



*Improving  
knowledge  
for those  
affected by  
Down  
syndrome*

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# HEART TO HEART

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# Welcome to Holland

by Emily Perl Kingsley

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome To Holland".

"Holland?!?" you say, "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy".

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes that's where I was supposed to go. That's what I had planned".

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

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# A Baby is a Baby First

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There is nothing quite like a baby...there's a lurch in the heart when we touch the beginning of a life in the small person of an infant. For some parents, the lurch is made more poignant, even painful, by the fact of their baby's diagnosis of Down syndrome.

Recently, I've had the great pleasure of holding a number of soft, beautiful babies who have Down syndrome. Their parents want to find out what it all means, what they can do, what to think about the future. The first professionals to talk to the parents of babies with Down syndrome tend to discuss the differences parents may see, difficulties babies will encounter. Armed with information about what milestones their child may not reach, what problems she may have, what services they should obtain to avoid potential problems, new parents want to help their babies as soon as possible. So they come to me (and to numerous others) to get this help...to find therapy, activities, and solutions to problems that may or may not exist.

We just don't know, at an early age, in exactly which ways Down syndrome may affect a child. She may be really good at cognitive activities, but have significant delays in movement...thereby falling behind her peers in playground and paper-and-pencil activities. He may be fairly good at gross motor, excelling in sports. Ocular control may be an area of need, or may be perfect. Language may be good, or may need lots of work. However, one thing we know for certain... babies don't deal with these things no matter what their chromosomes look like. They lie down and expect to be carried, cuddled, talked to, fed and generally catered to. They learn they are lovable, cute, and the center of the universe. They begin to know who their family members are, and who is the soft touch in the house in the middle of the night.

If these adorable creatures have Down syndrome they are at risk for certain physical and cognitive delays. It behooves parents to keep an eye open for problems that could arise. It's important that they know something about their child's diagnosis so that they can be alert and helpful. But my belief is that the most important things that parents of babies with Down syndrome can do are exactly those things that all parents do. You know: they cuddle, feed, sing and love. Not the kind of things you need a Developmental Therapist for... or any other therapist, for that matter.

I want to be clear. Young children with Down syndrome often show delays that need to be remedied so that these kids can be happy with themselves and do their very best. Very young babies with Down syndrome have specific concerns about early development. And doubtless, parents will find themselves driving this child about for ear infections, speech therapy, developmental evaluations, etc. But the main advice I have for parents of new babies with Down syndrome boils down to this:

You have a beautiful new baby. There will be some areas that need work, but what you have right now IS PRECIOUS AND PERFECTLY RIGHT.

*Excerpted from Kate Sefton, Master Developmental Therapist*

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# Announcing the Birth

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Most importantly, your baby is a baby first and secondly, a baby who happens to have Down syndrome.

It is generally suggested that parents not wait to tell friends and family members about their baby having Down syndrome. Even though telling family members and friends about your child having Down syndrome will be one of the most difficult things you face, don't be afraid. Most parents who have a new baby want others to be happy for them and to extend best wishes.

Generally, the longer an announcement is put off, the harder it may be. Most people know very little about Down syndrome, so education is important. Some people will think back to people with Down syndrome that they know as children. Their thoughts will tend to be out-dated, because today society is more accepting of people with disabilities. Children born with Down syndrome today have available to them more inclusive educational and community opportunities than children born even a decade ago. For some people, it may be extremely difficult to accept your child. That will be their problem and misfortune if they choose not to be a part of your family's life.

Generally family and friends will follow your lead. Most people will want to sincerely share your experience in a supportive and encouraging way as with the birth of any child. It may also be helpful to share your child's accomplishments throughout his or her life so that friends and family can continue to share developmental and educational milestones. On the other hand, it will also be helpful to share any difficult times, such as an illness or surgery.

Oftentimes, a child with Down syndrome will cause others to reflect and find new, different and deeper meanings in their own life.

©Nancy J. Murray, MS and William I. Cohen, MD  
Source: *When Your Baby Has Down Syndrome*

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# Advice for New Parents....

## *What is Appropriate Medical Care for a Newborn with Down Syndrome?*

*By Laura Cifra-Bean, M.D., Co-Chair, NDSC Professional Advisory Committee*

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All newborn care should begin with a thorough physical exam. If the clinician suspects the infant has Down syndrome, then a definitive diagnosis from a blood test to study the chromosomes is necessary. All babies who might have DS, need a cardiac evaluation that includes an echocardiogram. There is a high rate of heart defects even if a heart murmur is not heard.

Pay special attention to feeding, weight loss and jaundice. Since abnormalities can occur, a blood count is needed. The routine state newborn screen will test for thyroid function.

Perform a hearing test soon after birth and have an ophthalmologist examine the baby's eyes before six months of age.

Give parents information about local support groups, up-to-date references for information and a referral for early intervention services.

### **Things to do when you learn your baby has Down syndrome... but you don't need to do them all today!**

Adapted from the Down Syndrome Association of Minnesota [www.dsamn.org](http://www.dsamn.org)

- **Enjoy your baby.** Play with her, read to her, rock her, cuddle with her, talk to her, gaze at her when she's sleeping, figure out what she likes - and do it often!
- **Connect with other parents of children with Down syndrome.** Look for a Parent Group in your area. Call the NDSC at 800-232-6372 to find the organization nearest to you.
- **Learn more about Down syndrome.** You've probably got lots of questions about your child's diagnosis and what it means for the future. Much information is available on the internet; some through local bookstores and libraries. Check out the copyright dates, though. Anything published before 1990, probably is out-of-date and may not be very helpful. Woodbine House Publishing ([www.woodbinehouse.com](http://www.woodbinehouse.com)) is a wonderful resource on Down syndrome, including books on developing gross motor skills, developing fine motor skills, developing communication skills, teaching reading and math, and medical and surgical concerns. There are also helpful DVD's and books for children.
- **Find out about early intervention programs in your area.** Every state has an Early Intervention Program for babies, from birth until the third birthday. A good source for locating your state's program is the NICHCY website: [www.nichcy.org](http://www.nichcy.org). Click on State Resources and look for Programs for Infants and Toddlers with Disabilities: Ages Birth through 2. This will help you locate the office that serves your county or area.
- **Take care of yourself:** While it's probably the last thing on your "to do" list right now, you can better care for your child if you care for yourself, too. Spend time nurturing

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the relationships with your partner, other family members and friends. Accept help when it's offered.

