

A Disability Planning & Case Management Services Project

The
RIPPLE
EFFECT
Consider the impact.

Family experiences at the time of diagnosis

By Veronica Sullivan & Meagan Wuchatsch

melbourne
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Acknowledgements

First and most importantly, a heartfelt thanks goes to the families who have contributed their stories and experiences to this book. Thank you for sharing your time and insights, without which there would be no book.

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Veronica Sullivan

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Meagan Wuchatsch (left), Veronica Sullivan (front) and Heather Boyd (right)



Introduction

The Disability Planning and Case Management Services team works alongside families of children or young adults with a disability.

Parents share many stories with us; stories of hopes and fears, of achievements and challenges. In over 20 years working with families one story stands out – the moment a parent learns their child has a disability. Of course this is a moment that stays with parents forever, but what is disturbing is that it is so often not only the news these parents are receiving that is life changing but also the way that news is delivered.

“The truth may be brutal but the telling of it should not be.” (Jonsen, et al. 1992)

The families you will read about in this book have generously shared their personal histories and experiences in the hope that they will remind health professionals of the critical role they play when informing a family that their child has a disability. How they deliver that news is as equally important as the news they are delivering.

Research both within Australia and internationally indicates that the way this news is delivered can have a direct impact on future outcomes for the family and child. It can mean the difference between a family who are well resourced, well informed and confident, and a family that feels hopeless, confused and unable to cope. It is well recognised that these families have a high incidence of family breakdown.

The simple message of ‘The Ripple Effect: Consider the Impact’ is that setting a family up with the best chance to thrive begins with diagnosis.

The idea of finding a way to communicate this message has been in the back of our minds for some time and I am thrilled to finally see this book completed. I say a very sincere thank you to the families who have contributed these powerful insights and I am privileged to be a part of sharing these stories.

Heather Boyd

Manager, Disability Planning and Case Management Services
Melbourne City Mission





Review of Literature

The effect deliverance of bad, sad or difficult news has on patients and care givers has been the focus of studies for over 30 years. To date, there continues to be countless attempts to formulate guidelines that assist health professionals in delivering such news (Amiel, et al. 2005). Difficult news is defined as any information that adversely affects the individual's view of their future. The level to which individuals are affected by bad news will differ depending on a person's understanding and expectations (Baile, et al. 2000).

Delivering bad, sad or difficult news, including informing families about their child's condition, is a task that the majority of health professionals will face at some stage in their career and can no longer be thought of as an optional skill (Fallowfield & Jenkins 2004; Baile et al. 2000). In 1977 it was recognised that the way in which a diagnosis was delivered impacted on parental acceptance of their child's condition regardless of parental characteristics or the severity of the condition (Svarstad, & Lipton 1977). This finding has been continually supported and expanded in subsequent studies which have also found that the perception of the condition, views of the future, beliefs, emotional state, attitudes towards health professionals and treatment options can all be altered depending on how diagnosis is delivered to parents (See Fallowfield & Jenkins 2004, for review of studies). Further to this, the way in which parents are informed about their child's disability can affect the parent-child relationship, and poses the risk of parents developing depression following diagnosis (Baird, McConachie, & Scrutton 2000).

In a review of studies relating to the delivery of difficult news, it was found that clear and accurate communication and information was consistently important to patients across several countries and fields (oncology, paediatrics – including the disclosure of disability, and acute trauma – including the disclosure of ABI; Fallowfield & Jenkins 2004; Sen & Yurtsever 2007). However Grassi et al. (2000) found in an international study of 675 physicians that less than half (44.8%) of participants believed that diagnosis should always be disclosed, with only 25.4% reporting they always disclose the full truth in relation to diagnosis (e.g. patients were informed of diagnosis but not of prognosis).

Starke and Moller (2002) identified that 70% of parents who felt dissatisfied with their interactions with health professionals at the time of diagnosis sought further information from a wide variety of sources. These parents sought information for the purpose of controlling the actions of their health professionals. While some parents who were satisfied with their interactions also sought information, their search was less extensive and their main reason was so they could better explain the condition to others.

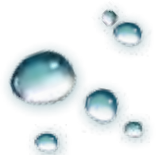
Satisfaction with the way in which diagnoses are disclosed remain low. Key factors that have been identified as influential in parental satisfaction are: the time lapse between the suspicion of disability and the diagnosis (Nursej, Rohde, & Farmer 1991; Baird et al. 2000); the stating of a known diagnosis compared with an unknown diagnosis (Quine & Pahl 1986; Quine & Rutter 1994;

Graungaard & Skov 2006); and if the doctor giving the information presents as sympathetic and understanding in their approach (Quine & Rutter 1994; Davies, Davis & Sibert 2003; Graungaard & Skov 2006). Research has also cited health professionals' dismissal of parents' concerns as being detrimental to satisfaction levels of the family, and their ability to cope (Sloper & Turner 1992).

In a small study, Cunningham et al. (1984) demonstrated that dissatisfaction with the deliverance of bad news can be avoided and is not inevitable. They found that when parents were informed as soon as possible after birth, together and in a private environment, in a direct, honest and sympathetic way and with immediate and easy access to services, parents reported 100% satisfaction with the disclosure of a diagnosis.

It has been identified that health professionals experience difficulty when it comes to delivering difficult news, especially when the patient is a child. Research has shown that experience does not necessarily equate to competence (Amiel, et al. 2005; Harrison & Walling 2010). Lack of skills and reluctance to deal with the emotions of patients have been identified as primary factors in the avoidance of difficult discussions by health professionals (Dosanjh, Barnes & Bhandari 2001; Cantwell & Ramirez 1997). Training programs in delivering bad news are perceived by participants as beneficial, and have been shown to be effective in increasing skills and confidence (Amiel, et al. 2006; Farrell, Ryan & Langrick 2001). However, it has been found that health professionals still feel communication skills can only be developed on the job and do not seek training in this area (Barnett 2004). The cohort least likely to seek training in the area of breaking difficult news has been identified as hospital consultants working in specialist clinics (Barnett 2004). Studies have supported the idea that health professionals can learn from listening to parents who have been through the experience themselves (Nursey et al. 1991). General guidelines such as the SPIKES have face validity and substantial general acceptance, however there is consensus that these guidelines are only general and must be adapted to individual situations (Harrison & Walling 2010).

Key elements in the successful delivery of bad or difficult news include: being prepared and having a pre-arranged meeting in a private setting; checking facts and ensuring information given is correct and consistent; establishing the patient's or care giver's knowledge; establishing the level of information that the patient or care giver would like to know; reviewing understanding; arranging a follow up meeting and providing a contact number for the interim; providing both personalised and general written information; and leaving time for questions and concerns of the patient or care giver (Barnett 2004; Graungaard & Skov 2006; Baile, et al. 2000). Further to these elements Kearney & Griffin (2001) also highlighted the need for hope to be offered in conversations with parents.



The Heany's Story



Joss is a 6 year old boy who was affected by a viral infection Cytomegalovirus (CMV) while in utero, resulting in extensive brain damage and severe disability. Joss is profoundly deaf and has spastic quadriplegic cerebral palsy.

For Joss's parents Nicky and Marcus, the pregnancy was a 'rollercoaster'. Early tests detected an echogenic bowel, so Nicky was sent for tests to rule out foetal infection, Down syndrome and Cystic Fibrosis. The results showed that she previously had CMV, but there was no current infection. "They couldn't

"The radiographer we had throughout the pregnancy was fantastic. He put everything on the table, told us what we were possibly facing, and gave us the best statistical outcomes. We asked a lot of questions and he gave us all the information that he could."

Nicky and Marcus were squeezed in to see a neurologist to discuss the results of the MRI. After a nervous one and a half hour wait, Nicky was called in while her husband was moving the car. "I asked him to wait, but he said there were other people that he needed to see." The

"The radiographer we had throughout the pregnancy was fantastic. He put everything on the table, told us what we were possibly facing, and gave us the best statistical outcomes."

rule it out. At that stage they didn't know, they said it was probably an old infection."

Nicky was very unwell for the remainder of her pregnancy. At 36 weeks, low lying placenta was detected and a subsequent ultrasound revealed enlarged ventricles in Joss's brain. Nicky was sent for an in utero Magnetic Resonance Imaging (MRI).

neurologist read the report almost verbatim to Nicky. "It was a nightmare and it was awful. The neuro was a grumpy old man at the end of a long day – it was just a routine exercise in his day. He acted like he was reading a shopping list, he treated me like I was dumb. Not only was the information I was receiving awful, but the experience around it was awful."



“He acted like he was reading a shopping list, he treated me like I was dumb.”

Half way through the appointment Marcus joined them, and was frustrated by the assumption that he knew nothing. “He said, ‘I could talk and mention lots of big words but they wouldn’t mean anything to you.’ Let’s try. Use the proper words and I’ll tell you if I get lost.”

