

An Unexpected Motherhood

By Leticia Keighley

A family story of how a young woman and a young man, both with Down syndrome, had a son...with Down syndrome.

Times are changing rapidly for people with Down syndrome as every year more and more parents are encouraged to have high expectations for their children and presume competence for their abilities. Despite this, it is still mostly assumed that people with Down syndrome are unable to have children of their own. Many parents have been told that males with Down syndrome are generally sterile or their fertility is so low that they cannot conceive. There are often concerns that the person will not have the capacity either mentally or physically for parenthood. As a result, there are controversial discussions around the rights of people with a disability to make their own informed choices about the control they have over their lives and bodies versus the parent's need to protect their children from circumstances that may harm them. Sometimes this has resulted in parents making executive decisions for their children in terms of birth control, restriction of access to sexual activity or sterilisation against a person's will or without informed consent.

So, in January 2016 when Patti White from California posted a photo to the National Down Syndrome Congress Facebook page, she did not anticipate the reaction it would receive worldwide. The photo was of her daughter Lisa, 50 who has Down syndrome with her arm around Lisa's own son Nic, 20 who also has Down syndrome. Social media went into meltdown and Patti received thousands of messages and comments. Some parents were incredibly hopeful that their children could become parents of their own one day and others were angry that this was allowed to happen.

I am one of those parents who began to question what I knew about people with Down syndrome having children of their own when the photo of Lisa and Nic appeared in my newsfeed. I had to know more so I contacted Patti who along with Lisa and Nic, graciously agreed to share some of their incredible lives with me by telling the fascinating story of what happens when the wants and needs of a person are closely linked to the family who supports them.

Patti lives with her husband of 30 years, Norm, in the California Central Valley. She has three adult children from a previous marriage; the eldest being Lisa, who has Down syndrome and turned 50 this year. Patti was 18 when Lisa was born and her philosophy was to see what her daughter was capable of and then to support her in the areas where she needed more help.

As Lisa grew, she proved to be a highly capable and independent woman with strong opinions about the path her life would take. At 16 years old, Lisa announced that she wanted to move out of home and plans were made to make that happen. Two years later she moved.

"It took a village to raise Lisa," says Patti as she described the enormous amount of resources the family employed over the years to assist Lisa in her efforts to live independently. By accessing a range of agencies and funding packages Patti has been able to find suitable housing for Lisa in various locations as the family moved multiple times due to Norm's job. Patti also engaged the use of a Circle of Support for Lisa. A Circle of Support is a formal way of gathering a range of people to contribute to the development of a person with a disability. Patti enlisted people from their lives who could all contribute something; like art classes, weaving classes or learning how to catch public transport. Lisa is a very accomplished artist today.

When Lisa was young, Patti worked as a Birth Coach and gave birthing classes so the idea of pregnancy and birthing babies was not foreign. Lisa was present when her baby brother was born at home and Patti recalls that when she was in full labour and in a lot of pain, Lisa said, "Mummy don't cry, I love you". This voice stood out strongly and helped Patti get through the most difficult part of the labour. "Lisa and her brother would pretend to have babies in the back seat of the car as I was driving", laughs Patti. "I was her role model so of course she wanted to have babies."



Lisa and Nic



During school Lisa received sex education classes as well as a modified course. She understood how babies were conceived. When she was seventeen, Patti and Lisa discussed the idea of having a tubal ligation as a form of birth control. Lisa agreed but when she was at the consultation, the nurse sat down with her and outlined the procedure. She explained how it would be irreversible and would mean she would be unable to have children.

“She said, ‘Oh no, then I don’t want to do it,’” recalls Patti. “At the time there was no medical power of attorney in place. She was seventeen and no doctor would go against the wishes of the patient’s clearly stated will.”

She was a young adult living independently around the time she became pregnant with Nic. Lisa had been living in her own apartment for about 11 years and working full time at the local Goodwill store, she travelled to and from work using public transport.

“...she got along with everyone,” says Patti. “She could do everything except the cash register. She liked it there and they liked her.”

