FRACP Psychosocial Log Book

Advanced Trainee in Paediatric Endocrinology

Contents:

Introduction:

Keeping this logbook has encouraged me to reflect on some of the more challenging cases that I have managed over the past couple of years. These cases are drawn from my work in a range of different settings including General Paediatrics, the Emergency Department and sub-specialty areas of Cystic Fibrosis and Endocrinology.

Whilst the majority of cases are children that I have looked after at Starship Hospital, some were seen whilst working at Christchurch Hospital. All were discussed with and supervised by [redacted] Child Psychiatrist at Starship Hospital.

In reviewing these cases some themes have become apparent to me. One is the concept of chronic illness or disability as a major stressor for children and their families. Although this group may be seen with a different focus in sub-specialty clinics, they still suffer from common Paediatric problems and it is often these issues that cause the most day-to-day distress.

It is thus important to take a holistic approach to the chronically ill child – remembering first that they are a child living in the context of their family and that the issues that they and their parents are most worried about may be very different to that of their doctors.

Chronic Illness cases

Type I Diabetes

Case summary - WA:

Problems:

1. Type I diabetes
2. Maternal anxiety and adjustment

WA is a 3 year-old boy who presented in moderate DKA and was diagnosed with type I diabetes aged 2 years and 6 months. Over the first 6 months his parents carefully followed advice about blood sugar testing and dosage adjustments. They received routine initial education and intermittent follow-up with a diabetic nurse specialist as well as 3 monthly medical reviews in outpatient clinic. His glycaemic control had been excellent and he suffered no severe hypoglycaemic episodes.

Impact on family:

I met the family in clinic 6 months after diagnosis and it was clear that his illness continued to have a profound effect on family functioning. His mother had previously worked as a primary school teacher and WA had been settled in a local crèche. However, following WA's diagnosis his mother left her work in order to be with him full-time and to attend crèche with him.

She admitted to an overwhelming fear of hypoglycaemic episodes and said that she felt uncomfortable entrusting his care to anyone else. She recalled an episode when, whilst having lunch in a café with a friend, WA became grumpy and pale and "nearly fell to the floor". Although his recorded blood sugar was only mildly hypoglycaemic she continues to regard this episode as a "near miss" and failure on her part.

WA's father, a builder, had also experienced significant anxiety in regard to his son's health. He had taken to returning home from work at lunchtime and early afternoon to see him. WA had 5-year-old sister who recently started school and her parents described her as having become increasingly demanding since WA's diagnosis.

The weekend prior to clinic I was told that, for the first time, WA's father was given sole responsibility for his care for 2 hours while his mother took the sister swimming. The maternal grandparents also lived nearby and were willing to assist in looking after the children but had not built up confidence in blood sugar testing and injections.

Management plan:

My initial action was to offer encouragement and congratulate WA's parents on the excellent job that they were doing. I reassured them that mild hypoglycaemic episodes are common in toddlers, usually related to variation in appetite and level of activity. I emphasized that the fact that WA had appeared pale and grumpy early was actually good as it gave them the opportunity to intervene well before his sugar became dangerously low. We reviewed management of mild and severe

hypoglycaemic events and I was satisfied that they had appropriate theoretical knowledge.

We talked about ways to increase support for the family. Psychological input was not acceptable to WA's parents who said that they "weren't crazy" and that they wanted doctors and nurses to focus on WA, not them. WA's mother admitted to feeling silly and worried that she would seem neurotic if she phoned the diabetic nurses without a good reason. We agreed to institute a weekly time where a specific nurse would expect them to call and "check in" with progress. At one stage WA's mother had been in contact with another family of a diabetic toddler, but this relationship had lapsed and she did not feel that it worth reviving. Unfortunately there are no organised groups of parents of diabetic toddlers that meet in our area.

The parents acknowledged that the level of supervision WA's mother was providing was not sustainable long-term. We talked about a step-wise strategy for slowly leaving WA at crèche – at first his mother would be there but allow the staff to check blood sugars, then be there and observe the staff making decisions based on these, followed by taking time out altogether. I encouraged WA's father to spend more time looking after his son on his own, with the additional benefit of this being that his mother would then be able to spend more quality time with her daughter. In future we would also hope to provide additional training for WA's grandparents and other carers, but I felt that WA's father and crèche were they key initial people.