- **Connect with a health care provider familiar with Down syndrome and its unique medical issues.** You may want to supplement care provided by your current doctor or nurse practitioner or you may be looking for a new provider. Some cities are lucky enough to have a Down Syndrome Clinic, specializing in the care of babies with Down syndrome. In other cities, you may want to look for a developmental pediatrician. Many HMOs and large clinic systems have a developmental pediatrician on staff. Providers who see lots of children with Down syndrome can be a wealth of information for you and your primary physician.
- **Investigate county resources.** Check your local phonebook and look for a county department name such as Human Services, Community Services or Developmental Disabilities. Your county also may have a Web site where you can find out how to connect with a case manager. A case manager should be able to help you find services that may benefit your child and your family. A case manager can help you connect with a school district, find available community services and tell you about financial resources you may qualify to receive. Families often use these services when their children are older. It's helpful to have connections in place to use when you need them.
- **Don't be afraid to grieve.** Grieving is normal and people express it differently - sadness, tears, anger, fear, depression or withdrawal. It's okay to cry. The baby you have may not be the baby of your dreams. Many parents of children with Down syndrome feel this way. Most also learn that - eventually - they dream new dreams.
- **Remember to enjoy your baby.** Marvel at his fingers and toes, stroke the hair (or fuzz!) on his head, read Goodnight Moon again and again, watch him watching you, sing to him and give him one or two - or more! - hugs and kisses.

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# An Open Letter to New Fathers of Special Needs Children for Father's Day, 2002

by Jeff Raefield

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June 7, 2002

Dear New Dad,

This is undoubtedly not the first time someone will say, "I know how you must feel", nor will it be the last. One thing is however true about this letter. I DO know how you feel. I was there 17 years ago. I'm still there now. I'll never leave this place of feeling both the highs of being a father, and the lows of losing my dream child. Don't let this discourage you though. Life will get better. You will feel "normal" again at some point. Your definition of normal will slowly change of course, but normal you will feel nonetheless. Things will never be the same; but then again, that was going to happen anyway just by becoming a father. Sure this situation is far different from "just" becoming a father, but hey, we're men. We analyze, we adapt, we change and we keep going.

When my son Travis was born 17 years ago, I didn't see that ton of bricks sliding down the ramp at me. My wife went into labor a month early. I was at work so I rushed to the hospital and met her there, all giddy with excitement and anticipation. I bought cigars. I loaded the camera. I called all the relatives and friends to let them know the sudden change in plans. After several miserable hours of labor, my wife and I went into the delivery room. A few more pushes and his head popped out, face down. I snapped the first few pictures. The doctor rotated him face up to begin working on the shoulders, saw Travis' face and said to the nurse "Looks like we have a Mongoloid here." That's it. Quick diagnosis. Matter of fact. Boom. "Would you like fries with that ton of bricks?"

I only share that story to let you know how low I went that day. The truth is I believe that we all go that low at some point in the grieving process. It is no better to be quick or drawn out, the low point is just as low. Think of a valley between two steep ridges and a deep wide river down the middle. You are on one ridge, called Today, and the other is called The Rest of Your Life. Some of us get flung off of the ridge directly into the river and have to climb out and up to the other side. Others find a gentle winding path to the valley floor and calmly wade into the river. No matter what, we all get wet, and it is still up hill to the other ridge.

As if I didn't have enough stress, when Travis was just 3 months old I was offered my choice of a transfer to Seattle or a pink slip. Analyze, adapt, change, and move on. In Seattle I found out about a "Father's Program" at the University of Washington run by a graduate student named Don Meyer and a father named Greg Schell. I didn't need a "program". That stuff was for wives and wimps. My wife, however, was in desperate need of some time off. OK, I remember thinking. I'll take the tyke and spend some one-on-one time with him, giving her some respite as a bonus. After all, happy wives make for happy husbands, no? Ulterior motives always being my best ones, I joined up. I loved it. A place where dads could be dads, and be weak, and be strong, and be supportive, and give support, and love our kids, and hate our circumstances. It was also a place where we never

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had to worry about what our wives would think of us. We could mention the unmentionable. Everyone understood.

Unfortunately, the program ended after I had attended only one session and a picnic. It ended due to a lack of funds and the fact that Don Meyer was moving on, but there was momentum and a following that would not be denied. Analyze, adapt, change, move on. Greg Schell and others convinced the folks at the Merrywood School that this was a good thing, and a “permanent” program was born. When James May came on board it really gelled into an entity with self-determination and continuity. I have since moved on to another state and another state of being, but I still wonder if I could fit into another Father’s Group down here. I don’t need to, I just want to. I am much better at talking about my life to “ordinaries” now, but they just don’t get it. Other fathers can’t accept my anger at having lost the son I thought I was having. In addition, they can’t really get the same feeling of joy and pride I have in the son I did get, because they see that he doesn’t perform well at sports or academics like theirs do. They measure their kids’ success by achievement compared to others. We learn to just appreciate achievements; any achievements.

One of my most memorable meetings happened when Travis was about 4. My wife and I had just made our second child, one with “ordinary syndrome”, and I was once again under the stress of a new job. The speaker that week was another dad, but more importantly, the dad of a 17 year old son with Down’s Syndrome. James had invited this dad in response to suggestions that we explore what the future had in store for us. He came to talk to us about what their lives were like, both growing up and now. He shared stories about his kid throwing plastic toys into the fireplace and putting a sandwich into the VCR. Normal kid stories. I forgot for a while that his was a “special needs” child, and I also forgot for a moment that mine was too. I came to see the power of a statement that I had heard once before, that our kids are more ordinary than they are special. Then came the big shocker. He invited his son to come in and talk to us too. At that time, almost all of us dads had kids under 6 because the program had started for new dads only a few years earlier. Most of us had never been in more than casual contact with a developmentally delayed person, let alone have one as a speaker.

That young man had a profound impact on my viewpoint. He was articulate, in spite of his speech impediment. He was witty, in spite of his being “delayed”. “Do you have a girlfriend?” we asked. “Not now” he said, “we just broke up. She was too bossy”. Smart kid. “Do you drive?” came a question. “Not yet” he said, and a wry smile came over his father’s face. We dads went back and forth with questions that we would not have thought to bother asking an ordinary 17 year old. About jobs, school, college etc.etc. Frankly, I would not be interested in the minutia of an ordinary kid’s life at 17. However, what I liked hearing from this person was PRECISELY those things. The normal every day humdrum things that all kids go through. He had answers and plans for everything. Not the same plans as an ordinary kid would, but plans none the less. It made me realize that Travis could live a good life and be happy. What more do we want for any child?