Joss’s parents fought to get a copy of the report from the neurologist, so they could do their own reading and begin to understand what was happening to their unborn child. “He said, ‘Don’t go home and Google this, you won’t get the information that you want – it won’t be helpful.’ But that’s what we did. He gave us nothing, and we needed to know what these terms meant.”

When Joss was born, his parents had prepared themselves for him to be deaf. “To us deafness is not a disability, we were fine with it.” Joss was given the standard newborn hearing test. The examiner refused to give the family

Joss’s results, instead stating there may be something wrong with the machine and Joss would have to come back for a more accurate test. “We told her it was okay, we think he might be deaf. She looked terrified.”

“I don’t think it’s acceptable for someone to not want to be the bearer of bad news in a job like that, and also to put a family through that. I remember with our first daughter we didn’t leave the house for a week or so, it was the biggest thing to leave the house. To be in that position where you have a child who is obviously not the same as every other child, and then you have to leave the house and go back to the hospital for a hearing test!”

The family returned to the hospital with their two year old daughter in tow, for a second hearing test that confirmed Joss was profoundly deaf. Again they had a practitioner who acted as if the condition was a death sentence. “I felt like I had to comfort this woman. It’s ridiculous, he’s just deaf!”

Shortly after that, appointments began rolling in thick and fast. Joss was referred to a paediatrician, who he still sees. “We were linked in with a paediatrician who straight away linked us in with the services and resources we needed. She is great, we have differences of opinion but we work it out.”

The family was constantly on the go. They were frustrated by the lack of communication between service providers, the lack of information and choice, and the disrespect shown by practitioners. There was also little consultation and they were unhappy with the dictation of treatments being used, and the grouping of their son into ‘these children with Cerebral Palsy (CP)’. “Overwhelmingly you are treated as a plonker. It was all vague, no one knows what anyone else is doing. They don’t communicate very well, there was no choice, it was just crazy.”





“The [doctors] that have been successful are the ones that ask us what our goals are, that are consultative.”

Interactions with health professionals took two directions - either negative or constructive. Nicky and Marcus trained Joss's health professionals to work with them, and to view their child as an individual. “The ones that have been successful are the ones that ask us what our goals are,

that are consultative. The ones that have been horrible are the ones where it is assumed that we know nothing, just going through the list and not viewing my child as my child.”

“It's hard sometimes. It's their job but it's our life.”





The Heany's Recommendations to Health Professionals

- » Be respectful to families; show some basic humanity and do not assume they know nothing.
- » Treat all children as individuals; do not group them, or assume what has always been done for that condition is the best option for that child.
- » Empower parents with knowledge and let them make decisions about their own children; treat appointments as consultations, allow time for questions and if there are unknowns, give families honest advice.
- » Refer families to services and practitioners they need to be in touch with.

The Lycett's Story



Mark is a four year old boy who was diagnosed with autism at two and a half years of age. Mark and his family had a great support system throughout the diagnosis.

Mark's mum Susie took Mark for his scheduled eighteen month check-up with the maternal and child health nurse. During that appointment Susie mentioned that Mark still had no speech. "I was not too concerned at this stage. Mark had his brother to talk for him." The nurse suggested that Susie put Mark on the waitlist for council speech therapy and if possible,

intervention and speech waitlist, because if it's not speech delay you are already in front." The support, information and advice she got from her GP was invaluable, "She was awesome!"

Mark attended a few sessions with the private speech therapist but Susie felt that Mark didn't really benefit from the sessions. After further research, Susie secured a position for Mark at a communication clinic.

During sessions at the communication clinic Mark was assessed across different

"He is still Mark and nothing is going to change that, he is just going to need a bit of help, but he is great at maths already."

have Mark see a private speech therapist while waiting for the council service.

Susie took Mark to see their general practitioner (GP), who the whole family had been seeing for many years. They had a long discussion about speech therapy for Mark, and completed an Enhanced Primary Care Plan. The GP told Susie, "I don't think it's anything to be concerned about, but make sure you put Mark on the early

areas. The family received an eight page report that explained Mark was having trouble in areas such as socialisation and play (his play was "very narrow"). The report also suggested Mark see a paediatrician for further assessment and diagnosis.

"They were fantastic...they told me about the carer allowance." Susie got a referral for a paediatrician, who was "just amazing". The paediatrician suggested a full assessment



“I was so lucky...I could hardly keep my head above water to take a breath. Everything was falling into place for Mark.”

with a psychologist. “This was when we got the diagnosis of mild to moderate autism spectrum disorder. It happened very fast...I was on a roller coaster.”

“We had an amazing GP who pointed us in the right direction. I could not thank her enough.” Susie and her family were also lucky to have family members who were very supportive and helped Susie to attend appointments and sessions without having to worry about her other son.

“He is still Mark and nothing is going to change that, he is just going to need a bit of help, but he is great at maths already.”

It was no longer than a week before Susie received a call from early intervention central intake to say that Mark had been offered a place in an early intervention program.

“I was so lucky...I could hardly keep my head above water to take a breath. Everything was falling into place for Mark.” The intake worker visited Mark and Susie at home, and explained the services available to help Mark and his family. “They provided brochures, which were very helpful. I could read them in my own time.”

“I was just extremely lucky to have such knowledgeable health professionals around that were able to point me in the right direction.”



“I was just extremely lucky to have such knowledgeable health professionals around that were able to point me in the right direction.”







The Lycett's Recommendations to Health Professionals

- » Give families the opportunity to read reports before they meet with specialists to discuss the content.
- » Provide families with direction on where to seek assistance.
- » Place patients on waitlists “just in case”.

The Frankhauser's Story

Mary and Terry are the parents of Jack (six years), Joel (five years), and Abby (four years). All three children have an autism spectrum disorder. Jack, Joel and Abby were all diagnosed within a two year period.

Joel was the first to be diagnosed. At eighteen months of age, the maternal and child health nurse raised concerns that Joel was not pointing. At first, this did not particularly worry his parents but his lack of speech and excessively clingy behaviour did.



“I was heartbroken, absolutely heartbroken... thinking about Joel’s future and what that entailed, and how he’d survive in this world.”

“The red flag was raised for us with Joel first. He was eighteen months when we sort of thought something was not right.”

With newborn Abby and an explosive three year old Jack in tow, Mary and Terry began the arduous diagnosis journey for Joel. Mary

took Joel to the local general practitioner (GP) and expressed her concerns. “I don’t think they believed me.” Joel was given a referral to see a private paediatrician. “I knew something wasn’t right. I wasn’t looking for a label for Joel, all I was looking at was his deficits. I just needed to get my child some help.”

Joel’s paediatrician showed little interest or concern for Joel or his family. “The paediatrician looked at him in his pram at eighteen months and said, ‘He looked at me, so he doesn’t have autism, he just has speech delay’. I hadn’t even thought of autism.” Mary left the appointment with instructions to go and find a speech therapist. “We weren’t given any direction, I ended up searching on the internet. I think I spent two days straight on the phone – everywhere had waiting lists.”



“The speech pathologist had a lot of compassion and empathy and understanding...and she was interested.”

Mary's persistence paid off, and she found a speech pathologist who was the family's saving grace. “She was brilliant – she got the ball rolling.”

The speech pathologist recommended that Joel go for an autism assessment. The family returned to the paediatrician and were referred to a psychologist for the assessment. “The psychologist we saw was a shark. An absolute shark.”

The assessment showed that Joel was autistic, with moderate to low functioning. “When I finally digested what the diagnosis was, I was heartbroken, absolutely heartbroken... thinking about Joel's future and what that entailed, and how he'd survive in this world.”



The psychologist told Joel's parents that he “didn't even know how Joel was functioning”. “He said, ‘Your son is going to need this supplement, and that supplement, and we must start ABA [Applied Behaviour Analysis] therapy immediately. It's urgent!’ He was very pushy, he made us feel as if we'd been the worst parents in the world because we had not started his therapy.” Joel did not start ABA therapy, and this encounter left Joel's parents panicked and questioning if they had done the right thing.

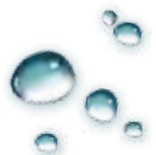
The family were left floundering; they did not know where to turn. Mary spent the next three months on the phone trying to source information and services. But it felt like a never ending torrent of barriers and misdirection. “I had no help...it was like you were trying to claw your way out of this hole, and you'd claw up one and you'd slide down three.”

They returned to Joel's speech pathologist. The speech pathologist was the only professional who provided supportive guidance to the family. “She was a bundle of information and had a lot of compassion and empathy and understanding...and she was interested, which was more than I saw in the GP, the paediatrician, or the psychologist!”

A year after Joel's diagnosis, the family finally found him the right service and he was enrolled in an autism specific child care service.