Lisa met Nic’s father (name withheld) at work when she was 29 and he was 24. They soon began a serious relationship. Lisa was living independently as was Nic’s father, who also had Down syndrome. They would date and visit each other’s houses. Patti explains that she understood her daughter had a healthy adult relationship with her partner but didn’t know if it was sexual, although she knew it was a possibility.

“I was happy that she was happy...We didn’t meet him until 6 months into the relationship on her birthday.”

There were many discussions about birth control and safe sex between Lisa and the people who supported her. The couple visited Planned Parenthood and were supplied with condoms and education about safe sex, but there was no guarantee the couple was practising it.

“At the time all the books said males with Down syndrome were sterile and people told us not to worry about it as they couldn’t get pregnant,” says Patti.

Today there is still very little literature about the chance of a male with Down syndrome fathering a child but it is generally believed that due to reduced spermatogenesis and sexual function, fertility rates are much lower.

One day, Patti was at work and after she returned from lunch, she checked her messages to hear one from Lisa;

“Hi mum, I just wanted you to know you are going to be a GRANDMOTHER!” Patti says, “My mind went in all directions. How could this be? Her boyfriend has Downs!”

At the time of Lisa’s pregnancy, Patti was working as the Early Intervention Intake Coordinator at the Regional Centre. “I was taking phone calls for referrals when a baby had a disability and the family needed a referral for Family Services. I knew how the team at the hospital viewed a disabled mother who was pregnant...in most cases it is called ‘presumed detriment’ meaning it’s presumed that some detriment would come to the baby if it stayed with the mother...I knew Lisa would be in that category and would lose the baby to Child Protection Services. That would have been tragic.”

When Patti was 5 years old, her own mother abandoned the family and because of that, it was ‘unthinkable’ for her to abandon her grandchild. She worried about the effect the decision to go ahead with the pregnancy would have on her own marriage but Norm was very supportive of the decision. Lisa and Patti went to genetic counselling sessions during the pregnancy and were shown a video. At one point, a woman said if her baby had Down syndrome she would have no trouble having a termination. Lisa became upset and shut down; she turned her back on them.

“It was hard to make Lisa understand that we weren’t trying to make her have an abortion but it was an option. The geneticist explained to her that it was just information and that she didn’t have to watch the film if she didn’t want to,” says Patti. So she didn’t.

“Lisa is proud of having Down syndrome. She doesn’t feel bad about having it. She might feel bad about the things she can’t do but the title doesn’t bother her at all. She said to me ‘If I have a baby with Down syndrome, he will be like me and I’ll be so proud of him.’ So, the family got into high gear to prepare for the baby. “We got busy and we’ve been busy ever since!” laughs Patti.

Lisa is a very articulate and passionate person. I asked her what it was like at this time. “I was dreaming to have three kids in my family someday. I had a dream of having three kids and when I was pregnant my belly was like this...really heavy,” she said. “I found out I was pregnant with a home pregnancy test and I left a message on her voicemail. I said she was going to be grandmother and she was surprised about it.”

“It was hard for me to walk around when I was pregnant, I was working five days a week. I had morning sickness and I wasn’t feeling good. I felt like I was going to throw up.”

Lisa had a pregnancy coach and attended childbirth classes as did Nic’s father. The pregnancy was considered high risk and treated as such. Towards the end of her pregnancy Lisa became very uncomfortable and one day Lisa turned to Patti and said, “One is all I can do, mum. Can you help me?” Lisa knew that one baby was going to be all she could handle and made the decision herself to have no more.

Lisa went into labour four weeks prematurely. She was in labour for five days before the decision was made to induce her. Lisa decided she wanted a natural birth and refused all medications because they made her feel ‘wobbly’. Nic was born into the world blue and floppy. His initial APGAR reading was very low and Patti was worried at first but his condition improved quickly.

“He was so cute when I held him for the first time but he didn’t talk, he was really quiet...I didn’t hear any voice from his mouth,” says Lisa as she described the birth. “I really loved him and he was hurting me a lot inside of me...and they handed him to me to hold...I was kind of tired after I had Nicolas but he had to stay in the hospital to gain more weight. He had a bunch of wires out of him. Had a machine to help him breathe.”