Now my son Travis is 17, and in payment for the kindness of that father years ago, I want to share his life with you. He is a Junior in high school. He attends a mixture of classes between “mainstream” (I hate that word) and Special Ed. He gets A’s and B’s in his modi-

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fied programs. He struggles with his homework. He takes Weight Training for PE and does well with the help of his ordinary “buddy” assigned to him by the coach. His buddy now calls him up on weekends and invites him to movies. He works in the cafeteria helping with the lunch prep every day. He daydreams about the cheerleader girls at school. He bugs me weekly about getting a driver’s license. He does not clean up his room. We cannot get him out of bed on school days, but if he has plans for the weekend, he is up at the crack of dawn. He attends EVERY dance, and dances more than any of the other guys. Because of this, he has no shortage of girls asking him to dance. He went to his Junior Prom with a girl from his Special Ed homeroom. Stacy has a beautiful smile, a bright disposition, and CP. Travis had recently broke up with HIS girlfriend Jenny because she was too possessive and bossy! Smart boy. He analyzes, adapts, changes and moves on.

Travis plays Special Olympics basketball, Challenger Little League softball, Special Olympics bowling and Challenger soccer. He loves the Oakland A’s and Raiders, plus the San Francisco Giants and 49ers. He watches them on TV whenever he gets time, which is not often enough for him. He wants a new girlfriend, but he sets his sights on the cheerleaders, the same problem his old man had. He doesn’t listen to my advice on that subject either. He says I’m just an old fart. He has a paying job as a “Junior Lifeguard” at the local community pool. They do not rely on him to save lives, but he helps with setup of lane markers, pool covers and swim meets. He does not know about his lack of authority. They gave him a whistle last year, but modified it to be quieter. The power went right to his head. He likes this job, mainly because he “gets to meet babes”.

His little sister loves him and hates him at the same time. They fight in the car, they fight over the TV, they fight over who is supposed to feed the dog or who is taking too long in the bathroom. My little sister and I still fight about some of those things. As a family, we were fortunate enough to get a trip to Italy this past summer on Frequent Flyer Miles before all the trouble broke out. It was a struggle for Travis. Not because of his disabilities, but because it is a struggle for anyone to be in a country where you don’t speak the language. In a way, the rest of us were able to experience a little of what Travis goes through every day. I can’t believe he makes it in the world as well as he does. I would be much more frustrated than he is. We have always taken Travis with us everywhere and treated him as if he did not have a disability, except where it was obvious or dangerous. As a result, Travis has grown up thinking that everything is possible for him. I often wonder if we have set him up for a lot of disappointments. Maybe we did, but to assume so underestimates Travis’ ability to cope.

So what are his plans? Ask him, he will tell you in a prepared speech that he is more than willing to recite. He thrives on having a plan and executing it. Next year, he will be getting his driver’s license and graduate from high school. He will go to the transition program at DVC (our local Jr. College) while he waits to get into “college” at Taft (a residential “life skills” program near Bakersfield CA.) There he will meet the girl of his dreams, get married, buy a house and have kids. He is convinced that he will be a good dad. He says this is because he watches me and is learning how. The realities of all of those plans will be far different, I’m sure. I used to worry about telling him. Now I don’t.

Those realities: He probably will not drive (or at least I hope not!). We are not saying no, but we told him he needs to pass the written test first. We got the California driver’s

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handbook for him to study, but he has not opened it in over a year. He will be going to the transition program at the local J.C., but there is a long waiting list for the Taft residential program. I have no doubt that he will meet a nice girl and get married someday. I doubt he will ever have the earning power to buy a house in California. Heck, I don't even have that earning power any more. We will work hard at providing him with some sort of living arrangement away from us. He expects it and deserves it.

What about the kids part? One day, Travis turned off the radio in my car and said he wanted to ask me something. I acknowledged him, and he said "Why do I have Down's Syndrome?" I gave him the clinical answer that I had prepared for just this occasion. He said "I know THAT part, but why did it happen to me?" I was floored. I searched my religious background. I contemplated a statistical analysis. I debated the philosophical aspects and all avenues to the truth came up with nothing. I had no good answer. What I finally resorted to was "I don't know". I steeled myself for a wave of depression, both from within and from him. Instead, he said "Will my kids get it? Because I don't want my kids to have Down's Syndrome. It's hard to do things and I can't do everything that other guys can." Wow, I thought. Here I was being all self absorbed about how I was going to deal with this, and he was focussed outside of himself, showing concern for his potential offspring. I was humbled. I was impressed. I was proud. I was going to tell him that as far as we know, he will not be able to be a father. I decided that I didn't want to take that away from him yet. Nature will do it for me eventually. I opted for a graduated approach. "If you can have kids, they might have a good chance of having Down's Syndrome" I answered. "Oh" he said, "maybe I should think about not having kids then. Would you be sad if I don't make you a grampa?" he asked. I told him that nothing he could or could not do would make me sad any more.

So why did I write this letter? To encourage you to use the resources available to you, such as the Father's Program, in an effort to improve yourself rather than trying to fix your child. I know that as men, we want to fix broken things. The trick here is to quit thinking of our kids as broken.

They are just kids. I believe that the best thing you can do is to let them be the best person they can be. Love and acceptance are more important than therapy and intervention. Our kids are eventually going to get to a place where you can feel pride and joy for them no matter what their circumstances are. Be ready for it.

Happy Father's Day.

