

Autism

& the Grandparent Connection

**Practical Ways
to Understand and
Help Your Grandchild
with Autism Spectrum
Disorder**



by Jennifer Krumins

This book is dedicated to our parents, Ed and Kay Gaffney, Ed Krumins, and Ausma and Jack Donovan. Thank you for your unwavering support, courage and faith. Together our family has faced the challenges of raising a child with autism and together we are stronger.

In loving memory of Mary Jean Walker, although I never had the chance to meet you in person, your faith, clarity of purpose, encouraging words and your prayers kept me writing this book. God bless you my friend. We did it!

A Special Thank You

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Kieran, you allow me to open your life and experiences up to the readers so that others may find hope and reassurance. You are a gift to our family and to the world. We love you.

My husband, Ivars, you are my partner and my best friend. You encourage me to be all that I can be and together we have made a difference. I love you.

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Who is Jennifer Krumins?

I think it is safe to say that I became more “me” when I became a mom. Each of my three children have fashioned the woman I am today simply by being themselves! Motherhood has taught me to appreciate more, love more deeply and live more fully!

Every child’s birth changes the face of the world and with it brings new hope and a fresh beginning. Never could I have imagined what gifts my children would bring to my life: passion, clarity and purpose. But life also has a way of delivering the greatest gifts wrapped in the disguise of grief. When our second child was diagnosed with severe autism, our life as we knew it (and planned it) changed dramatically. My husband of 18 years and I learned the most important lessons in life through these difficult times: stay close, act on your instincts, stay positive and keep the faith. Riding the tidal wave of autism is a voyage of a life time but the rewards are profound and immeasurable. This is not to diminish in any way the heart -wrenching, exhaustive and heartbreaking nature of autism but we refused to look at it that way. Even through the tears, we knew that our son was here to teach us something.

Individuals with autism have gifts that they bring to the world. Sadly, the world doesn’t always recognize these treasures. Our own son and the students I have the privilege to teach made me take a hard look at what I value and what I believe about purpose and fulfillment in life. They have collectively taught me that getting ahead doesn’t bring happiness, but, looking into the eyes of a child that finally conquers a skill - now that is pure joy! My kids taught me to really tune into my senses; truly feel the sun on my skin and the smell of a spring day. My kids taught me to slow down and really look at even the most seemingly insignificant things in life and see their glory with new eyes. I learned that our productivity doesn’t make us loveable; we already are. Our purpose in life isn’t about financial gain and material prosperity; it is about accepting ourselves and being at peace with the essence of who we are; living our lives for the sake of bringing some peace and light and love to others. My kids with autism taught me more than I could hope to teach them. Yes, they have brought me frustration, exhaustion and sometimes some pain but, beyond that, my students and my own children have pushed me to greater understanding, higher levels of learning and elevated awareness of the gifts that surround and live within us.

My husband and I have three children: two daughters aged 16 and 8 and our son who is 14 years old. Twenty years of teaching equipped me with vast experience in all kinds of learning differences and challenging learning difficulties. But none would compare with teaching my own son both in the general classroom (for two years) and in private therapy at home. These experiences drained me emotionally and inspired me professionally. Being a teacher and a mom brought me face to face with my own teaching philosophy and practices. I earned my Special Education

Specialist and I undertook extensive training from Queen’s University in Kingston, Ontario and the Geneva Centre for Autism in Toronto, Ontario. I had the privilege of working in a private therapy program for my son under the guidance and direction of the

Behaviour Institute in Hamilton, Ontario. Most importantly, I was privileged to work with students with autism and they have truly educated me.

I have been blessed with a family and a career that enriched my life and made me who I am today. We have not been alone on our journey of raising a child with autism. Ivars and I are grateful for the role that our parents have played throughout the years. Together, as a family we have been through the highs, lows and all of the in betweens of living with autism.

Why write this book?

Gazing into that beautifully innocent face, you beam over the distinctly familiar shape of the child's nose and those tiny eyes look back at you with the radiance of a cherub. Ah! Your grandchild: what a precious gift! It is the chapter in your life of which you have dreamed: an opportunity to develop a bond that is sacred and unmarred by the responsibility of child rearing. Grandchildren give the gift of seeing the world with fresh new eyes and awe. Nothing can compare with the boundless love that a grandparent feels for their grandchild. You are no longer limited by the need to juggle work, a household and raising children into mature, self reliant adulthood; the gift of grandchildren is one of life's greatest blessings. But life doesn't always deliver it's blessings in the package we expect.

