



Down Syndrome NSW

LIBRARY

Resources for families, carers, professionals and teachers

FAMILY RELATIONS

**Down Syndrome NSW
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DOWN SYNDROME NSW LIBRARY COLLECTION - FAMILY RELATIONS

Adventures in the mainstream: coming of age with Down syndrome

Greg Palmer. Bethesda, MD : Woodbine House, 2005

The author, an award winning writer and producer of PBS documentaries and plays, chronicles two of the most important years in the life of his son, Ned, who has Down syndrome: the time when he's making the transition from high school to work, from adolescence to adulthood. Ned struggles to learn to handle money, responsibility, and the death of a friend.

Another Season: A coach's story of raising an exceptional son

Stallings, Gene and Cook, Sally. NY : Broadway Books, 1998

Gene Stallings is a famous US football coach. His son Johnny was born in 1962. Johnny has Down syndrome and had an inoperable heart condition. An interesting account from a father's perspective.

Anecdotes Inspired by Renee

Herbert, Annette. Fyshwick ACT : Australian Institute of Intellectual Disability, 1997

A mother's reflections on her relationship with her daughter who has an intellectual disability.

Bethy and the Mouse: A father remembers his children with disabilities

Bakely, Donald C. NY : Brookline Books, 1997

A father writes about his experiences of having two children with disabilities, one of them a girl with Down syndrome.

A book About Rhys

Walden, Susanne. Sydney : Carers NSW, 2004

The author and mother of Rhys lives with her family in northern NSW. This is her story about her son's transition into school. Susanne has also included information about the resources she and her family found useful.

A book about Tyler

Burrows, Jennie. [Sydney]. The Author, 2005

A delightful "brag book" of photos compiled by Tyler's mother.

Caring for Kathleen: A Sister's Story about Down's Syndrome and Dementia

Fray, Margaret. Worcestershire, UK : BILD Publications, 2000

An unusual insight into the life of an older person with Down syndrome. Born in 1928, Kathleen was a much loved and valued member of her family. The author cared for her sister after their mother died. Kathleen developed Alzheimer's disease and died at 70. This book is a celebration of their lives together.

Catharine with an A

Keir, Edna. Charnwood, NSW : Ginninderra Press, 2003

The author has captured a real feeling of country life in NSW and of her relationship with her adult daughter Catharine who has Down syndrome. Catharine's move away from home establishing a measure of independence is reflective of one of the most significant issues families will face and often struggle with.

Changed by a child: companion notes for parents of a child with a disability

Gill, Barbara. NY : Broadway Books, 1997

Short “meditations” about a very wide range of specific issues and feelings raised by parenting a child with a disability, written by the mother of a young man with Down syndrome. Some offer comfort, others will delight with humour, some ring with penetrating insights.

Choosing Naia: A family’s journey

Zuckoff, Mitchell. Boston : Beacon Press, 2002

A powerful story based on an award-winning series of newspaper articles first published in the Boston Globe, about a young couple whose first child is diagnosed with a significant heart anomaly and with Down syndrome. The book traces their emotional and intellectual journey through making a decision to continue the pregnancy, and the first months of baby Naia's life.

Climb Every Mountain: Radhika's Story

Chand, Indeera. New Delhi : HarperCollins, 1997

An Indian mother’s account of her daughter’s life, living with her family in India, Hong Kong and Australia, and Radkika’s development as a painter of considerable talent.

Common Threads: Celebrating Life with Down Syndrome

Kidder, C. and Skotko, B. Rochester, Michigan : Band of Angels Press, 2001

An essay and photographic celebration of inspirational accomplishments of people of all ages who happen to have Down syndrome.

Count Us In: Growing Up with Down Syndrome

Kingsley, Jason and Levitz, Michae I. NY : Harcourt Brace, 1994.

The authors, two young men who have Down syndrome, discuss in their own words school, friends, family, independence, politics, careers, sex and marriage. Described by reviewers as inspirational and moving.

Count us in: Growing up with Down syndrome

Kingsley, Jason and Levitz, Michae I. Updated edition. 2007. T

his groundbreaking book originally published in the 90s about the life and views of two young men with Down syndrome, has been republished with an afterword by the two men, now in their 30s, telling us the next part of the story.