Discussion:
WA's parents were clearly suffering from significant anxiety with regard to the care of a diabetic toddler. Studies show that significant anxiety (often consistent with post-traumatic stress disorder) is common amongst parents of diabetic children. It is more common in mothers than fathers and generally decreases over time.

It's important for medical teams to recognise this phenomenon as well as to be aware that not all families will follow the same time-course of increasing confidence. Although I believed that specialised psychological input would likely be beneficial to WA's parents, I was reassured that they were still making positive progress. My strategy was to utilise time and to maximise existing supports for the family.

WA presented as an out-going and confident child. It is important for his ongoing development that he be allowed a degree of independence. Crèche or nursery attendance is a way that a lot of toddlers build up social experiences and become increasingly confident away from their parents. Similarly, his 5-year-old sister is also going through a time of change in starting school. Although described as demanding at home she was said to enjoy school and time with her Grandparents. In the interest of her ongoing sense of self and development it's important that she too has special time and recognition from her parents.

Type I Diabetes (ii)
Case summary – DP:

Problems:

1. Type I diabetes
2. Poor diabetic control
3. Lack of social support
4. Risk-taking behaviour

I met DP as a 15-year-old girl with poorly controlled diabetes. She was first diagnosed with diabetes in 2003, aged 12 years. She went on to have several months of good control followed by an increasing HbA1c and several hospital admissions with DKA. It was clear that she frequently missed doses of insulin and had little family support. DP and her family had repeatedly refused input from the South Auckland adolescent team (Center for Youth Health) or a clinical psychologist. Their reasons for this have not been clear although I believe transport and time commitment to be major obstacles.

At the time that I first met DP she presented to hospital with acute abdominal pain, considered most likely to represent a form of temporary autonomic neuropathy. Her HbA1c was 14.6% and the team had been made aware by the school nurse that she had missed a lot of insulin over the summer holidays, with improvement on return to school and daily supervision from the school nurse.

She presented as withdrawn and difficult to engage. Our rapport slowly increased during her admission and I was able to obtain further background history and perform a HEADS assessment. DP admitted irregular insulin use over the school holidays. She had been particularly upset because her Mother and stepfamily had gone overseas for a few weeks and left her in the care of an Aunt whom she did not like.

She had told the school nurse that she just couldn't be bothered taking insulin and monitoring her blood sugars – and didn't care if she died. However, she did not report her current overall mood as low and denied suicidal ideation. The school nurse agreed that she seemed her usual self and remained engaged and interested in her usual activities.

Social supports:
It had been evident to the diabetes team from the outset that DP was expected to manage her diabetes with very little family support. She comes from a Laotian family and her mother has little spoken English. Her parents are separated and mother re-married, so that DP lives with her mother and stepfather plus 2 younger siblings. Her father lives overseas but she has good relationships with her two older siblings (18 and 20 years) and their partners. Her siblings or the school nurse generally brought her to diabetes clinic. Typically her mother did not attend.

Over the years there had been multiple family meetings and threatened CYPFS involvement – resulting in short periods of maternal supervision of insulin injections and improved control. DP nominated the school nurse as the adult she was most likely to talk to about problems.

Towards the end of her in-patient stay I arranged a further family meeting with DP's Mother, a Laotian interpreter, DP and the ward social worker present. Unfortunately DP's older siblings were not able to attend. DP and mother had had an argument beforehand and DP spent much of the time crying and staring at wall. My intention was to highlight the difficult position that DP was in and enlist support from her mother. My impression was that this was not forthcoming.

HEADS assessment:
DP enjoyed school and was an average academic student who most enjoyed English. She was part of the top school Soccer team and derived a great deal of pride from this. She also had a small group of close girl friends that she relied upon. She was known to have turned up to school intoxicated once the previous year. This was something that she and two friends did together, having met before school and drunk from a flask of Bacardi rum. She was allowed to spend weekends with friends and they sometimes drank alcohol if available. She denied sexual activity but said that she knew all about safe sex. She described herself as a generally happy person who looks forward to the future.