However there was no rest for the family. Almost at the same time Joel was settled, Jack's kinder teacher expressed concerns over his ability to regulate his emotions, and his highly-fixated play. Mary took Jack to a new GP. “The GP completely ignored Jack, didn't even say hello to him.” The GP gave Mary the referral she requested, for the paediatrician who had seen

Joel. The paediatrician gave a referral to a psychologist that Mary had sourced. Mary poised herself for a fight, but within a month Jack was diagnosed with Asperger syndrome. “Jack's was easier, I knew what to do and what I was in for. It was clinical, it was about the diagnosis, and that was it.” Again, there was no assistance in finding services for Jack, and the family were left to do it on their own.





“They sent the report to us in the mail. We were angry, very angry, we wanted to tear it up.”

But this was not the end of the family's journey. While Jack was in the process of being diagnosed, Mary and Terry's youngest child, Abby, had taken part in a sibling study. "We had no concerns about Abby. We thought the results of the study would come back that she had age appropriate development."

The results came back that Abby was at high risk for autism and that she was a candidate for depression. "For me, that experience was the worst. This was probably the worst report, it just had horrible stuff in there without recommendations. They sent the report to us in the mail. We were angry, very angry, we wanted to tear it up... but my conscience got the better of me."

Despite wanting to reject what they were so abruptly and bluntly presented with, Mary eventually decided that she needed to have Abby assessed for autism as well. "I was devastated by it...it's damning and it's

lifelong. It's not something that can be fixed with an operation." Mary sourced a new GP and paediatrician. Abby was diagnosed with Asperger syndrome just a few months after Jack. Abby's paediatrician finally provided the support, warmth, compassion, and empathy that the family had been seeking. "He told me exactly what I needed to know. He was just brilliant." Abby was enrolled in the same child care service that Joel was attending, and with intensive intervention improved drastically.

The greatest struggle for the family through the diagnoses of all of their children was the lack of direction, information and education available. Mary was constantly left to pick up the pieces, do her own research and source services. "There was a lack of information – for me that is what is missing, just that guidance. Where do I start? What does he need? I know he needs a speech therapist but does he need OT [occupational therapy], does he need a psychologist? I don't know. What does he need?"





The Frankhauser's Recommendations to Health Professionals

- » Listen to and believe what parents say.
- » Be aware of, and be sensitive to parents' feelings; show concern, empathy and interest in the families you're working with.
- » Give parents information and resources, and let them know how they can access the services available.

The Ellul's Story



Ricky is an eleven year old boy with neurofibromatosis type 1 (NF-1), resulting in a large brain tumour, causing blindness and an intellectual disability. Ricky's family, especially his parents Silvana and Mario, are still reeling from their struggle to have doctors listen to their concerns.

Silvana's pregnancy and labour were both uncomplicated. Ricky arrived early and spent two days in the special care nursery with breathing difficulties, "But after that

seconds he diagnosed it. He said, "It's called von Recklinghausen disease." The family sought a second opinion from a paediatrician, who confirmed the diagnosis, which is more commonly known as NF-1. Other than being told that this was a neurological condition, the family was given no information.

"They don't explain to you what it does or what happens. I came home and looked it up on the internet – hmm, I wasn't very happy."

"They don't explain to you what it does or what happens. I came home and looked it up on the internet – hmm, I wasn't very happy."

everything was fine, he was fine."

Silvana remembers thinking there was something wrong with Ricky's eyes. "The only thing was his eyes. He was a little bit cross eyed...but the doctors didn't even query it." He was so young that Silvana dismissed it as something he would grow out of. But it would ultimately be his eyes that would give the first indication that there was a tumour growing in Ricky's brain.

At six months of age, Ricky developed spots on his back and his mother took him to the local family doctor. "Straight away, in two

For the next two years they thought the condition lay dormant, but at the age of three, Silvana noticed that Ricky could not see. "In those two years I could see he was having trouble with his eyes; they just weren't right. I said that to the doctors, but they said, 'Nah, nah it's okay.'" Silvana returned to the doctors saying, "Look, something's not right!"

Silvana returned to the internet and found that NF-1 could result in optical gliomas, and assumed this was causing Ricky's visual problems. Ricky was referred to a NF-1 specialist at the children's hospital



“I kept saying if there is something there, then he needs a scan. But none of them would do it. After they found the tumour, someone asked why I hadn't just paid for an MRI. I didn't know that was an option.”

and an ophthalmologist. “I went to the doctors, but none of them wanted to give him a MRI [magnetic resonance imaging]. I was getting pretty annoyed.”

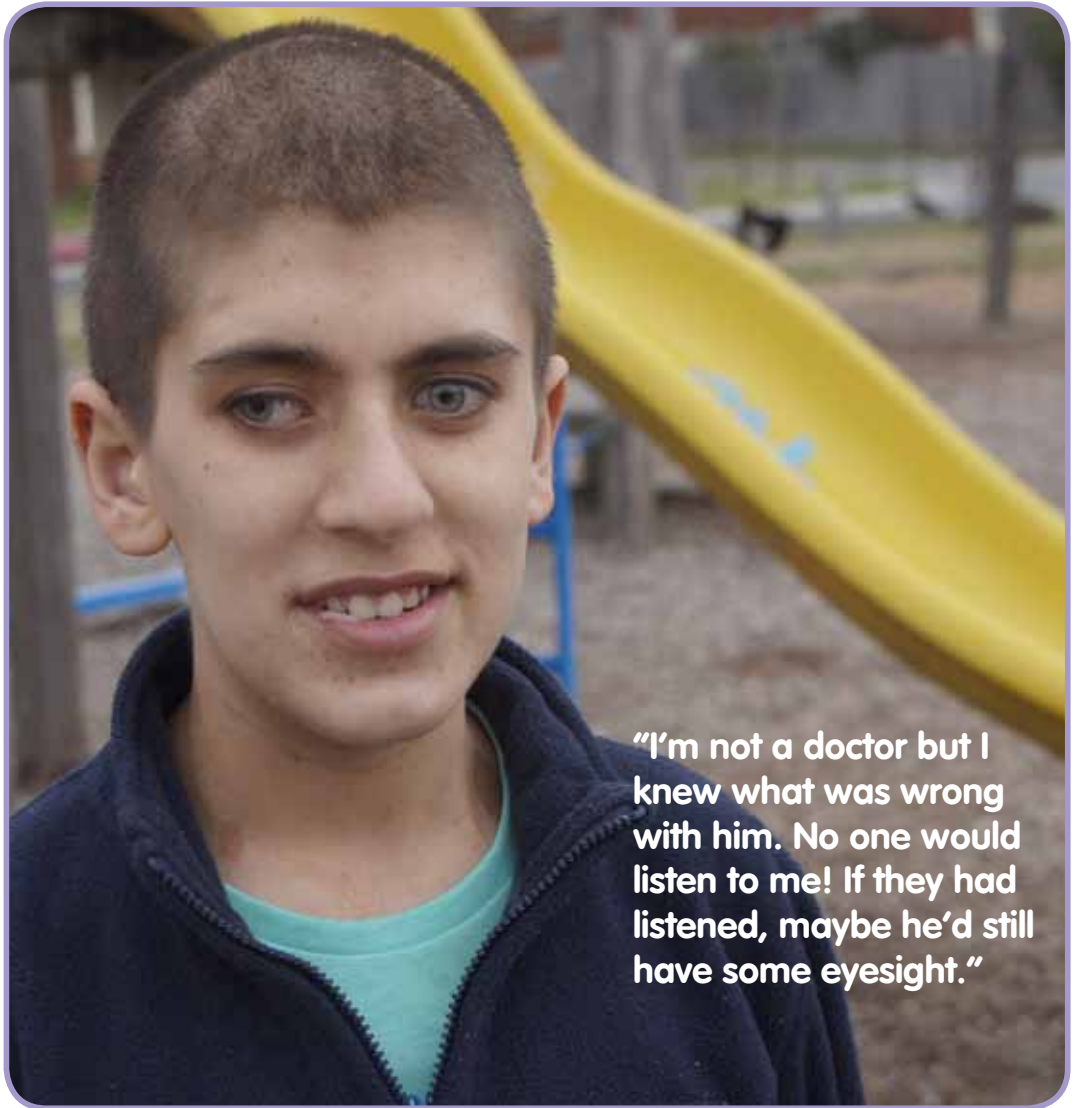
Over the course of a year, Silvana took Ricky to six different optometrists and ophthalmologists, who all agreed that there was a problem, but none would act on it. “I kept saying if there is something there, then he needs a scan. But none of them would do it. After they found the tumour, someone asked why I hadn't just paid for an MRI. I didn't know that was an option.”

At the age of four, a year after his eye sight began to deteriorate, a follow up appointment at the children's hospital showed a rapid decline in Ricky's sight. Silvana demanded a MRI and it was finally approved. The doctor said that it was “now warranted”. A week later

it was confirmed that Ricky had a large tumour growing in his brain. “They finally told me he has a massive abnormal growth on the brain, and we needed to come in and start seeing the doctors...I knew, I knew from before.”

