the range of choices in residential services.

### In-Home Supported Living

AN INDIVIDUAL AND HER FAMILY may choose to have supports provided in the natural home; this is called In-Home Supported Living.

### Living at Home

IF YOU CHOOSE FOR YOUR DAUGHTER to continue to live at home, you can still receive supports to help with her care, fund home modifications and equipment, and provide respite services.

### Share Your Home

ONE DRAWBACK TO RECEIVING SERVICES at home is the fact that you will be sharing your living space with support providers who come and go. This can be a huge invasion of privacy if your home is small, or if you are not fully at ease with her support staff. One alternative is to choose times to do errands or have a regular standing day or two out of the house during the week. If your caregiver is allowed to transport your daughter, encourage her to get out into the community as often as possible. You could set aside a specific room or area in the house for your daughter's activities to take place. Some people choose to close in the garage or add a room on to make space for caregiving.

### Final Thoughts

#### Creating a Positive Future

IN A NUTSHELL, THESE ARE THE IMPORTANT THINGS to strive for:

- Excellent health care
- A good place to live

- A place to work if desired
- Friends and fun
- Community resources
- Family support

*How blessed we are in Jenn and how blessed we are in her gracious handling of RS. We are always being touched by the goodness of others.*

*Heather did not learn to walk independently until she was eighteen. Now, she often crawls into the living room, pulls up on the couch, turns around, and walks back into her room. She will repeat this several times, and I'm certain it is just something she's enjoying doing because she's discovered she can. She has also made small progress in other things. She actually watches TV now, when she used to never be interested in it at all, and loves classical and semiclassical music programs like the Boston Pops on TV. She's always liked classical music, but is clearer in her preferences now. She is more assertive, more demonstrative about what she does and does not like than when she was younger. All in all, she is becoming more observant and seems more "with it" than she was when she was younger.*

*It seems the older Mary gets, the better she has been doing. Lately, we've noticed that when she reads a book, she is turning the pages on her own, which is a skill lost years ago. She is hooked on the television game show, Wheel of Fortune and becomes agitated when a contestant chooses a wrong letter or guesses wrong. Many of her physical skills have improved.*

*I know I'm getting old. I have more gray hair, my back aches and my knees make sounds like gravel. There's a strange little trick Mother Nature is playing. I see my friends who have children Carol's age and they seem so much older. They talk of retirement and downsizing ... they've moved on. But I have come to realize that having Carol has allowed time to stand still for me. I'm still doing all the things I did twenty-seven years ago. I enjoy the little things and having a retirement fund isn't important to me, because I'm still having fun and acting too young for my age. I know all the words to every Disney movie, I'm an expert at coloring inside the lines, and no one can dance with Carol like I can. One day, I suppose I'll have to grow up, but not today.*