Management plan:
We concentrated on ways of supporting DP. The school nurse is a major adult ally for DP and they have a close relationship, with DP visiting each school day for blood sugar testing. The major limitation is that this contact is maintained during school term only. The diabetes nurses regularly liaise with the school nurse but have had difficulty in reaching DP. They tried text messaging as a different, more acceptable, way of maintaining contact with some success and also visited the school to talk about diabetes with DP and a key group of friends.

In terms of DP's medical care, the decision had been made almost from outset that the best insulin regimen was the simplest. DP was thus managed on twice daily penmix, with irregular blood sugar testing accepted. We were also fortunate as the diabetic service recently began a combined clinic with the Centre for Youth Health. This has been an acceptable way for DP to access the specialised skills of an adolescent team. She left school at 16 years to work in a restaurant and has chosen to attend this clinic most months.

Discussion –
Diabetes control can often follow a stormy course during adolescence. Adolescents who are forced to take independent care of their diabetes may "burn out". Thus the team often places the adolescents on the simplest possible regimen and adopts a short-term attitude of "damage control". Adolescents typically see themselves as invulnerable, experiment with risk taking behaviour and are not motivated by the fear of long-term complications.

For DP I believe that anger, rebellion and denial all manifest in missed insulin doses. Part of my responsibility to DP was to ensure her safety whilst continuing to support her increasing independence. Her home situation may not be ideal and this necessitates a search for alternative ways to support her, as outlined above. She is at a stage where the peer group often sets behavioural standards – which we tries to utilise positively by educating DP's close friends about diabetes. Diabetics have a particular risk of hypoglycaemia with alcohol that her friends need to know about.

DP, as an adolescent with a chronic illness and little family support, is at high risk for depression. We were very concerned to hear that she reported not caring if she died and were careful to exclude depressive symptoms and active suicidal ideation at the time. In addition, we were grateful for the ongoing monitoring of the Centre for Youth Health team.

Cystic Fibrosis
Case Summary – MK:

Problems:

1. Cystic fibrosis (homozygous delta F508)
2. Pancreatic insufficiency
3. Moderate lung disease
4. Multiple, prolonged hospital admissions
5. Chronic infection with *Pseudomonas aeroginosa*
6. Allergic bronchopulmonary aspergillosis
7. Poor nutrition despite gastrostomy tube
8. Short stature and delayed puberty
9. School avoidance

MK is a 13-year-old boy with from Christchurch with cystic fibrosis. I was closely involved with his care during my run as the Respiratory Registrar. He had moderate lung disease, with an FEV1 of 50% at best and FEF 25-75 of 30%. His CF had also been complicated by 2 * episodes of allergic bronchopulmonary aspergillosis for which he required treatment with prolonged courses of steroids.

He had reasonable compliance with daily physiotherapy but said he found it boring and time consuming. He had been chronically infected with *Pseudomonas* for some years with deteriorating lung function and had required multiple prolonged hospital admissions. He tended to stay in hospital for a full 2-3 week course rather than switching to home IV treatment as his mother worked.

Impact on Family:
His mother was a single mother who had always been very involved and conscientious with his care. She also worked full-time in a chemist and admitted that over the last couple of years she had found it increasingly difficult to look after MK. She said that she knew he missed doses of medicines (especially Creon), took shortcuts with physio and wasn't great with overnight feeds. MK's parents separated when he was an infant. He spent time over the weekend with his father but was expected to look after himself there and his father had not come to CF clinic for some time. He had no siblings.

My impression was that MK's mother had become burnt out from looking after MK. We arranged social work review to assess and optimise financial and social supports. I spoke to her with about making sure that she had time for herself, was eating well and had some balance to her life. The CF nurse specialist spent some time with MK's father reviewing his son's needs and encouraging him to become more involved again. This was especially important as MK was at an age where he tended to give his mother a hard time and listen more to his father. We validated the idea that MK should be encouraged to take control as able, and that it was OK to use incentives to motivate him.

Nutrition:

A major issue was MK's poor nutrition, this despite gastrostomy placement several years prior. It was clear that he was not compliant with overnight feeds. He said that he strongly disliked them as he felt that the equipment interfered with his sleep and worried about becoming tangled in the cord. He recalled with horror a night shortly after the gastrostomy was placed when the site detached and he woke in pool of fluid.