Sometimes, dreams collide with reality. Grief and fear replace excitement and hope when we hear the diagnosis: autism. For many parents and grandparents it is a jolt into a new world: one that many have not even heard of or at least have minimal knowledge. The diagnosis tears at our hearts and brings the future crashing down (at least for a time).

But, time will show that the diagnosis is not a "death sentence." Life will find a "new kind of normal" and life will take on new meaning. There are therapies and educational programs that will make life more enjoyable for a person with autism.

The role you play may be different than the role that you expected to play, but it is vital nonetheless. In fact, your adult children may need you more than ever. As a grandparent, your ability to embrace your grandchild and support his or her parents is perhaps one of the essential gifts you can offer your children. This book is intended to help guide and encourage you in your efforts to play a positive role in the life of your grandchild and your family. You have the power to make life more manageable and pleasurable for your children and grandchild. You can enhance the whole family's ability to cope or you can choose to undermine an already fragile situation.

In an effort to gain a wide and objective perspective of the role of grandparents, I have collected 50 surveys from parents and grandparents from in Canada, the United States and other parts of the world. People have openly shared their stories and experiences about coming to terms with a diagnosis of Autism Spectrum Disorder. I am truly honoured and humbled to be invited into the lives of so many people. Their responses have given me a wider vision and deeper respect for the role grandparents play in our

lives. The ideas expressed in this book come from my own experience and more importantly, from the experiences of all of those who contributed. I am deeply grateful.

I believe many grandparents desperately care about their grandchildren and the impact that an autism diagnosis will have on their families. I learned that many grandparents take an active role in supporting their adult children in whatever way they are able. Parents gave me insight into what they need from their parents as they try to navigate this new territory. Some grandparents openly shared their own frustrations at wanting to help but not being allowed the opportunity. Others told stories of unconditional love and family togetherness. Through this wide variety of responses there is a common element: each individual loves the child deeply. This is the foundation on which a strong family can be built. Love will create a new kind of normal, and life will be rich.

One thing is for certain, parents of children diagnosed with autism need support; a lot of support. The divorce rate among those raising a child with autism is very high: the pressures, too great, in many cases. The potential role of grandparents and extended family cannot be overstated. At times it may seem that I repeat myself in this book. I intend to do so; some points are often restated in the surveys and they warrant repetition in this book. It has been said that, "It takes a village to raise a child." This could not be any more true for parents facing the challenges of raising a child with autism. The burden is emotional, physical, financial and social. Parents need communities, schools, governments and most of all, they need family to help them with this responsibility. It is a load too heavy for one human to bear alone. Our children born with autism are here to teach us, to lead and challenge us as a society and a family.



**Life's challenges are not suppose to
paralyze you; they're supposed to help
you discover who you are.**

Bernice Johnson Reagan

Chapter 2 The Grandparent Connection



“Other things may change us, but we start and end with family.” ***Anthony Brandt***

When Ivars and I had our second child 20 months after our first, we knew we would need the help of my parents (who lived an hour away). We enjoyed spending Sunday night dinners at my parents’ home and they would often keep the kids while we shopped. Both, my parents and my in- laws played a considerable role in our new little family. But, as Kieran aged, his development did not always resemble that of our oldest daughter, and he became more demanding. We became more dependent on my parents (they lived closer than my in- laws). Since Kieran’s diagnosis, my parents have played a more important role than perhaps, we had all anticipated.

In his book, *The Grandparent Solution*, author, Arthur Kornhaber, contends that the people who raised us - our parents - are a natural and vital aspect of coping with the huge demands of raising a child. Kornhaber, a child and family psychiatrist and foremost authority on child-parent-grandparent relationships, believes unequivocally in the necessity of these relationships. According to Kornhaber, when we bring a child into the world, we become parents forever: not until the children move out, not until they marry, but, forever. Even when we choose not to like our children or they choose to distance themselves from us, we are still connected.