A week later Ricky started his first round of chemotherapy. Seven years later he is still going through chemo, his tumour continues to advance and he is now almost completely blind. Silvana still feels anger and disappointment over the lost opportunity to catch Ricky's tumour while it was still small. “What got me angry was this guy was supposed to be a specialist for NF-1... you could see the spots, you could see he had problems with his eyes. Six different eye doctors had said there's something there but they didn't know what...I'm not a doctor but I knew what was wrong with him. No one would listen to me!





“I’m not a doctor but I knew what was wrong with him. No one would listen to me! If they had listened, maybe he’d still have some eyesight.”

If they had listened, maybe he’d still have some eyesight.” Silvana recalls having to put that grief and anger aside while her four year old son went through chemotherapy for the first time.

It was a year before Silvana realised they needed support and started searching, however services were hard to access.

Nothing was offered to Silvana; she would overhear conversations at the hospital and have to ask, or look up services on the internet. “I found everything...the amount of forms is just ridiculous. Information should be available at the hospital – parents should not have to go hunting for it.”





The Ellul's Recommendations to Health Professionals

- » Listen to and take parents' concerns seriously; they know their children and will recognise when something is wrong.
- » Treat patients as individuals; acknowledge parents and the family system surrounding the patient.
- » Give families their options – if there is a fee-for-service or private option, let families know.

The Harper's Story



Daniel, the son of Hillary and Mick, was born prematurely at seven months and was diagnosed with Down syndrome at birth.

After the standard 12 week scan, Hillary and Mick were told their baby had a one in ten chance of having Down syndrome. After a number of failed pregnancies, the family would not consider termination. "It was a nine in ten chance that he'd be fine."

When Daniel was born, he was taken straight to the Intensive Care Unit. Mick was told that it was likely his child had Down syndrome. Daniel's health became the priority – he had two holes in his heart and required assistance to breathe.

Two days after Daniel's birth, the diagnosis of Down syndrome was confirmed by the professor of the neonatal intensive care unit (NICU) and head nurse of the ward.

"We asked, 'What does this mean for us, to have a child with Down syndrome?' The nurse said, 'Well, Daniel will never go to university.'" Both Hillary and Mick were shocked by this comment and were left speechless. "We just wanted to know if he was going to have friends and be okay." During this conversation, the doctors gave the family the contact details of an organisation that provides information and support for people with Down syndrome and their families or carers.

"The Intensive Care Unit was wonderful; they were great at facilitating Daniel's care and letting us know what was happening."

"The Intensive Care Unit was wonderful; they were great at facilitating Daniel's care and letting us know what was happening. We felt that there were no barriers."

Daniel stayed in the NICU for six weeks, and during this time the family received a home visit from the organisation they had contacted. "This was very helpful, and nice to speak to someone who had a child with Down syndrome."



“We asked, ‘What does this mean for us, to have a child with Down syndrome?’ The nurse said ‘Well, Daniel will never go to university.’”

The organisation gave the family lots of information, and they received a DVD that provided even more support and advice. Hillary said that looking at the front cover of the DVD was a real click moment for her that put everything in perspective. “Daniel will be cute, and I will find him cute. He will be like any child, just a bit different.”

Daniel was discharged from hospital at two months of age, and spent the next two months at home before some planned heart surgery. During this time, the family had an appointment with the paediatrician. “We had a whole list of questions to ask about Daniel’s future.”

At the appointment, the family started discussing all the questions they had around Daniel’s development, until the paediatrician said to the family, “Go home and enjoy your baby. Deal with heart surgery, and come back in two months.”

This was the ‘human reaction’ Daniel’s parents needed. They were reminded they had a beautiful baby boy and their future was just that, the future.

“Go home and enjoy your baby. Deal with heart surgery, and come back in two months.”

Daniel’s heart surgery went well; Daniel went from strength to strength. The hospital and the doctors at the children’s hospital were very supportive and professional.





A book about butterflies



The Harper's Recommendations to Health Professionals

- » Organise relevant parties to be at meetings when discussing a diagnosis, such as social workers.
- » Give parents information and all the relevant options for them to explore, before having to make any decisions.
- » Acknowledge positives as well as providing information about what help or treatments are available.

The Dalziel's Story



Madelyn, known as Maddie, is a sixteen year old girl who lives with her parents and two brothers. She has a severe intellectual and physical disability.

At birth Maddie was a healthy baby with no presenting complications other than some initial concerns about her breathing, however at eleven weeks she started to have seizures. Maddie's parents, Fran and Steve, describe her early years as a "perpetual merry-go-round" of medical appointments

Throughout this process, Fran became increasingly frustrated by the lack of coordination and communication between the various health professionals, and the need to continually re-tell Maddie's story. "Nobody talks to each other – nobody even reads what the other has written. As a parent you have to remember almost from conception, and then repeat it and repeat it...it did my head in."

The doctors discovered that Maddie did not have just one diagnosis, but a host

"When you're pregnant you have these dreams – they're going to grow up, get married, have kids..."

in search of a diagnosis and treatment.

"When you're pregnant you have these dreams – they're going to grow up, get married, have kids, and they're all going to be brain surgeons. And when you get jibbed, you get jibbed big time. All those dreams are crushed...you try everything to get this 'normal' child back."

By the time she was one year old, Maddie had accumulated a team of more than thirteen health professionals, including but not limited to: a neurologist, paediatrician, cardiologist, gastroenterologist, dietitian, physiotherapists and the maternal child health nurse.

of issues that when combined resulted in severe disability. She was diagnosed as epileptic, which resulted in brain damage and curvature of the spine, reducing the capacity of one lung. She also had an enlarged heart and kidney, two holes in her heart, a duplicated urethra and low bone density.

Following these diagnoses, Maddie and her family were caught in a maze of health professionals, with nobody looking outside their own sphere of speciality. "For two to three years I was totally in the dark...I had no idea about who to turn to for anything."



“For two to three years I was totally in the dark...I had no idea about who to turn to for anything.”

It was not until Fran broke down over the cost of medication, when Maddie was three years old, that one of her doctors realised the family had not approached Centrelink for financial support. “I said, ‘Do you know it’s \$60 a box



plus for this medication?’ He looked at me and said, ‘What do you mean? Why don’t you have a health care card?’ He may as well have been talking medical terminology to me, cause I had no idea what he was talking about!”

The doctor was surprised that nobody had mentioned the social services available to the family. Fran felt she was expected to be so many people to her daughter – speech therapist, dietician, physiotherapist and nurse. She never got the chance to just be mum.

“You’re dealing with so much grief, but you have to put that aside. My role as mum stopped...it’s an awful, awful time.” Initially Fran did not know she could access a dietician or a therapist, and she’d never heard of early

intervention. Fran also didn’t realise that she had a say about what treatments the doctors were prescribing for her daughter. The doctors would come, tell her what they were doing, then leave. “There was no one to translate.”

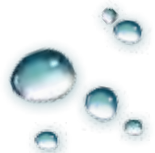
“Doctors act like God – you sit there cause you’re still in grief and say ‘okay’ because you think they know best. There’s nothing worse than having a doctor stand at the end of your child’s bed and speak medical jargon to you. This might be the tenth child with a disability that they’ve seen today, but it is the first time that the family are hearing it...they walk in, then they walk out and you’re left there.”

Maddie commenced an early intervention program when she was three, and with this came a social support network with a wealth of information that finally

“There’s nothing worse than having a doctor stand at the end of your child’s bed and speak medical jargon to you.”

gave the family the knowledge and access to the services they needed.

Going through the process to enter school was the first time Fran and Maddie’s doctor spoke about her official diagnosis. Fran watched the doctor write a diagnosis letter. “He wrote cerebral palsy, failure to thrive and developmental delay. I said, ‘So she has cerebral palsy?’ And he said, ‘No.’” Fran directed her doctor to tell it like it was. Maddie had a severe mental and physical disability, and she was not going to grow out of it or ‘catch up’ to other children. “Be upfront with me now. Let me plan what I’ve got to do rather than live in hope...”







The Dalziel's Recommendations to Health Professionals

- » Involve allied health; have information about services available to families, and be prepared to refer to relevant services.
- » Be mindful that you might be shattering these families' dreams for their child, that they have not heard what you are telling them before and may not understand; show respect.
- » Be upfront with families; don't offer false hope and be sensitive to how they might be feeling.

The Martin's Story



Tina and Brendan are the parents of three year old Nicholas. Nicholas was diagnosed with Velo-Cardio-Facial Syndrome (VCFS) shortly after he was born.

Tina had Gestational Diabetes, but otherwise her pregnancy with Nicholas had progressed normally until her thirty seven week scan, which showed issues with blood flow to Nicholas. Foetal monitoring was conducted, but Tina was allowed to go home. Later that week, she was back in hospital for routine foetal monitoring.