Nic’s father was present at the birth. Nic has seen the video of himself after the birth and saw his father talking to him. Nic says, “I was in the hospital and after they take me out of the body I was all messy and gooey. My parents tell me I was floppy. (My dad) said, ‘I want you to live and I want to take you to Disneyland and stay in the hotel’.”

Lisa and Nic’s father attempted to live together around the time of the birth but it didn’t work out. Nic’s father passed away when Nic was five and it was a difficult time for Lisa. She became quite depressed and also had to have heart surgery not long after.



Patti and Nic

Patti imagined she would have to be supportive of Lisa but had no idea how much help Lisa would ultimately need. They learned as they went along the way but they assumed Lisa was more capable than she turned out to be.

Lisa moved closer to Patti and Norm when she was six months pregnant. After Nic was born, he would stay three nights a week with Lisa and a support person stayed with her overnight to help with tasks Lisa couldn’t do on her own. It was very important for Patti to keep Lisa’s self esteem as a mother up so Lisa was involved in all the aspects of raising Nic including his therapy classes when he was young. Patti repeatedly told Lisa that she was the best mother she could be but the reality was that Patti and Norm had to raise Nic themselves in their own home.

Nic who has just turned 20 is a very handsome, accomplished young man with a wicked sense of humour. Talking to him was a riot. Nic swims everyday and competes at a high level. He loves singing and dancing as well as playing football. He has had a girlfriend for the past year, Hannah, who is a few years younger than him.

Patti describes what it was like for Nic growing up. “For Nic, it was easy. It’s just normal for him because he doesn’t know anything else. He knows Lisa is his mum but he calls me mum too.”

I asked Nic about his mother: “She’s fine and she’s loving... and I do love her as my mum and my mum always trying to teach me how to speak. I was learning to crawl and I was learning to walk.”

“I have two mums. My mum Lisa is my greatest future in my life. She give me life and she give me love and she give me birth and she give me special needs and she is always wonderful and she is beautiful.”

The challenge is now on to help support Nic in his adult life by establishing a new Circle of Support for him and Hannah to model what good relationships look like and help the couple make good choices for the future.

While talking to the family I am struck by how happy, loving and contented they all are but Patti explains that this life has come with some great sacrifices too. Lisa was living a very independent life before she became pregnant but afterwards she was unable to work, her social life changed dramatically and she needed to remain much closer to her parents. She also lost a lot of female friends as their parents were afraid association with Lisa would influence their daughters to want babies too. For Patti, the sacrifice has been enormous. At times she has held some resentment towards Lisa.

“Lisa had no idea how much the course of my life had changed because of a decision she made...she was very clear about what she wanted but had no idea about the impact on others,” Patti explains.

“The word independence is a wonderful word and Li often uses it...we are all dependent to a certain degree. Their dependence is different than ours; it never goes away. They cannot survive without parents or agencies. It's a big deal. If people think I'm going to give them permission to go out and do this, they don't know”, says Patti as she discusses how her story may inspire other parents.

“It wasn't a fairy tale, it could have been a nightmare turned out pretty good. We wanted Nic to know his life's been a sacrifice but we can't go back and I would want to go back. I have no regrets.”

While Patti's story is a cautionary tale in a lot of ways, it is also quite incredible. The Catch 22 that Patti had between respecting the personal autonomy of her daughter and handling the consequences of those decisions is really striking. It means parents have to think very clearly about the possibility of their child's desire for a family of their own one day. It blows the discussion wide open to consider the kinds of supports someone with a disability may need to do this and the kind of planning someone may need to prevent it depending on their wishes.

Patti and her family didn't choose this path but have made it work through a lot of hard work. Knowledge is power. Patti's story helps us rethink another assumption about people with Down syndrome and provides valuable information for others to help make their own decisions. Patti is in the process of writing a book of their life which will be a must read for a lot of families.



Nic and Lisa



An event to celebrate
World Down Syndrome Day

Morning tea events around
the country to celebrate
World Down Syndrome Day

More information at:
www.downsyndrome.org.au

March 21



Lots of Socks

Lots of Socks is a Down Syndrome International campaign to create conversation and bring awareness of Down syndrome on 21 March, World Down Syndrome Day.



Can your school take part?

Find out more at
www.downsyndrome.org.au