Defiant birth: women who resist medical eugenics

Reist, Melinda Tankard. Melbourne : Spinifex Press, 2006

Tells the personal stories of women who have given birth despite medical expectations: women who were told they should not have babies because of a perceived disability in themselves or some imperfection in the child.

Differences In Common: Straight Talk on Mental Retardation, Down Syndrome, and Life

Trainer, Marilyn. Rockville, MD : Woodbine House, 1991

A collection of essays in which the author writes about her son Ben growing up. A personal view of the challenges, disappointments and triumphs. Not all parents would agree with Marilyn’s view but it is a stimulating read reflecting the realities of family life over time.

Down syndrome: where do I start?: how one family coped with the challenge

Kaly, Sigrid . Glebe, NSW : Wild & Wooley, 1998

An Australian mother's account of her family's life with her son with Down syndrome, who is now an adult.

Emma's gifts: A story of love, hope and possibility

Charlotte NC : *Endless Horizons*, 2004

Video. Duration: 40 minutes

Emma, one of twins has Down syndrome. The video is a great resource for parents of children with special needs and educators who seek information about early intervention and building an inclusive classroom setting.

Eric's Gift

Thompson , Kimberly. Tampa, Florida : *Eric's Gift Enterprises*, 1998

"A mother discovers unconditional love on the 47th chromosome".

An Everyday Inspiration: the authorized biography of Matthew Ian Terry,

Terry, Kayla C., *BookSurge*, 2007.

"This is not a story of tragedy or triumph; it is not a story of an adult who has "beat all the odds" or "overcame" anything. It is a story about a family who recognizes that an extra chromosome is just one more thing that makes their family wonderful. If you are looking for a tear-jerker, or a story of heroism, look elsewhere. All you will find here is a story of a family who realizes that the "everyday" is something special!" (amazon.com reader review)

A family love story

Magnus Family. Salt Spring Island, BC : *The Magnus Family*, 1994

A Canadian family's account of their life with a son who has Down syndrome.

From the heart : on being the mother of a child with special needs

Marsh, Jayne D. B. (ed.). Bethesda MD : *Woodbine House*, 1995

Not specifically about children with Down syndrome.

Gifts: Mothers reflect on how children with Down syndrome enrich their lives

Soper, Kathryn Lynard (ed.). Bethesda MD : *Woodbine House*, 2007

Has sixty three personal essays from mothers from a wide range of backgrounds. They write of grief, hope, struggle and rewards. This is a book of love, hope and joy.

Gifts 2: How people with Down syndrome enrich the world,

Kathryn Lynard Soper, ed., *Woodbine House*, 2009.

Sequel to Gifts. This one includes stories by siblings, grandparents, other relatives, friends, teachers and mothers of older children.

Going the distance

i.d.entity.w.a. Perth, WA : *i.d.entity.w.a.*, [1993]

Video. Duration 30 minutes

Gives an honest portrayal of the lives of three fathers of children who have intellectual disabilities. This video seeks to explore relationships, work and family responsibilities, dealing with feelings and other issues. Winner, Bronze Medal NY Film Festival 2003

It's a long road

Lange, Noreen. Perth, WA : Carers Association of WA, 2000

Video. Duration 52 minutes

A portrayal of the emotional journey of four women raising children with disabilities. The many stages of the grieving process along with relationships, siblings, genetics and other relevant issues are explored.

Just like us: parenting children with intellectual disabilities

Martin, Carol. Melbourne, Vic : Lothian Books, 2003

The author's story of her life after 1980 when she became the mother of identical twins with an intellectual disability and cerebral palsy.

Karina has Down Syndrome

Rogers, Cheryl and Dolva, Gun. Lismore, NSW : Southern Cross University Press, 1998

A mother's account of her young daughter, who has DS and is later diagnosed with ADHD.