*Jeff Raefield*

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# Raising Your Other Children

by Sue Levine & Brian Skotko

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1. **Be open and honest.** Encourage other children to ask questions; answer them on their level as honestly as possible.
2. **Talk about the disability as early as possible.** Your children are smart, and they have questions. Don't wait for them to bring up the important topics.
3. **Be fair.** Listen to both sides of the story and be certain to make sure each child has responsibilities appropriate to their level of ability ("Don't blame me cause I'm the oldest").
4. **Allow siblings to express negative feelings.** Acknowledge the fact that sometimes it is hard to be a brother or sister to someone with a disability ("When I have troubles, let me talk to you about it."). Allow them private space and time and don't expect them to be saints.
5. **Recognize the individuality and uniqueness of the siblings.** Be sure to point out what makes your children special; they want to know that you notice them, too. Celebrate their accomplishments and schedule special time with each of your children.
6. **Welcome other kids into your home.** Demonstrate very early on how their friends can feel comfortable with their sibling with a disability. Help the siblings explain your child's disability, if needed or requested. This will lessen feelings of embarrassment or fear of rejection.
7. **Limit caregiving responsibilities.** Children need to be children. Allow them to be brothers and sisters, rather than becoming an extra parent. Your children with disabilities also benefit from having siblings rather than a family full of parents.
8. **Use the word "normal" when describing your children's traits.** Sometimes siblings will become acutely sensitive of their abilities and body morphology ("my ears are too big"). Reassure them that these characteristics are normal. Be caution, however, in telling them that they, as a person, are normal; doing so robs them of their individuality and implies that your other child is abnormal.
9. **If needed, encourage the siblings to participate in brothers & sisters workshops.** Both local and national groups have opportunities for siblings to meet each other. Such experiences are often validating.
10. **Laugh.** Humor is healthy for all family units.

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# How Grandparents Can Help!

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The following recommendations were identified by grandparents, as four important ways they can help their children after the diagnosis of Down syndrome has been made:

- Listen carefully to your children as they explain what Down syndrome is, how it was diagnosed, what is expected to happen in the short term and the long term, and then ask about the things you don't understand. The new parents of a child with Down syndrome will need a sensitive and understanding listener. If it also happens to be their own parents, all the better.
- Educate yourselves about Down syndrome. Contact local and national organizations and talk with experts in the field. It will be important for your children to know that you are educating yourselves about Down syndrome, just as they are.
- Keep a positive attitude. Your children are having a hard enough time as it is, and will need the steady support of their more experienced parents.
- Consider joining or starting a grandparent's support group through the local Down syndrome parent organization.

*By Robert M. Greenstein, MD*

*(Excerpted from June, 1990 newsletter of the Connecticut Down Syndrome Congress)*

*Contact the National Down Syndrome Congress at 800-232-6372 or [info@ndsc.org](mailto:info@ndsc.org).*

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# Focus on Grandparents

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The impending birth of a child generally fills an entire family with anticipation and delight. The hopes and joys of the prospective parents and grandparents tend to be dashed however, when the eagerly awaited infant is born with Down syndrome. Both parents and grandparents may experience similar feelings of confusion, shock, and grief.

The grandparents' reaction however, is doubled – grandparents suffer not only for the newborn but for their own child's pain as well. As the grandparents of a child born with Down syndrome commented, "I worried, of course, about the welfare of my grandchild, but my heart broke even more for my son and daughter-in-law for what they were going through and for not being able to experience the normal joy of becoming a parent.

## **Initial Reactions:**

The initial reactions to the birth of a child with Down syndrome may be numbness. Numbness is nature's way of protecting us from feeling unbearable pain, and it gives us time to develop ways of coping. A frequent coping mechanism that follows is denial. Feelings of unreality, that this really didn't happen or it is a mistake, are common examples of denial.

Grandparents frequently cling to denial reactions, hoping against hope that their grandchild was incorrectly diagnosed. In extreme situations a grandparent may avoid visiting or even telephoning, thus not having to come to terms with the painful truth.

Unfortunately, this type of behavior can be mistaken for disinterest, compounding the new parents' sorrow and robbing them of much needed support. It is important to recognize that clinging to denial is one way of not having to grieve. Persistent denial, as understandable as it is, will only backfire because we must grieve in order to heal. Grief is the natural expression of all the emotions we feel when faced with an upsetting experience.

Not allowing oneself to feel these tremendous pangs can often result in depression, stress-related physical illness, insomnia, and other emotional problems.

Paradoxically, the only way to relieve grief is to permit the sorrow and pain to surface. Feelings of grief shared with someone else, such as a spouse, friend, or member of the clergy, gradually lessen in duration and intensity.

Grandparents who believe they are grieving strong by denying or suppressing their grief feelings run the risk of compromising their ability to function and being of any assistance.

Very often the grandparents who believe they are grieving strong by denying or suppressing their grief feelings run the risk of compromising their ability to function and being of any assistance.

Very often the grandparents and new parents are unable to communicate with each other exactly how they feel. Both may feel vulnerable or wish to protect each other. However, sharing feelings honestly and openly will bring the family closer together. Sympathetic words or tender encouragement can go a long way at this point.

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One of the most frequent reactions to tragic circumstances is anger. This can be a generalized response such as “why did this happen to me?” Or can be directed to others such as the doctor or the hospital where the child was born.

Anger in its extreme form can manifest itself as uncontrollable rage, thus paralyzing and frightening at the same time. Frequently, anger is displaced and serves as a way of assigning blame to others, especially to the doctors and therapists. At times misplaced anger is directed towards the child with Down syndrome for being disabled and this unhappy situation can result in rejecting the child altogether.

Unfortunately, there is no easy answer to dealing with anger. Although anger is understandable, it is ultimately non-productive. As one young parent told the grandparents, “My anger went away when one day I looked down at my child and though not, “why me?” But “why him?”

Of all reactions, feelings of guilt and blame are the most cumbersome. Comments from other family members: “This never happens on our side of the family” – only adds more distress. In some cultures the birth of a child with a disability is seen as a form of punishment for something that happened in the past, even in a previous life! Some parents and grandparents feel that having a child with a disability is a sign of weakness or an inherent imperfection even when this is patently untrue. Guilt of laying blame serves no purpose; it shuts out the world and closes off avenues of help.

Grandparents can play a major role in assuaging the unfounded guilt by assuring the young parents that laying blame at their doorstep is unthinkable.

Depression and anxiety are other reactions that can occur and recur. The best way to deal with depression is to recognize that sad feelings are justifiable under the circumstances. Active involvement in the child’s welfare may dispel the gloom or lessen the intensity. However, when the depression is generalized, pervasive, or extreme, professional intervention is indicated. Acceptance is the hoped-for reaction to the birth of a child with Down syndrome.

Although sorrow over the event may never disappear entirely, the unhappy feelings do lessen in intensity as time passes. There is a more positive side to the picture for, as the child grows, parents and grandparents alike have the opportunity to experience joy and pleasure just as with any other child.

