



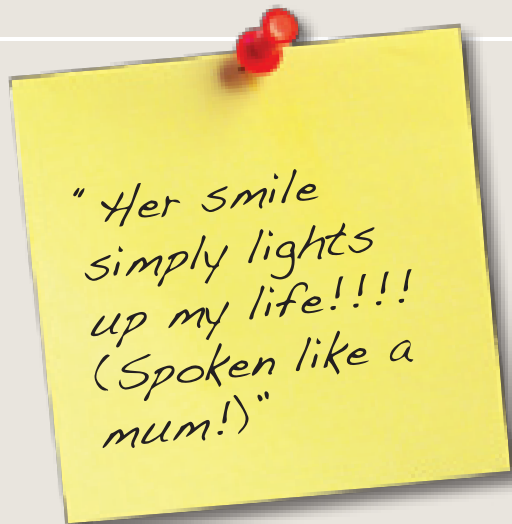
We invited Sylvanvale parent, Bev Nugent, to write about our theme for this issue, *'Better Together'*. Bev's daughter Angela has attended our day program in Sutherland for many years.

Angela Sheree Nugent has complex, high support needs with a diagnosis of Conradi Syndrome being one of the severe forms of Punctate Epiphyseal Dysplasia (In short – severe intellectual/physical disabilities)

My "angel/devil" daughter has always required the intervention of "someone" to get her through her day - starting with Mum and Dad, paediatrician, neurologist, orthopaedic surgeons, ophthalmologist, physiotherapists, occupational therapist, remedial therapist, orthotists, exercise therapist, specialists in seating, positioning, orthopaedic footwear, teachers, social educators, team leaders, podiatrists, a super GP, dressmaker, family and friends.

I guess as her mum, I have gone from an average person to the "mother from hell" as I advocated her best interests, well being and safety even to this day.





Looking back, “highs and lows” swung like a pendulum on a clock. I remember the frustration, energy, time and effort required to get her to eat vegetables (one has to eat to survive) and the concoctions that worked made doctors cringe but were successful at the time. So, concoctions and perseverance F I N A L L Y won !!!

Times when she was in hospital, I had to stand and watch as they wheeled her to theatre for corrective surgery - be it an osteotomy, tendon releases or spinal fusion. I bit my fingernails to the elbows until I was allowed to see her in recovery. I still get a lump in my throat today when I think about it. She was always the only one on the trolley confused and distressed with eyes wide open in terror regardless of the pre-med injection.

Of course there have been some wonderful moments too. One of the best being when my older daughter Michelle insisted on Angela being her bridesmaid. My mind boggled! I stood in the church (frantic I might add). I was sure Angela would throw her bouquet or pull the flowers out of her hair! Or at least vocalize loudly her confusion. However with planning, the right people, right attitudes, plus a timeframe – the outcomes were better that one could imagine. Hence once again *‘Better Together’!*

Angela’s non-verbal. Her communication is idiosyncratic, complex and limited--but gosh what a teacher she is! She has taught me a whole new language and that is “NON VERBAL REASONING”. She attempts to make sense of her environment by drawing on a variety of cues and responds to consistent routines, actions, gestures and some familiar spoken key words. ‘Chat’ books, communication dictionary, and touch objects – all go to support one way or another her limited skill base.(Her favourite ‘touch object’ is a set of keys to start the car. Her non-verbal reasoning being: “Lets Go / Move!”)

To me, I see a beautiful young lady (if I ignore the inappropriate behaviour) as she enjoys family celebrations, bowling, wheelchair dancing, massage, the 2009 wheelchair roll, day program community access, friendship link-ups, her beloved spinning barrel, music (“old time” and with a beat - she’s a great wheelchair bopper/rocker) and not forgetting wheelchair transport with her bus buddies!! Her smile simply lights up my life!!!! (Spoken like a mum.)

So, TOGETHER (and with everyone’s support) we will continue to be BETTER! Best wishes to everyone in a “caring role” (I salute you!)

Bev Nugent.