"I asked if there was a problem...we were in the middle of the special care nursery, and there were people around. She said to me, 'Your baby has a syndrome.'" Just like that, Tina was given the news that there was something wrong with her baby.

There were no further details provided – the doctor could not tell her which syndrome Nicholas had, or what it meant for him. Tina could not contact Nicholas's paediatrician until the following day.

"I asked if there was a problem...we were in the middle of the special care nursery, and there were people around. She said to me, 'Your baby has a syndrome.'"

She was told nothing, but suspected something wasn't right. "Nobody told me anything, but I could hear them talking in the corridors."

After several hours of foetal monitoring, an obstetrician told Tina that the placenta was breaking down due to her diabetes. She was taken in for an emergency caesarean.

At birth, Nicholas struggled to stabilise his blood sugars, so he was placed in the special care nursery. Two days later when family and friends had gone home, Tina went to visit Nicholas in the nursery where she found a junior consultant fussing over him.

"I just lost it...they had to call the head paediatrician on duty to calm me down, but she couldn't tell me anything either." Tina was left to call her family and tell them the devastating news.

"That was the worst night of my life. I have a background in disability, and all I could do was think of all the horrible syndromes and what this might mean for Nicholas and my family."

Nicholas was diagnosed with VCFS. Tina and Brendan were told that heart conditions and feeding difficulties were associated with the syndrome.



“Nobody focused on what Nicholas could do. They made assumptions about him based on his diagnosis, without meeting him.”

Nicholas's paediatrician said that he would need to conduct genetic testing to confirm the diagnosis and run tests for any medical conditions. Fortunately, Nicholas was cleared for medical conditions, but the syndrome was confirmed. The paediatrician stated that the worst scenario for Nicholas would be attention deficit hyperactivity disorder (ADHD) and learning difficulties. Nicholas was just ten days old, and he spent three weeks in the special care nursery. Once his diagnosis was confirmed, everything Nicholas was or wasn't doing was blamed on his condition. “Nobody focused on what Nicholas could do.

forms for disability payments was harrowing. “We didn't even know to what extent Nicholas would be affected...I wasn't ready to face this, I was still processing it.”

There was no follow up, so when Tina developed depression in the months after Nicholas's birth, she had nowhere to turn. Her condition went unrecognised until she sought help for herself.

“There should be follow up. You can't just tell someone something like that, then never talk with them again.”

“There should be follow up. You can't just tell someone something like that, then never talk with them again. The doctor should call in a week or two, discuss what it means and make referrals. But they need to give the families time to digest.”

Nicholas was referred to the Developmental Medicine Unit at the children's hospital for his follow up care. Tina was unable to go to the hospital by herself, because she was constantly fearful of what they might say to her. She had gone to one physiotherapist who was perpetually focused on negatives. Tina recalls a session where she sat and cried while she was told what she and Nicholas should be doing. She also visited a maternal and child health nurse who frequently posed threats of failure to thrive. “She would say, ‘He needs to put on weight or he'll be considered failure to thrive.’ She never recognised anything good. She said, ‘Oh you poor thing, it must be so terrible having a child with a disability.’ Nicholas has a syndrome, not a disability!”



They made assumptions about him based on his diagnosis, without meeting him. It was always about what he wouldn't do or couldn't do.”

A pastoral care worker and a social worker visited Tina in the days after Nicholas's diagnosis, but she was not ready for them. The thought of filling out the Centrelink







The Martin's Recommendations to Health Professionals

- » See the individual not the syndrome, disorder or disability, and do not make assumptions about what they will or will not be able to do.
- » Be sensitive to the fact that this is a person that you are discussing, and the impact that you're having on their family.
- » Be prepared with information for families; don't make blanket comments that cause undue stress.
- » Take things at a pace the family is comfortable with and ready for; be aware of what the family is able to cope with.

Josh's Story



Josh is the eight year old son of Tracey. He was born prematurely, and was diagnosed with cerebral palsy two weeks after birth. Late one night, when she was twenty nine weeks pregnant, Tracey drove herself to the

they were gone for three hours." Tracey was still in the birth suite when a counsellor came in to talk to her about the baby that she had not yet met. "A lady came in and started counselling me...she thought my baby had died."

"They told me nothing. He was wired up, but they never warned me. No one told me about premature babies."

hospital in pain. At the hospital she had no time to think – she was told she was nine centimetres dilated, and was admitted straight away. She contacted her husband and he made his way to the hospital. Tracey was told, "You've had two normal pregnancies. We don't see this as being a problem."

When Josh was born, Tracey was left in the birth suite on her own for three hours. Her husband had left the hospital to care for their other two sons. "I didn't even know if it was a boy or a girl. They just left me. They kind of just vanished..."

After a long wait, Tracey was taken into the intensive care unit to see Josh. "They told me nothing. He was wired up, but they never warned me. No one told me about premature babies." After two days, Josh had an ultrasound that came back normal. Josh had another ultrasound at two weeks of age and it was then that the family was taken into an office and told the devastating news. "He had a brain scan, and they saw brain damage. The outcome of that would be cerebral palsy." Tracey stayed in hospital for four days, in a shared room with other mothers who had recently given birth.



"They gave me two days notice for him to go home... I had nothing, I didn't even have a capsule."

Tracey remembers clearly the other mothers were celebrating the birth of their new babies, while she was grieving, not knowing what the future was going to hold for her family. "This was very hard – to see other families happy."

After Tracey was discharged, she visited Josh in intensive care every day for two months. She had two other boys at home to look after, on top of going to the hospital every day. "Everyone in the family was suffering because all my energy was going to Josh."

Tracey was given very short notice that Josh would be discharged, and she felt she was not prepared for him to come home. "They gave me two days notice for him to go home...I had nothing, I didn't even have a capsule." On discharge, the family received no support regarding what they should do for Josh once he was home. Tracey didn't receive any information on what services she should make contact with, or what support was available for Josh and his family.

"How do I look after a child with cerebral palsy? I didn't know him because I wasn't able to look after him."

Tracey did not feel capable of caring for her baby son. "I didn't feel confident in looking after him, and I didn't know where to get help...I developed anxiety." Tracey's husband took ten months off work to help care for Josh, but only three days after he went back to work, her mental health went downhill. It was her church that suggested services that could assist with her and Josh's needs. Tracey contacted Josh's paediatrician, and from there he was linked into early intervention and case management services. Tracey's health continued

"I thought of adoption, as I was not confident and didn't think I could look after him."

to deteriorate, so Josh went into foster care for three months. "I thought of adoption, as I was not confident and didn't think I could look after him." She felt inadequate; as a third-time mum, she was expected to know the system and understand what Josh needed. Tracey says it

was Josh's foster mother and the support services that gave her the tools and confidence to look after Josh. His foster mother took Tracey under her wing, and gave her the faith that she could do it.

"I needed somebody to take control." With the assistance of support services, it took two years before Tracey felt like she was "back on track."





Photos of Josh are courtesy of Cerebral Palsy Support Network, taken by Memories of Mine photography



The family's Recommendations to Health Professionals



- » Provide an information pack to parents that explains the diagnosis and what support is available.
- » Spend more time with the families when you are talking about the diagnosis.
- » Provide families with support even after they have left hospital.

The Paniczko's Story



Sarah is an eight year old girl who lives with her parents and grandmother. She was diagnosed with autism spectrum disorder when she was three years old, but it was six months before support services could be accessed. Sarah's parents, Monika and Richard, still feel an immense sense of guilt over how long it took to have her diagnosed, and to get the help she needed to thrive.

"We suspected earlier but we couldn't do anything...almost since the beginning we saw something was wrong."

At two years of age, Sarah did not smile, showed nearly no interaction with others, was not interested in toys, and was non-responsive to her name. She was placed on a waitlist to have her ears checked, but her hearing was confirmed to be fine.

Sarah teethed late, walked late and never started talking. When Sarah did start walking, she was a toe walker. Monika was told by other parents that it was cute and she would be a ballerina! But it was the toe walking that finally prompted Monika

"The doctor said it like it was a normal thing. She is a good doctor, a specialist in autism... for her it was just another autistic child."

Sarah was an 'unsettled baby'; she cried a lot and rarely responded to attempts to console or engage her. When she was one year old, the family was referred to a clinic for unsettled babies. "She was crying all the time. They should have recognised it, but they didn't."

The family found the clinic to be unhelpful and unsympathetic. "Instead of helping us, they started making jokes." The family's fears about their daughter were dismissed and they were told, "All children are different."

to return to her general practitioner (GP), who referred Sarah to a paediatrician.

"Ten minutes she looked at Sarah and said, 'She's autistic.' My husband was so upset he stood up and said, 'Don't even say that.' The doctor said it like it was a normal thing. She is a good doctor, a specialist in autism... for her it was just another autistic child."