Lessons from my child: parents' experiences of life with a disabled child

Thomas, Bernadette (ed.). Sydney : Finch Australia, 2004

A favourite with readers. A collection of short stories from parents who openly and honestly share their feelings, under chapter headings titled grief, denial, anger, depression, acceptance, empowerment, love, joy and laughter. Presents all aspects, good and bad, challenging and rewarding from the parents' perspective.

Lessons from Toby 52 life lessons,

Galper, Arie, 2008.

Ari Galper is a Sydney father and businessman. He has drawn "life lessons" from his little boy Toby, and passed them on to his clients, resulting in this collection.

Letting go: the story of Deb

Broughton, Brian and Broughton, Betty. Ferntree Gully, Vic : The Broughton Family Trust, 2005

Our reviewer found this book both reassuring and challenging. It is not a manual with answers. It is the story of how one young woman and her family prepared for the future.

Life behind glass: a personal account of autism spectrum disorder

Lawson, Wendy. Lismore, NSW : Southern Cross University Press, 1998

The author describes her journey from her sense of self as being non-existent to becoming a mother of four and university graduate.

Life as we know it: A father, a family and an exceptional child

Berube, Michael. NY : Pantheon Books, 1996

An American professor of English reflects on his family's life and thinking since the arrival of their young son who has Down syndrome.

Lily Videos: a longitudinal view of life with Down syndrome

Melbourne : Educational Media Australia [nd]

Video. Set of three videos: duration of 15 minutes each.

Lily's mother compiled video footage of Lily who has Down syndrome, at age 10, 20 and 30 years over the years 1975-1995. A good quality series, showing a young woman

growing and learning, speaking for herself about her life and about the supports she uses to maintain the lifestyle of her choice.

Little Ones Like Sarah

Pagliano, Paul and Ainge, David (eds.). Townsville : John and Claudia Power, 1999
A family's memories of their daughter, Sarah, who was born with Down syndrome. Sarah died as a toddler, from causes unrelated to Down syndrome.

Living in the real world: families speak about Down's syndrome

Goodney, C. F. (ed.). London : Twenty One Press, 1991
Contributors to this book are parents with a child between the ages of two and eight, in the East London borough of Newham. Many of these are migrant families, from Pakistan, West Africa, the Punjab, and Ireland. Parents speak about the intelligence, physical beauty and sexuality of their children, their places in the family, school and society, and about their own personal and intellectual growth as parents.

Living with Max

Lewis, Sandy, London:Vermilion, 2008.
A mother's story of her son, Max, who has Down Syndrome and their family. She relates her feelings about the birth, education, family dynamics, dealing with friends and strangers, holidays, the start of the teen years and her own battle with depression. Max is an actor and was in the film, Notes of a Scandal as well as other roles

Love you to pieces: Creative writers on raising a child with Special Needs,

Kamata, Suzanne,ed., Beacon Press, 2008.
Poets, memoirists and fiction writers relate their experiences caring for their children with special needs. The stories are all beautifully written and include a contribution by Michael Berube (father of a child with Down Syndrome) who wrote Life as We Know It.

The Madonna in the suitcase

Hellendoorn, Huberta, 2009
A self-published mother's story to her daughter, Miriam, who became an excellent artist. It tells the story of migrants finding their place in New Zealand, having a child with Down syndrome in the 60s, encouraging independence and dealing with and deciphering health issues. The photos and Miriam's beautiful paintings really add to the story. This book may be of interest to those interested in artists with Down syndrome as well as those wanting to read about a family who dealt with many issues.

A Minor Adjustment

Merriman, Andy. London : Pan, 1999
Sarah Merriman is six years old, conventionally naughty and enchanting, and a radio star and she has Down syndrome. The story of the family behind the hit BBC radio series.

Moose: a very special person

MacDonald, W. Scott and Oden, Chester, W. Cambridge MA : Brookline Books, 1978
Told to place their child in an institution, this African American family instead resisted this advice and raised their child as part of their family.

Mummy, why have I got Down's syndrome?

Philps, Caroline. Oxford : Lion Books, 1991

Caroline Philips's thoughts on her family's life as Elizabeth grows, and her reactions to Elizabeth's insight into her disability.