As one grandmother commented, “Although I can never completely accept the fate that has befallen my children it doesn’t get in the way of the love we feel for my little granddaughter. Somehow that makes the reality of the situation not as grim.”

### **Things to Remember:**

Most grandparents who have financial resources and leisure time at their disposal find great pleasure in the relationships they develop and the activities they share with their grandchildren. In many cases grandparents have a more relaxed attitude towards their grandchildren; they are not as pressured or fearful of spoiling children as when they were young parents themselves. Tales of doting grandparents who indulge their grandchildren’s every whim are legendary, however, including allowing grandchildren forbidden

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sweets, staying up late, or ignoring family rules, although prompted by the most loving of intentions, indulging grandchildren can create family friction – especially if the child has special dietary restrictions or needs careful behavioral monitoring.

Grandparents can avoid hard feelings by sitting down beforehand and requesting careful explanations regarding their grandchild's care, including for example what activities are most beneficial, hints on handling, and dietary needs.

By becoming as expert as possible, grandparents will be able to provide consistent care and help when and where it is most needed. Use leisure time to your grandchild's best advantage. Because grandparents tend to be removed from the day-to-day care of children, they are better equipped to do things.

The grandfather, for instance, who patiently tosses the ball back and forth to help with coordination, or the grandmother who spends hours teaching shoelace tying is providing a loving service that delights both grandparent and grandchild. The best gift a grandparent can offer is the gift of time.

Providing actual financial gifts, however, requires careful evaluation. Many well meaning grandparents leave bequests or send funds to their grandchild who has Down syndrome, not realizing that it may not be the best way to provide for the child's needs. Grandparents and parents should seek the advice of attorneys or experts in the field before drafting wills, planning estates or giving sizable gifts. Regulations vary from state to state so it's a good idea to contact your local Down syndrome group for information and guidance.

### **Do's and Don'ts**

- Do be aware that most schools, agencies and parent support groups welcome attendance by grandparents. Some associations even have grandparents groups. This is a good way of keeping abreast of information on Down syndrome and related issues and sharing support with other grandparents who have grandchildren with Down syndrome.
- Do avoid the pitfalls of cliché-ridden advice. Comments about God's will, or Pollyanna statements about things not being as bad as they seem sound condescending and don't provide the comfort you wish to imply.
- Do remember that if you have a positive, tender, loving attitude towards your grandchild, others in the family will feel the same way. The more support from family members, the better the parents may tend to feel.
- Do remember that no-verbal expressions – a loving pat to your grandchild's head, and hugs to the parents, convey what words cannot express. By the same token, pitying glances and an anxious tone of voice deepen gloom.
- Do be aware of any heightened sensitivity in the parents. Be careful about what you say and remember that your most well intentioned remarks can be taken the wrong way. Handle this with grace and humor.
- Do let your children know that they can rely on you in good times and bad. Many grandparents have flexible schedules that can be arranged to meet the needs of the

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grandchild. Just knowing that this kind of help is available can lessen anxiety and strengthen family bonds.

- Do offer to visit or help out with your grandchild regularly. Sometimes staying at a nearby hotel can ease the logistics and make the visit even more rewarding for all concerned.
- Do find out the best time for you to visit or telephone. Your children might relish their privacy or be in the middle of things and, unless you ask, your visits or telephone calls might come at an inconvenient time for them.
- Don't allow any frictions between yourself and your children to interfere with your relationship with your grandchild. The bonds of love between grandparents and grandchild can be genuine and profound. The relationship can enhance and nurture a grandchild's feelings of self-esteem and self-worth.
- Do be aware that there may be revolving cycles of emotions. Feelings of depression, anger, non-acceptance or sorrow may surface around birthdays or other milestones, such as when your grandchild should be driving or getting married. Knowing this ahead of time can prevent the reaction from becoming extreme.
- Do remember that above all, the relationship of grandparents to a grandchild is unique, and the love that is generated is freely given and like no other. Your grandchild is first and foremost a child – more like other children than unlike. The needs of your grandchild differ only in degree, not in kind. Your grandchild with Down syndrome will respond to your love, your jokes and games, and your abiding affection exactly like any of your other grandchildren.

*Reprinted with thanks from the Down Syndrome Center of Western Pennsylvania.*

### **Tips for Playtime with Your Grandchild**

As an infant educator I am often asked how I teach babies. My reply, which is really an introduction to infant development and the effects of early intervention, is often a surprise to people. But, basically what I do is play.

I use the word “play” in a very broad sense. Newborns “play” as they look at their parents. Babies play as they bang their spoon on the high chair, or dump out the contents of every container they can find. Children learn through these experiences with their environment. They also learn by playing with other. There are several things I keep in mind as I play with the babies in our infant classrooms. I'd like to share them with you to help your playtime be more fun for your and your grandchild.

**Observe.** Take time out to watch your grandchild play. Whether the child is two months or three years old, what a child does during independent play may give you ideas on the types of games you can play together.

If your grandchild is beginning to reach toward objects, offer her a variety of things to reach toward – brightly colored balls, a rattle, a musical teddy bear...If your grandchild is picking things up for the pleasure of watching them drop, let him drop a variety of objects,

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perhaps into the bathtub, into your purse, or into a kitchen drawer. Look at what the child is doing and think of games to help her practice that skill.

**Be Creative.** To engage a child in a game with an object, present the object in a playful or challenging manner. Rather than handing the toy to the child, make the toy “walk” over to the child. Try making the toy “fly” and let the child reach up for the toy. Cover the toy and let the baby discover it, or tie a string so that the baby must pull on the string to get the toy. Use your imagination. A playful and challenging presentation of a toy can capture a child’s interest and get your game off to a good start.

**A Favorite Early Game.** Much of what babies learn, they learn by imitating. Turn-taking games can give your grandchild an opportunity to imitate you. Taking turns is also an important part of communication and becomes a part of most any game. Whether you are stacking blocks, making sounds, shaking a rattle, or scribbling, you can reinforce turn taking. After you take a turn, pause to give your grandchild a turn. A five-second pause may not be long enough. Try waiting up to a minute, especially with younger babies.

You may be surprised at the number of things they will imitate, and the number of turns they will take. Wait for any “social” signs, such as a reach toward you, a smile, or a sound that shows the baby is communicating with you. While you play with your grandchild, keep in mind the importance of eye contact during communication.