“One thing that we know for sure is that our parents resonate emotionally, biologically and spiritually to our state of well being and material circumstances. They are tuned into our needs. This happens whether we get along with one another or not, whether we live near or far from one another, and whatever age. Whether seen or unseen, expressed or unexpressed, this vital connection is always turned on,” states Kornhaber. (Kornhaber 2004, p. 3)

Autism has a way of demanding action from everyone in that child’s life. Giving birth to a child with special needs may cause us to take a second look at the role of family. Maybe the nuclear family is not enough. Maybe the help we really need must come from within our own blood relations. One of the first things that parents need to do upon receiving a diagnosis is to rally the troops in terms of doctors, service providers and community organizations. More important, will be the task of rallying the child’s grandparents and other family members. I wonder if the rise in autism diagnoses will force parents and grandparents to re-evaluate their own relationships. I hope so.



“The measure of love is not how much that child loves me, but, rather how much I dare to love that child.”
Lois Wyse

Why are Grandparents so Important?

Kornhaber speaks of the “two dimensional family.” Those are the families that are living as a nuclear unit with two generations: parents and children. For years, the trend was for children to grow up, get a job and move as far away as possible from parents. The point was to raise our families away from our own families. This was supposed to make us more independent. This line of thinking leaves many parents disconnected and overburdened. Kornhaber makes the case for the practical need to bring grandparents back into the fold, creating “three dimensional families.” This may be even more critical for parents raising children with special needs such as autism. Let’s face it: it is impossible to meet all of the needs of a child with autism by ourselves. Those that think they can, often end up burned out, unhappy and resentful. To quote an overused cliché: “It takes a village to raise a child.” The natural “village” consist of those who are biologically, emotionally and psychologically connected with the child.

Whether or not we have a good relationship with our parents, the link between a child and grandchild is far from something that we can take for granted. Emotional security is gained through the grandchild – grandparent connection. Kornhaber asserts that, “The grandparent – grandchild duo is hardwired to be with each other and to transmit wonderful things back and forth.” (Kornhaber 2004, p. 52) Dr. Kornhaber’s research indicates that our brains and our spirits yearn for that connection. We may be totally unconscious of this linkage. But, it is present, nonetheless.

Grandparents offer roots to a child - a past and a future. Grandparents connect history with the present. They are a living history text. Knowledge, traditions and past experiences are invaluable assets to children. Our son is passionate about military history. There is no textbook that describe things like my husband’s Latvian father who served in WWII and survived prisoner of war camps. Interestingly, it is our son with autism who is the most interested and connected to his Latvian and Irish roots. He can be counted on to listen to Grandpa’s stories for hours!

Grandparents can nurture emotional health and well being in children with autism and their siblings. Siblings of children with autism may need the grandparent’s relationship more than anyone. Parents can be so focused on the child with autism that there is little time or energy left for the siblings. Grandparents can be a “soft spot to land” when things at home are too much. Parents raising a child with special needs simply cannot be all things to everybody. The burden must be shared. Most parents who are raising a child with special needs have felt guilty about not having enough time, patience and energy to give to all of their children. It is often the most challenging child that requires the most attention from us. A quieter, more capable sibling may get ‘lost’ in the day - to - day affairs of a busy family. Grandparents are a natural and built - in team. They play a

critical role for siblings in families that are coping with very challenging children. They can offer the emotional security that builds confidence and self worth.

Grandparents solidly connected to their grandchildren hold a great deal of influence in their lives. Many grandparents become a spiritual role model and guide for their grandchildren. Through the surveys, numerous people reported their parents' faith became a strong force in the family. Religious traditions once lost were restored after a diagnosis. The grandparents' faith and prayers were sometimes the only things they could offer to a struggling family. From their example, children can learn the values of hard work, persistence, tenacity and collaboration.



“Grandparents can be role models about areas that may not be significant to young children directly but that can teach them about patience and courage when we are ill, or handicapped by problems of aging. Our attitudes toward retirement, marriage, recreation, even our feelings about death and dying may make much more of an impression than we realize.”

Eda LeShan

Families of children with autism are often stuck on waiting lists or at the mercy of staff that changes frequently. There is no waiting list for a grandparent. They can be a constant presence. Often there are more children needing help than there are service providers and human resources to respond. Given this reality, family members need to reach out to each other. Yes, we can (and should) lobby governments to increase financial and human aid and assistance. But, I think it is necessary to take steps to build our own human resources within our family. Grandparent support can reduce the negative impact of a diagnosis and promote positive family growth. When parents feel supported by their parents, it stands to reason that children feel safe and more stable.