Our strategy was to accept his feelings and allow him to make choices. We felt strongly that he should receive the full feed most nights (5 * per week), but suggested that he sometimes have it watching TV in the evening (over 2-3 hours) and sometimes at night (6-8 hours). MK complained about the feeling of fullness from having the feed run over a shorter period but his weight gain improved over the following months.

Body image and mood:
MK was below the 3rd centile for height and fully pre-pubertal aged 13 years. He was very self-conscious of his appearance and short stature, especially since starting high school that year. It was felt that this contributed to the low mood noted during his admissions.

We had a medical discussion with MK and his mother about his predicted adult height and variation in pubertal timing and discussed the option of induction of puberty with testosterone. This was a sensitive issue for MK and something that he needed time to consider. He had previously got on well with a male psychologist and we arranged for them to meet again to discuss this.

School avoidance:
During his in-patient stays MK found multiple excuses to sleep in and miss school. He was popular with the ward nurses and they were very sympathetic towards him. We knew that he also missed a lot of school at home when "unwell," with his mother finding it difficult to judge whether he was actually too sick to go to school. He was enrolled in the hospital school system but put little effort into this and was struggling with his schoolwork. It was clear that high school was a scary place for him, especially due to teasing from older students.

We were sympathetic to MK's high school experience and again asked his psychologist to help him with this. Strategies used included positive self-talk and helping him to come up with responses to teasing. Both his mother and the CF nurse specialist visited the school to explain his illness and frequent absences as well as to arrange support to catch up on missed work. His teachers were made aware of the bullying he had experienced and the school counselor involved in this. We set some hospital and home parameters for being too "unwell" for school, with the expectation that after 2 sick days MK must come to hospital for review.

Discussion:
See next case

Cystic Fibrosis (ii)
Case Summary - AB:

Problems:

1. Cystic Fibrosis (heterozygous delta F508)
2. Pancreatic Insufficiency
3. *Mycobacterium abscessus* infection
4. Procedural anxiety

AB is a 14-year-old girl with Cystic Fibrosis. She had a background of well controlled CF with mild lung disease and relatively few respiratory exacerbations. Unfortunately, she presented with several months of increased wheeze and deteriorating lung function tests. Serial sputum samples revealed *Mycobacterium abscessus,* an unusual and highly pathogenic organism.

She thus required significant intensification of treatment. This was not an organism that we were familiar with locally and advice was obtained from several different experts. Recommended treatment included a minimum of 6-12 weeks IV antibiotics. This necessitated a PICC line, which was extremely distressing for AB and unfortunately blocked. Her weight and nutrition also deteriorated with the infection.

Impact on Family:
AB's parents were initially very angry at our plans to intensify her treatment. They were considered by staff to be difficult to deal with and seemed to "blame the messenger." AB was an only child and very close to her mother. Our impression was that AB's mother had a strong influence on her reactions. She had a pessimistic attitude to the treatments suggested and expressed that they would be "too hard" for AB. Her father was more accepting of intervention.

We had several meetings with AB's parents. Initially we tried to encourage the family – acknowledging how well AG had done prior to this illness and reassuring them that there was nothing that they could have done to prevent the infection. We also spent time explaining the significance of her infection – reviewing the changes in her CT and lung function tests and sharing expert opinions as they became available. We understood that their anger reflected their own feelings of guilt and failure and discussed this with the key staff involved.

AB's mother wanted to be the one to explain things to her daughter, which we supported and I was in attendance for. We also spoke directly to AG, modeling a more positive interpretation and getting her to reflect back the way she saw things. The family accepted input from a clinical psychologist who offered additional support.

Procedural anxiety:
At first AB's main concern was around procedures. The nurse specialist spent time with her and her parents discussing the equipment used in PICC lines, including

visibility and practical aspects of care. The play therapist also assisted with relaxation, controlled breathing and visualisation techniques. Her PICC line was inserted under sedation with her mother acting as "coach" and was well tolerated.

Nutrition:
AB had always been tall and thin but had lost a considerable amount of weight with her infection. She didn't like any of the supplementary drinks available and complained of feeling too full to eat more. We discussed the possible use of a gastrostomy for overnight feeds, but this was not acceptable to AB or her family. Her mother expressed the opinion that we were already expecting "too much."