"I was so shocked I left Sarah and I went upstairs. We didn't even know what the name meant...those first few months – disaster."

The paediatrician started telling the family statistics about how many children were diagnosed last year. "It was not really what we wanted to hear – we didn't care." The family wasn't given information about what autism was, or what it meant for Sarah.

"She began to talk about what should happen next, but we didn't hear it, we didn't want to hear it. The worst part is when you go home. You're not really sure what autism is and you go to the internet – that's the worst of the worst. You should never go there...it's shocking."

Another appointment was booked for six months later, so the family were left to call the hospital and arrange their own autism assessment. This news had been a shock – Monika and Richard had not suspected this or been given any warning. They were not prepared to hear the news that was unceremoniously given to them.

"I was so shocked. I left Sarah and I went upstairs...you're panicking, you don't know how to start with her; she is like a different person. You see her with different eyes, you just see a sick child. We didn't even know what to expect...we didn't even know what the name meant. Those first few months – disaster."

Monika booked Sarah in for an autism assessment through the hospital, and after waiting for over six months, Sarah was assessed over a period of two months. "We knew that with autism the most important thing was quick help, quick speech, quick everything. How can you be quick when you have to wait for everything? Everybody knew the problem, but we still had to go through the process."

The family made three visits to the hospital as part of the assessment, after which the reports from the speech pathologist and

"With English as a second language, everything was hard for us."

psychologist were sent to Monika and Richard in the mail, along with a page of contact phone numbers for services. This was a year after they had first seen the paediatrician.

Now that they had an official diagnosis, they could start trying to access services for Sarah.

"With English as a second language, everything was hard for us. They said to me, 'You have to wait.' It was six months before she could access anything! It takes ages, absolutely too long."

The turning point for Monika and Richard came when they were given access to a case manager. After a tumultuous two years, finally they felt they were making progress, and the family began to settle.







The Paniczko's Recommendations to Health Professionals

- » Address issues as they arise; don't wait to see what happens – refer to the appropriate person as soon as possible and give reasons for your actions.
- » Direct families to where they need to go at each stage; make referrals for families, as they are often in shock and need direction.
- » Support the family, or link them with services that can offer support. Be aware of the capacity of the family to make their own referrals, and be aware of possible barriers such as English as a second language.

The Stewart's Story



Lachlan is the six year old son of Carly and Grant, and has been diagnosed with severe quadriplegic cerebral palsy. He is a surviving twin, born at twenty five weeks' gestation.

Lachlan's mother Carly went to her obstetrician at twenty four weeks and four days feeling 'leaky'. She was given the all clear, but the next day she went into early labour. Doctors were unable to halt or slow the labour, so Lachlan's twin sister Isobel was born. After this, the labour was slowed and two days later Lachlan was born. While still in labour with Lachlan, Carly and

Nobody spoke with the family about what they wanted for their children, what the children's outcomes might be, or what the impact on the family might be. They were told that there was a high risk of complications. "Nobody had any discussions about what we wanted to happen, or what was likely to happen."

At eight days of age Isobel was taken off life support and passed away in her parents' arms. Her parents had been told that she had severe and irreversible brain damage, and were left to make the decision to turn off the life support. A

"I'm in labour at twenty four weeks, I don't know what the hell's going on. 'Save my baby,' that's all you say, but they don't talk to you about what saving the baby means."

Grant were told that their daughter Isobel had suffered two major brain haemorrhages and the damage was global. The family was asked if they wanted to end Isobel's life support. Carly and Grant felt unprepared to make the types of decisions that they were now faced with.

"I'm in labour at twenty four weeks, I don't know what the hell's going on. 'Save my baby,' that's all you say, but they don't talk to you about what saving the baby means."

family member with some medical knowledge acted as translator for Carly and Grant, explaining what the medical language meant, and highlighting that if it was an inappropriate option it would not have been suggested.

"I don't feel like the staff gave us the support we needed to make an informed decision for her. They were very uncomfortable talking about those end-of-life type decisions."



“It seemed like something happened whenever we were away. We reached a situation where we felt one of us always had to be in the hospital – we were doing rotating shifts.”

Lachlan had been doing well, but while his parents were attending Isobel's funeral, he took a turn for the worse. They returned to find him on an oscillating ventilator; he was unable to come off without the aid of steroids.

Lachlan was a fighter and survived. He spent the first one hundred and twenty days of his life in the Neonatal Intensive Care Unit (NICU), and everything was a battle. Carly and Grant reached a point where they felt they couldn't leave Lachlan alone, for fear something would go wrong. They recalled an incident when a nurse read the wrong results and went to give him a blood transfusion that would have killed him. “It seemed like something happened whenever we were away. We reached a situation where we felt one of us always had to be in the hospital – we were doing rotating shifts. We never left him alone.”

The hospital enforced extreme privacy and confidentiality practices, refusing to let Carly or Grant read their son's file, discouraging

discussions between parents in the NICU ward, and drip feeding information, even when direct questions were asked. “They didn't offer things, it was all privacy, it was all drip fed. There was always this feeling that they knew more than they were telling us.”

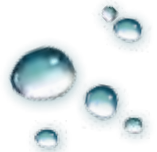
At thirty two weeks an ultrasound was done on Lachlan's head. He had been having regular scans since birth, showing 'bright spots,' which had been interpreted as developing blood vessels. In this scan, the bright spots were

“There was always this feeling that they knew more than they were telling us.”

no longer present. Both Carly and Grant left the hospital on a high – their little boy was getting better. During the ultrasound, Carly asked if there were any bright spots, and the nurse said no. “I didn't pick up on her tone of voice, I assumed that was good news.”

Elated, Lachlan's parents returned to the hospital the next day, after taking their first break since the birth, and were called into a meeting with two doctors. “They told us that his brain had developed cysts throughout, and that he was going to have severe quadriplegic cerebral palsy. That he would probably never walk, never talk, never hold his own fork or spoon. That they didn't know what he would be able to see, didn't know what his intelligence would be like – a pretty dire prognosis really...”

“In my life, that was probably some of the most devastating news I'd ever had...the future looked so scary and so bleak.”





“The loss of a child, that’s traumatic, but there’s an end point...but the loss of the life we had hoped for him and for us as a family is ongoing.”

“We fought so hard to keep him healthy. We felt like we did everything we could – we didn’t leave the hospital, to make sure they couldn’t do the wrong thing. He was our charge, our responsibility...it was a very horrible time.”

“It was a loss of something, but we didn’t know what at the time. The loss of a child, that’s traumatic, but there’s an end point... but the loss of the life we had hoped for him and for us as a family is ongoing.”

The strong family network swung into action and began to work around Lachlan’s devastated, catatonic parents. With their support, Carly and Grant were referred to a social worker in the hospital, the children’s hospital, community early intervention services, speech therapy, occupational therapy and physiotherapy.

“In some ways, as shocking as that was, it actually made life easier for us. We knew we could be linked in straight up. We didn’t have to take a screaming baby home to cope by ourselves.”

Carly and Grant’s family eased them through the process of accessing services. “You just don’t know where you’re going...the services are so

disjointed. The right hand doesn’t know what the left hand is doing.” Their family members attended appointments and took notes, spoke to doctors and interpreted the ‘cryptic’ messages that they received from the doctors.

They were made to feel ‘lucky’ that they had received an early diagnosis, and ‘lucky’ that they were receiving services. “We were supposed to feel lucky and be thankful that we were getting such good service. We were seeing a speech therapist every three months, we were seeing a physio therapist fortnightly... it’s horrible to be made to feel that way.”

Things settled when Lachlan, after a lot of advocacy, was accepted into a cerebral palsy-specific service and began receiving six and a half hours of intensive therapy a week. Carly and Grant continue to struggle with the ramifications of having a child with a severe disability and the choices that were taken from them due to lack of information when Lachlan was born.

“We went from being on two salaries and living comfortably to needing help with the mortgage and not knowing when I’ll be able to work again. We’ve had six years of sleep deprivation, that will never go away. He won’t grow out of it.”





The Stewart's Recommendations to Health Professionals

- » Work with parents as a partnership and listen to them; it is their child you are treating. They have a right to information and education so that they can make informed decisions. Provide them with an idea of what they might be facing and what it might look like.
- » Consider more than your conversation with a family, ask yourself: what's the impact of what you are telling the family? What happens after? Who do they need to know? Where do they go? What do they do?
- » Check in with the family and keep checking in. Do not leave the onus on the family to find what they need.
- » Talk to other health professionals and respect their input.
- » Do your research – look at what is going on overseas, and if it's not your area of expertise, provide referrals.

The Wallace's Story



Toby is the three year old son of Felicity and Doug. He has a chromosomal abnormality that has resulted in developmental delay – it was a harrowing ten month process to obtain this diagnosis.