Natural Harmony: Jade's Story

Albrechtson, Gail. Victoria BC : Trafford Publishing, 2003

Jade, born with a congenital heart defect was placed in foster care at birth. Eventually reunited with her mother, the story traces the universal life themes of frustration, coping, sadness and joy.

One day at a time: children with a disability-family experiences

Davies, Sue. (ed.). Kurrajong NSW : Kurrajong Early Intervention Service. 2001

Families openly and honestly share their lives. The title reflects the advice that many families have found helpful, to take "one day at a time".

Onward Crispy Shoulders! An Extraordinary Life with an Extra Chromosome

Perry, Mary Haakenson, Wizard Works, 2004.

Biography written by the sister of a man born with Down syndrome in 1945 in Alaska. It describes with humour the struggles and successes of growing up in rural Alaska at a time when doctors either didn't tell the parents that their child had Down syndrome or else advised them to put their child in an institution and forget all about it.

Opening the doors: the hidden lives of carers

Holdsworth Community Centre. 2008.

A collection of personal stories by carers in the Woolahra, NSW area. Includes stories by Fiona Place and Paul & Sabine Doney, parents of children with Down syndrome.

Pencil portraits 1971-1990

Perske, Martha. Nashville TN : Abingdon Press, 1998

The artist's pencil portraits of people with disabilities, many with Down syndrome, have illustrated many books and a wide range of publications. She has given permission for these works to be used for non-commercial purposes by community groups representing people with disabilities. The drawings bring their subjects to life, and ability and personality shine through.

Retarded Isn't Stupid, Mom!

Kaufman, Sandra. Baltimore MD : Paul Brookes, 1988

An open, thoughtful account of a daughter's growing up and leaving home.

Road Map to Holland,

Graf Groneberg, Jennifer, NAL Trade, 2008

Released only a few weeks ago, this book has been very well received by the community of parents of children with Down syndrome. Jennifer Groneberg is a professional writer, who lays out the "road map" that she needed to navigate the first two years of her son's life. Avery was born prematurely, has Down syndrome, a fraternal twin, Bennett, and a big brother, Carter.

Ryan's Rainbow: The first eighteen years in the life of Ryan Clark, a boy with Down syndrome told through the eyes of his dad.

Clarke, Gerry. Hallett Cove, S. Aust. : Gerry Clarke, 2003

The author removes some of the myths and mystery that surround raising a child with a disability, and will inspire parents and siblings facing a similar challenge.

S for Stephen: S for Special

Evans, Pearl. Wales, UK : The author, 1999

The author was Stephen's teacher at school and remains a friend.

Sally: Face Like a Flower

Anderson, Bill. Pickering N Yorks : Dent Dale, 2004

Sally, a talented young woman with Down syndrome died at age 25 years. But in her short life she produced many paintings, and was well known as an artist in the UK. Her works, originals, reproductions and Christmas cards raised over a quarter of a million pounds for charities.

Shorty

Revolution Earth Productions. Rutherford, NJ : Revolution Earth Productions, 2003

DVD. Duration: 86 minutes.

A documentary about the life and work of a 55 year old man with Down syndrome and his relationship with his brother .

Show me no mercy: a compelling story of remarkable courage

Perske, Robert. Nashville, Abingdon Press, 1992

A novel about a young man with DS and his father, and how they coped with a family tragedy.

Smiling at Shadows: a mother's journey through heartache and joy

Waites Junee, and Swinbourne, Helen. Sydney : HarperCollins, 2001

An Australian mother's account of family life with her now adult son, who has autism. Very readable.

Sometimes Miracles Hide: Stirring letters from those who discovered God's blessings in a special child

Carroll, Bruce. (ed.). Louisanna : Howard, 1999

Parents share their stories and prayers. Accompanied by a music CD of the same name.

Special Parent, Special Child

Sullivan, Tom. NY : Putnam Books, 1995

Parents of children with disabilities share their trials, triumphs and hard-won wisdom.

A Special Kind of Hero: Chris Burke's Own Story

Burke, Chris and McDaniel, Jo-Beth. Lincoln, NE : Authors Guild Backprint.com, 2001

Biography of actor, musician and self-advocate, Chris Burke, born in 1965 in New York. Chris starred in the TV series *Life Goes On*.