For a newborn, looking at a face is “work”. A newborn will look away, then look back again. Let the newborn lead this game. With an older child you may want to be more direct. As you play and you say the child’s name, try waiting for the child to make eye contact before you continue. Eye contact should be a pleasant experience. When your grandchild makes eye contact, smile and show your pleasure.

**Watch for Signals.** Babies can tell you a lot about whether they like or are ready for the games that you play with them. If you begin to play, with or without toys and the child is interested, engaged and/or happy, it is probably an appropriate game. If the child is not attentive or begins to fuss, that tells you something else. The child may not be ready to play at all, or the game may be too easy or too difficult. Watch for these signals. If the child is happy, keep going. If not, stop or change the game.

Keep in mind some of these ideas as you play with your grandchild. Playtime is an extra special time that can provide positive learning experiences for adult and child. So grab that rattle and have fun!

*Excerpted from Janet Osborne, M.Ed, University of Washington, Seattle, WA*

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Improving  
knowledge  
for those  
affected by  
Down  
syndrome

## Enhancing Family Resilience: “Pants First, Then Your Shoes”

I’ve worked with families for over 40 years, many of whom are parents raising children with special health care needs. It’s been a privilege to do so. They have taught me about courage, patience, and unconditional love. They have also given me an understanding about factors that promote family resilience, defined here as “the ability to bounce back, to rebound in the face of life’s stresses and pressures -- to land on one’s feet and continue to move forward.”

What is it about some families that not only cope with life’s stresses but they flourish, while others struggle? Some families are made stronger, while others flounder. Are there factors that can be isolated and taught to enhance the well being of all families and family members? An increasing body of research says there is.

Families have changed dramatically in the past 20 years. The so-called “typical” family does not really exist. Single parent homes are on the rise; homes where grandparents constitute the primary caregivers are increasingly common. Full custodial, father-led homes are one of the fastest growing populations in the U.S. For economic and personal reasons, increasing numbers of families are at-risk for problems, including depression, addiction, and abuse.

The famous sociologist, Urie Bronfenbrenner, once wrote “A family is a group of people who make an irrational commitment to each other’s well being to the point of making each other crazy.” While his remark is humorous, it also contains great truth. Families strive to do the best they can, with many facing a scarcity of personal, social and economic resources. For the purposes of this article, family will be defined as “anyone who play a positive role in the life of a child” - emotional, physical, spiritual, or financial. It could be the biological parents, an extended family member, a teacher, neighbor or church member. Indeed, it “does take a village to raise a child” these days.

Families are like mobiles; they are all interconnected and interdependent; what happens to one member impacts everyone else. I remember watching “60 Minutes” a few years ago and Mike Wallace was interviewing a family whose child was born with genetic anomalies due to the mother’s use of the drug, Thalidomide. The son - in his 30’s - had undersized arms and legs and was in a wheelchair. He talked about the difficulties of growing up, but felt he had overcome many obstacles and lived with independence and respect. While the young man did not deny there were difficulties, he felt his disabilities had been essentially surmounted.

However, the mother gave another picture of the family. Her husband had died five years before, from the effects of high blood pressure and a heart attack. The mother said “the stresses of raising our son is what really killed him. He was not a man who openly shared his feelings, and the stresses of constantly providing for his needs, and the needs of the rest of the family, were often overwhelming to him.” She talked about how lonely she was now that he was gone. She also had two daughters; one had left home at age 16, the other

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at 18. She had little contact with them since their leaving, as they felt great resentment and anger about the energy and time that had gone into raising their brother. They felt they had been neglected and asked to serve in the role of a second parent. With a look of despair and profound sadness, the mother declared, “Isn’t it a shame that the only person who turned out okay was the person with the disability.”

This story provides us many insights about the impact of raising a child with special needs and what enhances or detracts from family resilience. Let us examine three areas:

1. *The places where stresses most likely will occur when a child is diagnosed with a disability;*
2. *Mother and father reactions - how their responses might be the same or be different; and*
3. *What will be most helpful, as a couple, and as a family; what will build family resilience?*

When a child is diagnosed with a chronic illness or developmental disability, almost all family members experience guilt, anger, sadness, depression, and periods of denial. “This can’t be happening to us.” “What did we do to deserve this?” “Why has God turned his back on us?” Nancy Miller, author of *Nobody’s Perfect*, calls this the “survival” stage.<sup>1</sup> Families live for the moment, coping with constant confusion, the ebb and flow of feelings, and view the future with great concern and anxiety. This period can be brief or very lengthy. Common responses to this survival period include:

- One parent becomes the “designated expert,” typically the mother. If a father is in the home, he might feel “left behind,” both in knowledge of the child’s condition, but also in his relationship with his partner. Lines of communication regarding the child may become strained, particularly if their decisions and roles become stratified and inflexible.
- The potential for over-involvement of one parent with the child is a distinct possibility. There are so many “must do’s” in regards to therapies, medical appointments, schooling issues. There never seems to be enough time in the day to accomplish everything. Time to nurture one’s primary relationship is often secondary to the health and well being of the child, with the resultant feelings of resentment, confusion and anger. Favorite activities are missed, a reduced sex life for the couple often occurs. The primary topic of discussion is almost always the child.
- If there are other children in the household, they will need to understand how they fit into this “new” family. They will often experience confusion, guilt (“did I cause this?”), resentment (with double standards for the child with special need often provoking such feelings), and fear about the future and whether they might need to be the child’s permanent custodian.
- Financial issues may also seem overwhelming, particularly if the family lacks adequate insurance and faces enormous bills. I think of the family in our program whose twin sons incurred over 8 million dollars in medical costs. Managed care often does not pay for the services of specialists nor necessarily make them available to families. There is generally a limit (cap) to how much an insurance company will pay.
- The world of disabilities can be a maze of regulations, acronyms and language, guaranteed to confuse, startle and bewilder. There are few central sources of information nor

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“one stop” shopping. A child with special needs does not come with a manual for parenting, and finding services can be a full time chore, particularly if one lives in a rural setting.

- The cultural context of a family is crucial. What does the family believe about disability and how s/he “should” be handled? Does their religious faith help or hinder? Is the child seen as a blessing, a curse, “a gift from God,” or the result of some personal failure? One man bluntly asked a rhetorical question, “God doesn’t make junk, does He?”