When Toby was eight months old, Felicity started to become worried that he was not meeting all of his milestones. This was particularly noticeable to Felicity when they were at mothers' group. At a paediatric appointment, Felicity brought up her concerns

multiple disabilities and you need to see the paediatrician." Felicity was left feeling sick, and she wasn't sure what to do next. "I cried all the way home. What did this mean?"

After this devastating news, the family made a time to return once again to the paediatrician, who then conducted a chromosome test, saying, "I expect it will come back ok."

The wait for the test results was long and stressful for Felicity, who at the time was eight weeks pregnant with her second child. Eight

"The paediatrician conducted a chromosome test, saying, "I expect it will come back ok."

that Toby was not meeting his milestones. The paediatrician said that Toby was fine and there was nothing for Felicity to be concerned about. Felicity left feeling like a paranoid mother.

When Toby was twelve months old Felicity returned to the paediatrician to raise the same developmental concerns but was told once again not to worry.

At Toby's eighteen month check-up with the maternal and child health nurse, Felicity said that she was still concerned about Toby not meeting his milestones. The nurse completed an intelligence quotient (IQ) test on Toby, which took two hours. When the test was finished, she turned to Felicity and said, "Your son has

weeks later, Felicity received a phone call from the paediatrician. He told her that the tests showed chromosome abnormalities, and asked that she and her husband come in for an appointment. The paediatrician then went on to say, "I know you have lots of questions but this is not the time or place."

The appointment was booked for the next day, and Felicity and Doug spent the night feeling extremely anxious and worried about what the future may hold for their son.

At the appointment, the paediatrician handed Felicity and Doug a piece of paper that said chromosome abnormality – Molecular karyotype



with a terminal deletion on chromosome two and a terminal duplication on the long arm of chromosome six. The paediatrician told them, "Your child will be severely disabled or a bit slow, I really don't know."

Felicity and Doug asked about treatment options for Toby and were told, "You can

"Your child will be severely disabled or a bit slow, I really don't know."

do physiotherapy and speech therapy," but they weren't given much confidence that it would help. The paediatrician wished them luck and said he would see them in a year.

The appointment had lasted ten minutes. Felicity and Doug were left shocked and completely speechless. They had no idea who to turn to or what to do next.

Felicity contacted her uncle, a general practitioner (GP), who researched Toby's diagnosis and helped Felicity and Doug to understand what it meant, and what they could do. He referred them to a new paediatrician, and Toby started at an early intervention program which included speech therapy. "The early intervention has been amazing."

Felicity credits the early intervention program with helping her understand Toby's condition and providing her with options. "Once we started seeing a therapist, that's when things actually turned around. The therapists have been amazing. They have been the most helpful in helping us understand Toby...I cannot thank them enough!"





Photos of Toby by Rebekah Rumble,
Little Red Photography



The Wallace's Recommendations to Health Professionals

- » See the individual not the syndrome, disorder or disability, and do not make assumptions about what they will and will not be able to do.
- » Be prepared when discussing the diagnosis with the family; have information about the diagnosis or refer the family on to someone who can help them.
- » Be sensitive to the family. Spend more time having a discussion about what's next.

The Sidiropoulos's Story



Jack is the son of Nicole and Peter. Jack had Batten disease, which claimed his life at the age of five.

When Jack was two and a half, Nicole noticed that his speech had regressed, and that he was dragging one of his feet. She took him to see a speech pathologist and a podiatrist, where it was suggested that he should see a paediatrician. Jack had an hour long assessment with the paediatrician, and was diagnosed with mild autism.

Nicole left the appointment feeling overwhelmed. "I did not believe that Jack had autism, but had to believe what professionals were saying."

After the diagnosis, Jack started to have

misdiagnosed. Jack was admitted to the cardiology department because his heart was not working properly, but doctors were unsure why. After five days, he was transferred to the neurology department, where he was diagnosed with myoclonic astatic epilepsy. Jack's medication was changed, and Nicole started taking him to a neuro-scientist who suggested a change in Jack's diet. Following

"I did not believe that Jack had autism, but had to believe what professionals were saying."

sessions with an occupational therapist, a speech pathologist and a physiotherapist. At three years of age, he began to lose his balance, falling over frequently, and having body shakes and seizures. He was admitted to hospital where Nicole and Peter were told that he did not have autism – he had been

the changes to his diet, Jack's improvement was significant, much to the relief of his parents. "Jack was at his peak – he was walking around and responding to requests."

Six months later, Jack started to have tremors. Nicole took him back to hospital, where they carried out a lumbar puncture and magnetic

“It felt like they wanted to shove us under the carpet, because they didn’t know what to do with him. They told me, ‘Jack has a future – we just don’t know what it is.’”

resonance imaging (MRI). The lumbar puncture showed that the sugar levels in Jack’s brain were lower than they should have been, and his parents were told that he had glucose transporter deficiency. The MRI also showed that there was less white matter than was typical for a three year old child. Another lumbar puncture was carried out, and this time a sample of spinal fluid was sent to Adelaide for testing. Jack was discharged. “It felt like they wanted to shove us under the carpet, because they didn’t know what to do with him. They told me, ‘Jack has a future – we just don’t know what it is.’”

A week later Jack’s parents received a call – the results were back. The neurologist told Nicole that they were not good and asked them to come into the hospital. At the appointment they were told that Jack had Batten disease and would not live past ten years of age. Nicole was given a diagnosis letter containing contact details for a Batten disease association, and when she went home she contacted them. They sent her a kit containing useful

information that helped the family to understand Batten disease and where they could seek assistance. “We just carried on and tried to

“I just wanted to spend time with Jack instead of having the pressure of all the paperwork.”

keep life as normal as possible for Jack.”

Nicole felt frustrated at having to continually explain Jack’s condition. She also felt confused by the different opinions and lack of consultation between the various doctors treating him. “I just wanted to spend time with Jack instead of having the pressure of all the paperwork.”

“Life changed; it made me appreciate every minute that I spent with Jack.”





Photos of Jack courtesy of Adam Elwood,
Leader Community Newspapers



The Siridopoulos' Recommendations to Health Professionals

- » See every child as an individual and treat them as such; don't just see the condition.
- » Understand that the child's condition affects more than just the child; look at the whole family system and what they might need. Let them know of the services available to them.
- » Do your homework – know what it is the individual has, and have information and the treatment options available to the family.
- » Show compassion, listen to parents and believe what they tell you – they know their child best.

Sam's Story



Rawiah's son Sam is seventeen years old. He was diagnosed with Rubinstein-Taybi syndrome after five years of searching for answers.

Rawiah had a good pregnancy and birth. "When he was born, he was born perfect." However she started to worry when, at seven days old, Sam was crying constantly. The doctors in the hospital dismissed Rawiah's concerns, suggesting she might be suffering from depression. When Sam's lips started turning blue, Rawiah sought a second opinion from a private doctor, who discovered a heart murmur and, after further tests, a hole in his heart.

Due to ongoing feeding problems, Sam and Rawiah were referred to a feeding clinic and given extra assistance at home. The nurse told Rawiah, "Some kids take a long time to relax... maybe after one or two months he will settle."

gain weight, and he barely slept. At two months, Rawiah noticed that Sam also had a turned eye, and later, that he had a hearing impairment.

"I had to give him medication before and after feeding...it was very difficult for me. Most of the time I had to stay in the hospital."

Sam continued to have issues with his heart, and at six months old he lost the ability to roll and sit up. The family was informed by their paediatrician that he was developmentally delayed, but could not give Rawiah or her husband a clear prognosis.

Rawiah recalls, "It was very hard for me to accept that every time I went to the hospital there was something else wrong..."

At one year of age, Rawiah was told that Sam had an unknown genetic disorder. It would be a three year wait before results from genetic

"It was very hard for me to accept that every time I went to the hospital there was something else wrong..."

Sam did not settle – he cried all the time. At one month of age, the family returned to the hospital because he dropped below his birth weight. Feeding issues continued, he failed to

tests would confirm the nature of the disorder. The lack of information was very distressing for the family. "They couldn't tell me how he was going to be, they just told me, 'He's sick.'"



“They couldn't tell me how he was going to be, they just told me, 'He's sick.'”

At three years of age, Sam began to have seizures, but the family had little support from paramedics. “They didn't believe me; I had to ask the ambulance to take me to hospital. They didn't want to, they said he was fine.”

The family was given a range of possible diagnoses over a period of five years. Sam was diagnosed with a hole in his heart, a turned eye, failure to thrive, dysphagia, epilepsy, global developmental delay, autism spectrum disorder as well as the non-specified genetic disorder. “They said developmental delay, they said autism, but they were just guessing. Nobody explained anything to me... I asked my paediatrician, ‘why is he like this?’ But he didn't know.”