Spinning Straw: the Jeff Apple story

Green, Phyllis. Eastman Quebec : Diverse City Press, 1999

Jeff Apple was a beautiful baby who one day hit his head. From that day forward his family was subjected to an epic voyage past autism, developmental disability and extreme self-injury. Never wavering on love, they always found hope, joy and laughter. Theirs was a lifetime of spinning straw into gold.

The teachings of Jon

Jennifer Owensby (Director). Durham, NC : Waking Heart Films, 2006

1 Videodisc (DVD). Duration: 56 minutes.

This soul-searching and funny documentary about Jon, a 40 year old man who has Down syndrome, ponders the serious questions of how we value each other and what is truly important in life. Made by Jon's sister and family, the message they impart is that although Jon has an IQ of 20 and does not talk, he has an important purpose; not necessarily to learn, but to teach.

These Are Our Children: Twins, Triplets and Down Syndrome

McDonald, Linda. Mooloolah, Queensland : the Author, 1997

The author has compiled a collection of stories from Australian families where a child with Down syndrome is one of twins or triplets.

Thicker than Water: essays by adult siblings of people with disabilities,

Meyer, Donald, ed., Woodbine House, 2009.

The essays, many by siblings of people with Down syndrome, cover a range of experiences, feelings and reactions. It gives much to relate to for siblings and much to think about for parents in how they deal with all the family and plan for the future.

Tuesday's child

Evans, Kathy. Bantam Australia, 2007

"In every life there is a defining moment: Caoimhe's diagnosis was mine...". Journalist Kathy Evans writes about the birth of her third child, born with Down syndrome. The book resulted from an award winning series of articles.

Uncommon fathers: reflections on raising a child with a disability

Meyer, Donald J. (ed.). Bethesda MD : Woodbine House, 1995

A collection of essays by fathers who were asked to reflect and write about the life-altering experience of having a child with a disability.

Up Close: a mother's view

Yaron-Field, Fiona, Bunker Hill, 2008.

Wonderful photographic journal of a girl with Down syndrome by her mother. The photographs cover the first twelve years of Ophir's life and together with some text, show the relationship between mother and daughter and their life.

Up Syndrome

Graves, Duane (ed.). Austin, TX : Trisomy Films, 2000

Video. Duration: 82 minutes

Screened at the Dallas Video Festival and winner of Best Documentary. About the filmmakers friendship with one of his childhood chums, Rene Moreno, a 32 year man with Down syndrome.

Ups and Downs: lives of love, challenge and commitment

Courtney, Catherine. (ed.). Blackburn, Vic : PenFolk Publishing, 2000

An anthology of stories from seventeen Australian families about their experiences of having a child with Down syndrome.

Windows into Heaven

Tetschner, Stacy & Michelle, Brookes Publishing, 2008.

Collection of stories by parents of all ages of people with Down syndrome. The stories are short and varied and very readable.

The Year my Son and I were Born: A story of Down syndrome, motherhood and self-discovery

Soper, Kathryn L., Globe Pequot Press, 2009.

The editor of the collection of parent stories, *Gifts*, tells her own story of her son's first year. She tells of her struggles with accepting a "special" child and looks at it in the context of her Mormon family.

You can call me Ellie

Rennie, Anne McCullagh. Sydney : New Holland, 2005

One Australian family's story of love and determination. A writer of fiction, Anne Rennie tells her story and the courage, persistence and downright stubborn refusal to budge as Ellie battles to prove that she is an individual with the ability to achieve beyond all expectations.

You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities

Kelin, S. and Shive. K. (eds.). NY : Kensington, 2001

A collection of short essays by parents of children with intellectual disabilities, most of whom have a child with Down syndrome. Each chapter addresses a particular issue chosen by the writer and covers the whole life span.

Your Name is Olga

Espinas, Josep M. London : Unwin Hyman, 1989

This book is a remarkable series of letters from the celebrated Catalan writer and journalist Josep M. Espinas to his thirty-two year old daughter, Olga, who has Down syndrome.