All of us bring dreams and expectations to our children. We want them to grow up healthy, live independently, be educated, and achieve great success. A child with special needs can threaten such dreams. Every family I have ever worked with can talk at length about the day they learned their child was diagnosed. It is a pain one forever carries in your heart. While the pain lessens over time, it often reoccurs and manifests itself in a variety of ways. The emotions associated with this pain can vary according to person and background, but for most it involves sadness (at times, despair), fear and anger. At times it feels as if everything is caving in on us, and parents experience long nights, long weeks -- and yes, long years. I’ve often heard the experience referred to in metaphorical terms, “cloudy days,” “dark nights,” “a loss of light.”

As adults we know that life is not a fair process, and the ups and downs of living are an equal opportunity affair. Yet, when something as outrageous as having a child with special needs occurs, many families do battle with issues of justice in the universe. I think of a family whose first son contracted an infection when the boy was just a few weeks old; the result was profound developmental delays. Their second child, a daughter, was born full term and in perfect health. Yet within a few months she had to have an eye removed due to cancer. All of us were literally left speechless. “How could this happen to them?” “Haven’t they already paid their dues?” “Why do some people seem to get off scott free?” Of course there are no answers to such questions, yet the frustration engendered by such thoughts can be very powerful. Jack Neafsey wrote some comical “Laws to Remember.” Two of my favorites include: “There are days when no matter which way you spit, it’s upwind.” He calls that “the first law of reality”). His second law is: “Whatever it is that hits the fan, it will not be evenly distributed.”<sup>2</sup> We can laugh at these, but the pain such “injustice” provokes is real and often overwhelming. Indeed, life should be “fair,” or at least equitable for all. Such concerns may threaten our core spiritual beliefs.

A recent Canadian study completed a longitudinal study of hundreds of families and the stresses they experience as parents of children with special needs. Their conclusions included:

- 88% of parents reported feeling tired or overloaded, and 90% stated they were stressed about balancing work and family obligations;
- 39% reported their employment status had been affected;
- 26% reported their choice of occupation had been constrained;
- 46% said their work schedules had been affected;
- 68% had turned down overtime;

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- 27% had to forgo opportunities for promotion;
- 64% of two-parent families with one parent unemployed reported their child's special needs were a major factor in their unemployment.<sup>3</sup>

Many families feel they are barely staying ahead in the race. It is no wonder that Robert Perske, author of numerous books on disabilities, says that parents of disabled children often experience “the speeds.” They run around, always taking care of their children, but rarely take time for themselves. At its worst, disabilities can be “crazy making.” For me, having lived with rheumatoid arthritis for 45 years, I still get angry almost every morning trying to put on my “damn socks.” The ups and downs are like a roller coaster ride, and we don’t know if and when “the ride” will ever end.

For most parents thoughts about the future are a major concern. Will my child finish school; where will s/he live? What about employment? Are our plans for retirement in jeopardy? What happens when we can no longer care for our child? What if no one wants to be our child’s guardian? Should we have more children? Will life ever return to “normal”? These are tough questions, and the answers come slowly -- and often with emotional pain.

Peter Steinglass, a noted Canadian researcher, published his findings about families raising children with special needs in an issue of *Family Process*. When responding to chronic illness and disability, families will:

- Experience guilt, anger, disappointment, helplessness and resentment;
- Talk about “the problem,” but rarely talk about the impact of the problem on the family;
- Will organize to handle the problem but find it difficult to change;
- Discover that the chronic illness / disability becomes a “family member” and may take over the family. He compares this family member to “a two year old terrorist”;
- Some families may actually function better after the crisis; and
- Some families who are functioning the best are seen as problem makers by providers. These families exhibit strong problem-solving skills and are risk takers. They know they are the true experts regarding their children, and they will take control and strongly advocate for their particular needs.<sup>4</sup>

Steinglass’ findings reveal several important ideas. The sheer power of disability in shaping families is evident, so powerful it may actually take on a personality of its own. My wife has referred to my rheumatoid arthritis as “a demon” in our lives due to its negative impact. The power of emotional response is obvious, but the ability to share that emotional “impact” is difficult. One is left to question the “why” of this. Are the emotional responses so painful family members are afraid to speak openly about them? Do family members limit their responses so as not to alarm or concern others? Do we always need to be strong for others so they can handle their feelings in the open?

Gender differences come into play. We know that mothers and fathers parent quite differently. Mothers typically are nurturing, even protective in their response to children. Men are usually very physical in their father-child interactions, and often want a child to exhib-

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it levels of independence and problem-solving. Mothers hold infants inward to protect them. Men often carry young children on their shoulders and playfully throw them in the air. Such differences are generally valuable and often complementary.

Parenting a child with special needs, however, can intensify and exacerbate such differences, what one parent called “turning up the volume on our relationship.” Issues such as proper feeding and child discipline can create tension. Grieving losses can produce very different responses. Women often freely express their emotions; many men hold them in. Women are relational and reach out to others for comfort and understanding. Men often choose to “go it alone” and choose a more stoic path to follow - the John Wayne mentality. “I am strong and don’t need any help” is a powerful injunction that many men embrace. Such a reaction is reinforced when we view the response to the Oklahoma bombing tragedy several years ago. Upon entering the memorial service, women received roses, children received teddy bears, and men received nothing. The statement is clear: “Men, you are on your own.” Many fathers suffer in silence, not knowing that what they are experiencing is similar to other men, and that their anger is really a cover for fear and sadness. Clearly, both parents need to be engaged in caring for the child with special needs, and they also need to be focused on enhancing their interpersonal relationship. Finding such a balance can be difficult.

Peter Steinglass concludes that “Some families may actually function better after the crisis.” What are the components that comprise this growth? What have they learned about family resilience? What enhances a family’s ability to cope, and even transform themselves into a stronger family unit?

The power of perception and attitude is viewed as a powerful indicator of family well being. Family resilience always starts with attitude. We generally receive what we expect, and our personal expectations dictate our behaviors. Without being overly simplistic or fanciful, living well with a disability is greatly determined by “how you look at it.” Researchers talk about “the power of positive expectations.” and well being. In a major study regarding families of children with profound disabilities, two University of Washington researchers, Karen Frey and Pat Vadasy, concluded: “Parental beliefs were the single most powerful predictor of family outcomes in coping with disability.” Beliefs about parental ability to “control their own lives” and believing in their ability to “cope better than most” allowed for effective personal and family functioning.<sup>5</sup> Rather than focus on the continual negatives of disability, such families view the glass as “half full,” and they strive to integrate the difficult learnings into their lives in helpful ways. Countless families have remarked that they would never ever wish to have a child with a disability, but they know this child has made them better parents: more patient, understanding, and sensitive to the needs of others. They view their child as a “teacher,” and they don’t allow themselves to become bitter or cynical. People are able to “re-frame” problems and find creative solutions to the outcomes. It is complex work, but it can be life enhancing.