Experience with real children and real families have informed me that the divorce rate is high for parents of children with autism. I am not so naïve as to try to heal a severe laceration with a bandage, but, it stands to reason that the more support parents have in raising a child, the better the chances of their marriage staying intact. Fewer stress cracks you might say. In many instances, raising a child with special needs means sleepless nights, financial hardship, emotional strain, disagreements, stress and maybe resentment. This is not exactly the foundation needed to create a great marriage. Parents need relief. They need time to communicate, time to sleep, and time to take care of their own physical, emotional and spiritual health. It makes practical sense to get relief by rallying the support of family members who have a hardwired connection with your child.

Someday, I may be a grandparent. My parents often joke with me that the way I treat my own parents will be the model that our children will use to treat us. They tend to bring this up when I am playfully tormenting them. Remember the old adage? “Treat others the way you want to be treated.” That was not meant to be wisdom for children

alone. The effort we adults put into to creating a family team by including our own parents and in-laws in our children's lives, will more than likely come back when we take our turn in the grandparenting role.

Reinventing the Family

If you are reading this and thinking to yourself that this whole three dimensional family notion is idealistic and unrealistic - a "Leave it to Beaver" kind of mentality, then I urge you to really take a good hard look at how your current relationships are serving you, your children and your grandchildren. Many conflicts arising out of personality differences or disagreements can be resolved. I am not suggesting that anyone should allow a pathological relationship from the past, to re-emerge unless real change has occurred. However, it is my firm belief that we should build the relationships given to us from birth to meet the unique requirements of special needs children. As you will see in this book, the needs of a child with autism necessitate strong family support. If you are living with a very broken and dysfunctional relationship between parent and grandparent, it may be time to get professional help. It may be time to stop putting off the rebuilding of the relationship. It may be time to stop denying that you do not need each other. If you have the will to make things work in the parent – grandparent relationship then you will seek the tools necessary to do so. If all you can come up with is excuses as to why it won't work and you are not open to communicating your emotions and actively listening to what the other person has to say, then you will prove yourself right. There is no hope.

I highly recommend, at the very least, that both grandparents and parents read books on healing their bond. I have found that the book, *The Grandparent Solution*, is an excellent and practical resource to make the changes that are necessary for a healthy relationship. Grandchildren need their parents and grandparents. Parents and grandparents need each other. We were made that way.



***“Chains do not hold a family together. It is threads, hundreds of tiny threads which sew people together.”
Simone Signoret***

Human relationships are tricky. When there is a history with a high emotional component, family relationships can be more problematic. Conflicts in personalities and temperaments lead to bumps along the way. As time passes we tend to grow up or at least change. Many of us look back and shudder at some of the ways we acted, the attitudes and beliefs we had while we were in our early adulthood. As a parent, I have changed and become more wise (I think) with each passing year. Like many oldest children, my daughter complains that I am more relaxed on rules with our third and youngest. In some ways, I am. I have aged. I have weathered more storms since my eldest was born, and I have learned from my mistakes.

My priorities and perspectives changed with time and life experience. I think many parents could relate to growing up at least a little over the years. My parents changed as well. Six grandchildren (one with autism) taught them a lot. My in - laws changed considerably since I have known them. Life has delivered some tough lessons and through them all we held on to each other. This is not to say, that there have not been arguments, anger, frustration and heartache. We are human after all. But the bottom line is that we need each other. Each person in our family recognizes this connection and we have chosen to forgive each other, accept each other and to continue to work on the relationships that give our children roots, security and confidence.



“The most powerful ties are the ones to the people who gave us birth it hardly seems to matter how many years have passed, how many betrayals there may have been, how much misery in the family: We remain connected, even against our wills.”

Anthony Brandt

If you are breathing, there is a good chance that you have made a mistake or two. Maybe you have even made some big ones. I relied heavily on the forgiveness of my parents, sister, husband, children, students, and colleagues - you get the idea. I had to do my sharing of forgiving also. If I want to move forward, emotionally, spiritually and psychologically, then, I must face the hurt and forgive those who hurt me. We must forgive past mistakes and allow space for new, life giving and healthy emotions to enter our hearts. These cannot reside where old resentments dwell.

You may be thinking that if I knew your father or your daughter or if I heard your side of the story, I would not even mention reinventing your family. Sometimes people choose to hold on to their pain. Their ego does not want to let go and it takes hold on their life. This experience, along with all of the related trauma, disappointment and hurt, becomes linked to their identity. It may be “their story.” Their ego loves it. Every time they recall the past, relive the experiences and the pain, they choose to be victimized again and again. It’s a trap. It keeps us “stuck.”