

# Lukes Story: The Getting of Wisdom, Courage and Hope

*Luke Farrelly is a well-travelled fourteen year old highschool student. Together with his mother, **Ann O'Brien**, they explored what it has taken to hold a vision of Luke's life; how they have safeguarded this vision, shared this vision and how, combined with the wisdom of experience, this vision has helped give the family clarity in enigmatic times. During the presentation, with the assistance of his father, Dan, and his teacher's aide, Darrel, Luke changed the slides using a switch connected to the computer.*

This is Luke's story. It is also about the getting of wisdom, courage and hope (for his parents). What you will hear about today are aspects of Luke's life that reflect what we believe have helped to shape his life and ours as a family. You might call them guiding principles or themes.

Luke and I put this presentation together using his Pragmatic Organisation Dynamic Display (PODD) book - this provides us with key words that allow us to work out what Luke wants to say. Luke communicates by answering yes or no to questions by lifting his hand or head for yes and keeping still for no. During this process Luke demonstrates great patience and tolerance as he strives to communicate with us. One of the teacher aides recently said to me how she admires a Luke's ability to show forgiveness for those of us who constantly ignore his potential, talk over him or not wait for the answer.

There is no doubt that Luke has much to offer to those who take the time to get to know him and listen to what he is telling them. As you listen to his story it is my hope that you will capture a glimpse of an inspirational young man who we and our family and friends are very proud to call son, brother, nephew, grandson and friend.

Luke is the eldest of 3 boys. He is almost 15, Isaac is 12 and Nathan is 10. Dan and I are very biased but we know we have 3 fabulous boys who constantly bring us joy, love and the usual frustrations, exhaustion and heartache that go with raising a family. As a family we aim to live an ordinary life and to pursue everyday activities. We plan holidays, go on weekend outings, attend sporting events and are involved with the schools our boys attend. We also spend days and weeks in hospital, many hours at appointments. We try to live a normal life ... whatever that means.

Luke has many professionals in his life: therapists, medical staff, teachers, teacher aides to name but a few and each play a role in his life. We appreciate their input and their expertise but at the same time we exercise our rights as parents and advocates when making big decisions. This has been something we have had to learn to do, and it hasn't always been easy. We are fortunate now to have a few professionals in our life who know us well and respect our opinion. There are of course times when we are not heard and we have to fight for what we believe is in his best interest.

We try to stay clear of the medical world and the world of disability because they tend to focus on what is wrong rather than right. Life does get really tough. Luke has extended periods of ill health, often with hospital admissions where Dan and I live between the hospital, home and work. Life has taught us that this will eventually pass and we do the best we can at the time.

## **Courage**

If I am to reflect on the place of courage in our lives, there are a number of significant decisions that we made that required us to take a risk. My husband and I, and our other boys, are called to be our sons ally; we are his voice; we hope we speak truthfully his hopes, desires, likes and dislikes. We hope also that we listen to what he wants his life to be like.

In 2007 we decided to approach our local state school about him enrolling into grade 5 fulltime. This decision was driven by Luke's desire to be with his peers in a stimulating noisy environment. He was already going to our local

school to attend philosophy and he was telling us through his actions where he wanted to be - in a regular school, with his peers

It was not an easy decision. We knew many would not understand our desire for Luke to be part of our local school where his brothers attend, nor would they appreciate that he had much to offer to other children. We put ourselves on the line and then couldn't back down until we achieved what we had set out to do. I can remember driving away from meetings fighting back tears while my husband was busy remembering every swear word he knew. After much discussion, disagreement and frustration approval was given and Luke began grade 5 in 2009.

Luke is now in grade 9 at our local high school. He enjoys school especially music and socializing at lunchtime. He is not so fond of maths. How do we know this? He often goes to sleep!

Wonderful things are happening at school for Luke. There is a cohort of students who have recently come together with the assistance of a teacher and have formed a circle of friends. These are students who have formed a connection with Luke over the last 18 months and now want to be more involved in his life. This group of students met to discuss how they could contribute to Luke's day. Suggestions included: reading the newspaper in the morning to Luke, taking Luke to the admin block at the end of the day, taking him to and from class and to lunch.

The school population is made of students from many different countries. Luke's presence at school does not faze them as many come from cultures which have a very strong sense of community and an understanding that all people contribute in different ways. If you were to watch Luke in that environment you would gain very quickly an understanding of what it means to him to be there in amongst the noise and life of a high school

While planning for Luke's inclusion into our local state primary school we also decided to take 6 months to travel around Australia. My husband and I planned carefully and ensured that we had thought through what we would need to keep Luke safe, given he has, at times, significant health issues. We were aware of the risks we were taking but decided that the experience and the benefits would far outweigh any of the risks. The reality was that we would deal with whatever life threw at us at the time.

Our trip was a wonderful time together. We saw only some of what this beautiful country has to offer, but memories of those days keep us going when times are difficult. Luke experienced all we did, often on Dan's back as we climbed mountains and explored gorges.

The most important lesson learnt was about the importance of taking a risk and following your dreams. Had our son's health deteriorated or the trip been too exhausting we would have rethought our plans or if necessary come home. If we had, however, allowed those potential risks to overwhelm us, what wonderful experiences we would have missed out on.

Luke demonstrates courage most days of his life. Wanting to be out there... dealing with the injustices of others, living with illness and hospitalization on a regular basis.

#### **A vision for Luke's life.**

When we talk about a vision for Luke's life we think of the ordinary: schooling, friends and all that comes with it, and therefore it is vital then that we listen to Luke. His schooling was a good example of this; he was telling us through his behaviour that he wanted a mainstream education and we could not ignore this. It is vital that we consider what he loves to do, what his strengths are and in turn that we believe he has much to offer to those he meets.

Family life comes with challenges but when there is a member with a disability it is all the more challenging. Making family work when there is a child with a disability is a conscious choice. If we spend all our time wishing life was different than we end up missing the beauty and the joy of what we have. This certainly applies to our life with Luke. This is our son and he has much to offer, if we take the time to listen and learn.

**The future....**

We need to ask ourselves a number of questions about what we want Luke's life to become. What are we doing to plan for Luke's future?

What does Luke want?

What do we think would be good for him?

We need to consider Luke moving out of home into his own place with support.

To help make all of this happen we also need to think about inviting family and friends to be a part of a circle of support. We need to have support of the village to raise our children. We need lots of heads and hearts together to dream what could be possible for Luke's life. We need to ensure that Luke will be safe by sharing what we know about him, with those who are prepared to be around for a long time. There will also be a wider support network to be there when times are tough due to ill health or hospitalisation. Luke's life will be so much richer by forming closer relationships with those who care about him.

If we look back on our life with Luke there were times of planning, living, reviewing, thriving and barely surviving. We look at his life in stages and never think too far ahead... It's too hard. We do think, and are aware that, there are times when we need to consciously plan and begin the process that will bring those plans to fruition.

**What have we learnt?**

Life is full of ups and downs and we need to appreciate and remember the easier times. We have learnt to respect the ebb and flow of life and to choose our battles.

We don't have or need all the answers now, we just need to keep asking the questions.

We are still learning about Luke and about ourselves.

Each person is unique and one size does not fit all.

We do not know if our son has a good life - that's for him to say... but we do strive to do what we think is in his best interest. We are listening and learning from Luke.