One dad used a Biblical allusion when talking about his child. He said, “You hit the Red Sea but it doesn’t part for you.” This loss of control can be overwhelming for many families. “That I can’t control the disability still leaves me confused. That I can’t seem to do anything about it just drives me crazy.” Men, in particular, are taught to “fix” problems. A disability or chronic health condition generally cannot be fixed. Yet, resilient families avoid

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catastrophizing. They don't gloss over the difficulties, but they also know that problems are solved one step at a time. The cartoonist, Gary Larson, showed a man sitting on his bed in the morning, with the sun streaming through the window; the caption read, "First pants, then your shoes." So it is for many families. They know all things get solved one step at a time, that there is light at the end of the tunnel if they persevere and "keep the faith." They are future-oriented, and often exhibit perseverance and faith. It is what the Danish theologian, Soren Kierkegaard, calls hope, "the passion for what is possible. It is not based upon reality as it is now, but on the reality as it might be tomorrow."<sup>6</sup>

An often used cliché has much truth to it -- "knowledge is power." Resilient families are knowledgeable about their child's disability, and in that knowledge they regain much personal control. They have a thorough awareness about treatment modalities, their legal rights, and schooling that speaks to their specific needs and concerns. They attend the I.E.P. and I.F.S.P. well prepared and are confident the outcomes will promote success for their child. Resilient families are indeed experts about their children and are not afraid to push for what they want. Our family mobiles take on new balance and we gain some equilibrium. Siblings, in particular, need the resources and knowledge they so richly deserve.

It is natural for parents to protect their children from pain and potential suffering, both physical and emotional. Yet in our desire to safeguard our kids with great vigilance and love, we potentially stop children from learning for themselves. Resilient families often ask this question, "What are we teaching our children about personal independence?" We owe our children a chance to make it on their own, and yes -- even to fall down, bruise themselves, and get back up again. That's how we learn, and that's how we gain personal confidence.

Sociologist Edwin Pratt, in discussing "The Energized Family," says resilient families encourage autonomy in all family members, including the child with the special needs. We live in a society where we are constantly bombarded by losses, whether that be the loss of a job, a move to another state, illness and death or divorce, to name just a few. Grief is the natural process that helps us cope with such losses and maintain emotional health. All family members need places to grieve their losses. Grieving is not a one-time thing; we don't just feel sad for awhile and then get on with our lives. It may take years before we make terms with some losses, and in those years we continually experience anger, sadness, depression, and denial. Researchers Wortman and Silver talk about "the myths of mourning."<sup>7</sup> "There are no discrete stages that all family members go through, nor does each member experience each stage." It is imperative all family members have times to share their feelings, to grieve. Siblings lose a brother and sister they always wanted; and grandparents grieve for two losses -- the loss of the perfect grandchild they hoped for, and the pain they know their own children are experiencing. Men, in particular, must learn that it's okay to cry, to show sadness, to ask for help. Big boys indeed need to cry, and we will all be healthier because of it.

One often hears the saying that "what goes around comes around." As a professional in the social service field, I know the world of disabilities is very small; if we cut too many ties they will come back to haunt us. Anger is so much a part of living with disability. It is tempting to blow people away, particularly health professionals who can't "fix" our child or solve our most pressing needs. I've done it myself -- and I regret it. I remember the dad

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who boldly exclaimed to some parents that “I decked my Doc” (physically knocked him down). Health and education providers and families must be allies, not adversaries. We need each other. Parents know their children better anyone else; they are the experts. Providers have skills and experience that families truly need and desire. Resilient families exhibit a desire to collaborate in the best interests of the child -- they work together.

For many families raising children with special needs, spirituality is critically important, an anchor that keeps them grounded in the midst of many storms. They find an inner calm that lends balance to the outward struggles. They discover a higher power, however that may be defined -- sources of hope and peace. For some, reflective walks bring a necessary peace; others meditate or visit an art museum or attend a concert. Prayer and contemplation can restore a tired soul.

The literature about families is clear. The single greatest contributor to family resilience is the willingness to surround oneself with support. As a mental health counselor and a person living daily with a chronic illness, I know that isolation promotes helplessness. Simply stated, it is very, very tough to make it alone! Kids need other kids, and families need other families. In his comprehensive study of families, Edwin Pratt concluded that “those who handle disability, chronic illness without major disruption are characterized by varied and frequent intra-family interactions” -- in other words, they talk, share, and communicate with each other. What greater privilege than to be listened to, and to listen to others.

In moments of frustration and anger I will often say, “Life should be simpler.” It is then I need to remember that I must not be so hard on myself. Richard Carlson says, “Make peace with imperfection.”<sup>8</sup> Life is a matter of mistakes and learning from them. None of us are perfect. Above all, we need to enjoy our kids, enjoy ourselves, and mellow out. All children, including children with disabilities, are first and foremost children, and they radiate an innocence and joy that must be celebrated each and every day. Keep laughter and humor in your life, as it smoothes out many bumpy roads.

M. Scott Peck, in *The Road Less Traveled*, talks about finding the inner strength to confront our losses, and to gain the courage to be patient, to persevere, and renew our faith in this journey of discovery called life. He talks about the necessity of courage and says:

“Courage is not the absence of fear; it is the making of action in spite of fear.”<sup>9</sup> May your journey be filled with much joy and understanding.

James May

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# The “Good” Grief Cycle

Improving  
knowledge  
for those  
affected by  
Down  
syndrome



- Shock:** The handicap is diagnosed
- Depression:** I can't go on – what's the use?
- Denial:** Not me!
- Guilt:** If only I'd not...
- Shame:** What will people think?
- Isolation:** I must protect my child from people.
- Panic:** What will happen to my child – what will I do?
- Anger:** Why me?
- Bargaining:** Just let me get through this – then no more!
- Hope:** Perhaps we will make it through this.
- Acceptance:** There will be days filled with anger and grief, and days when I will feel strength.

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