After a three year wait, the results of the genetic testing finally put a name to Sam's condition – Rubinstein-Taybi syndrome. He would be highly dependent on others for the rest of his life.

Despite the distressing news, the diagnosis was a relief for the family. The rareness of the condition gave Rawiah and her husband the confidence to have more children, and allowed the family to adapt to Sam as a person. They could finally stop treating his condition as something that might pass or improve, and focus on their future as a family.

“They said developmental delay, they said autism, but they were just guessing. Nobody explained anything to me.”





Photos of Sam courtesy of
Waratah Special Developmental School

The family's Recommendations to Health Professionals



- » Be prepared to talk to families; have information for them and be prepared to refer them to where they need to go. Vague information causes unnecessary stress and worry.
- » Warn families of waiting lists, and give them options if they are available.
- » Act on risks – if a risk or problem is present, investigate it – do not leave it.
- » Remember you are talking about, and working with, a person.

Moustafa's Story



Moustafa is eighteen years old and has an intellectual disability. His mother was told he would have brain damage when she was five months pregnant.

Rouba started to have pain at five months gestation. She took herself to the hospital, where she was admitted and given a scan that indicated that her child had brain damage. "The hospital said that I needed to have an amniocentesis." They gave Rouba the amniocentesis, but she did not understand the purpose of the procedure and she wasn't given a language interpreter to explain what was happening.

She was told that she would need to call her husband to the hospital so they could

Rouba was still in hospital when a doctor came in to say that everything would be ok, but later that day a second doctor came in to the room and told her they believed Moustafa would be born with a disability. "I was so confused and scared, I was getting told something different every time a new doctor came into the room."

After two long weeks, Rouba and her

"I was so confused and scared, I was getting told something different every time a new doctor came into the room."

explain the results of the amniocentesis. At that time, she found out there was an 80% chance of a miscarriage during amniocentesis. She wasn't made aware of this risk until after the procedure was complete. "I thought it was something I had to do."

husband were called into a room to be told that their unborn child would be likely to have brain damage, and that labour may need to be induced due to the size of the baby's head. The hospital monitored this, and Rouba was induced at eight months.



Moustafa's Story

She gave birth at eight months, after being in labour for three days. During labour, a paediatrician came into the room to let her know her baby had a bad heart and would be disabled. Rouba was very upset by this and told the paediatrician to leave the delivery suite. "I was in so much pain and was already worried about my baby – I did not need to hear this." Her sister requested that the hospital provide another paediatrician, who would be sensitive to her situation. "Moustafa was born and everything appeared normal. He was given a scan that came back clear."

After Moustafa had been home for two weeks, Rouba noticed that one of his eyes was bigger than the other, and that the

bigger eye was blue, unlike the other eye. She mentioned this to the maternal child health nurse, who told her to go to the children's hospital to get it checked out. The check-up identified that Moustafa had glaucoma, which was creating pressure in his eye. She was informed that this needed to be operated on straight away, or Moustafa could end up blind for the rest of his life. "It was very hard."

At six months of age, Rouba noticed that Moustafa was not focusing on, or interacting with her. She found that Moustafa did not want to play with her, and showed no interest in following her. The paediatrician referred the family to the children's hospital where they were told they would have to wait one year

During labour, a paediatrician came into the room to let her know her baby had a bad heart and would be disabled. "I was in so much pain and was already worried about my baby – I did not need to hear this."



for a computed tomography (CT) scan. At this time Moustafa also had a hole in his ear drum which caused him severe pain.

Between the ages of six months and three years, the family continued to see their paediatrician. They were also linked into a vision association and an early intervention program.

Moustafa was three years of age when the paediatrician met with the family to talk about his diagnosis, saying that he was going to have a disability for the rest of his life. "This is when we realised Moustafa was not going to get better. This paediatrician has been so supportive over the last eighteen years of Moustafa's life."







The family's Recommendations to Health Professionals



- » Pick appropriate places and times to talk to parents about their child.
- » If they cannot change the outcome of the situation, talk about what help is available and not the negatives.
- » Be prepared with what will be needed, so that families can fully understand what is being told to them. For example, use interpreters when they are required.
- » Ensure the family is prepared and procedures are well understood.



Key Recommendations from Families

Addressing Initial Concerns

- » Actively listen to parents and hear what they're saying.
- » Show compassion, listen to parents and believe what they tell you.
- » Take parents' concerns seriously; they know their children and will recognise when something is wrong.
- » Address issues as they arise: don't wait to see what happens – refer to the appropriate person as soon as possible and give reasons for your actions.
- » Act on risks – if a risk or problem is present, investigate it; do not leave it.
- » Put patients on waitlists "just in case".
- » Give families their options – advise if there is a fee-for-service / private option.

Informing Families of Diagnosis

- » Pick appropriate places and times to talk to parents about a diagnosis.
- » Organise relevant parties to be at meetings when discussing diagnosis, such as social workers.
- » Spend more time with the families when talking about diagnosis.
- » Be aware of how parents might be feeling and the emotions they might be experiencing; be sensitive to this, show concern, empathy and interest in the families you are working with.
- » Be mindful that you might be shattering these families' dreams for their child, and that what you are telling them they have not heard before and may not understand; show respect.
- » Be upfront with families; don't offer false hope.
- » See the individual not the syndrome, disorder or disability, and do not make assumptions about what they will or will not be able to do.
- » If the outcome of the situation cannot be changed, talk about what help is available, not the negatives.

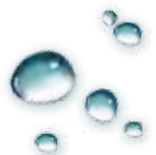


Providing Information

- » Do your homework, know what it is the individual has and have information and the treatment options available to the family.
- » Be prepared with what will be needed so that families can fully understand what is being told to them e.g. use interpreters when required.
- » Be respectful to families; show some basic humanity and do not assume they know nothing.
- » Give families the opportunity to read reports before they meet with specialists to discuss the content.
- » Give parents information and resources. Let them know what they can access and how to do it.
- » Acknowledge positives as well as including what help or treatments are available.
- » Work with parents as a partnership and listen to them; it is their child you are treating. They have a right to information and education so that they can make informed decisions. Provide them with an idea of what they might be facing and what it might look like.

Offering Follow Up

- » Treat all children as individuals; do not group them, or assume what has always been done for that condition is the best option for that child.
- » Arm parents with knowledge, let them make decisions about their own children.
- » Treat appointments as consultations, allow time for questions and if there are unknowns, tell the family with honesty.
- » Check in with the families and keep checking in; do not leave the onus on the family to find what they need.
- » Get families started with people they need to be in touch with; check what they have; and refer them to services they need.
- » Support the family or link them with services that can offer support. Be aware of the capacity of the family to make their own referrals, and be aware of possible barriers such as English as a second language.
- » Talk to and respect the input of other health professionals.
- » Do your research; look at what is going on overseas, and if it's not your area of expertise, provide a referral.



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Further Resources

Australian Resources

Resource

Communicating with Patients: Advice for Medical Practitioners

This document outlines issues in relation to breaking bad news, how to communicate well and the consequences of poor communication.

General Guidelines: For Medical Practitioners Providing Information to Patients

This document includes information that patients should be given, such as the approach to diagnosis, and the limited circumstances when information may be withheld.

Good Medical Practice: A Code of Conduct for Doctors in Australia

This document was put together by the Medical Board of Australia and outlines principles that characterize good medical practice. Areas of particular relevance are sections 2.2, 3.2, 3.3, 3.5, 3.9, 3.12.10, and 4.5.

Further information

www.nhmrc.gov.au/guidelines/publications/e58

www.nhmrc.gov.au/guidelines/publications/e57

[www.amc.org.au/index.php/
about/good-medical-practice](http://www.amc.org.au/index.php/about/good-medical-practice)

International Resources

Resource

Informing Families of their Child's Disability: National Best Practice Guidelines

This document outlines national best practice guidelines for how families are informed of their child's disability. This is the guideline used in Ireland.

Further information

[http://www.informingfamilies.ie/
fileupload/
Informing_Families_Guidelines.pdf](http://www.informingfamilies.ie/fileupload/Informing_Families_Guidelines.pdf)





The Melbourne City Mission Disability Planning and Case Management Services team





"I cried straight away...he told me to take it easy."

"They don't explain to you what it does or what happens. I looked it up on the internet."

"Ten minutes she looked at Sarah and said, 'She's autistic.'"

**"The truth may be brutal, but the telling of it should not be."
(Jonsen et al. 1992)**

A resource for health professionals, this is a book of reflections from families who have experienced the impact, positive or otherwise, that health professionals can have when delivering the news of a diagnosis. It draws on their experiences to provide recommendations for those facing the challenging task of delivering difficult news to individuals and their caregivers.

"For two to three years I was I was totally in the dark."

"He acted like he was reading a shopping list, he treated me like I was dumb. It was awful."

"They sent the report to us in the mail. We were very angry, we wanted to tear it up."