The issue is not yet resolved – AB's weight has improvement a little with a dietetic plan but is not optimal. We understood and respected AB's concerns about the "mutilation" of her body and being different. We knew of several other local adolescents with a gastrostomy and our plan was to arrange for a meeting (wearing masks) and to continue with further discussion about day-to-day practicalities and advantages.

Building strengths for AB:
AB was a talented artist and took pride in this ability. We had an art therapist available on the ward who spent time with her making sure that she had the utensils she needed and also being present as another person to talk to at a time when she felt relatively positive and relaxed. AB enjoyed school and was eager to attend during her in-patient stay. Her school was rural and took almost an hour to get to from hospital. A plan was made for her to spend 3 nights a week at home with school the next day and to do correspondence work and art the other days.

Discussion:
There is no doubt that CF is a complex and demanding illness. In my experience the level of care needed tends to increase over adolescence, putting great strain on children and families. Adolescents and their families thus need to adapt to a worsening medical condition and increased care at the same time as developmental issues such as body image, peer relationships, sexuality, and planning for the future.

There is conflict between the adolescent task of developing personal identity away from their family and enforced dependency for medical needs. Many of the adolescents I worked with wanted to self-manage aspects of their care – but intermittently with varying degrees of success – and clearly parental supervision was still required. I had a number of discussions with parents about the need to boost and support age appropriate behaviour, e.g. time hanging out with friends, responsibility for getting self to school on time.

Noonan Syndrome
Case Summary - EN:

Problems:

1. Noonan syndrome
2. Hypertrophic cardiomyopathy (mild)
3. Pulmonary artery dilatation
4. Dysplastic mitral valve
5. Asthma (mild)
6. Bereavement
7. Anxiety and panic attacks
8. Short stature

EN is a 14-year-old girl diagnosed with Noonan syndrome at birth. Her mother was known to have the same condition. EN's major medical complication was cardiac disease, in particular HOCM, for which she received cardiology follow-up but was on no medications. She was of normal intelligence and coped well in a mainstream class. I met her in the context of Endocrine growth clinic, where it was immediately apparent that there were other more significant issues present. She has mild short stature – on the 5th centile for age – but was not particularly concerned about this.

Unfortunately when EN was 11 years old her Mother died suddenly and unexpectedly as a result of her cardiac problems. EN was an only child whose father lived in Greece and moved in with her Maternal Aunt and family. She had always had a close relationship with her Aunt and liked her 3 female cousins, who were of similar ages.

EN had been very anxious since the death of her mother, complaining of difficulty sleeping and worries that she might also die in the night. Over several months this had escalated and she had also begun to experience discrete panic attacks. EN said that she was afraid of doing things that could make her heart worse, worried that she was having a heart attack when she felt panicky and was also embarrassed about episodes occurring at school and in public.

Bereavement:
EN had had several sessions with a psychotherapist after the death of her mother, mainly to work through her initial anxiety of dying in the night and the loss of her mother. She generally got on well with her Aunt's family and this was to be her long-term home. Her Aunt encouraged her to be open about her worries and to talk about memories of her mother. They were both often tearful when discussing her.

Anxiety and Panic attacks:
EN's panic attacks began several months before I met her in clinic. They were described as occurring without warning approximately once a week - experienced as breathlessness, a racing heart, dizziness, coughing spell and often a headache. Her family dealt with the episodes by letting her recover in own time. When they occurred at school she said she felt very embarrassed and went home. She

described feeling breathless after running 50m or climbing stairs and was reluctant to partake in PE.

We arranged for an up to date cardiology review and exercise tolerance test – this showed no significant symptoms or compromise at a good exercise workload. Her cardiologist advised her that her exercise symptoms were most likely due to lack of fitness and gave her guidelines for mild regular physical activity. She also had a reassuring respiratory review and normal lung function test.

Her cardiologist also arranged for psychiatric consult liaison input. Initial therapy included relaxation training – breathing, guided imagery, muscle relaxation – and cognitive behavioural therapy – with an explanation of the "panic cycle" and how thinking affects feelings

Sleep difficulty:
EN reported difficulty getting to sleep as well as settling after night waking. She said that she sometimes worried about death, but then often became wound up about not being able to sleep and how tired she would be the next day.

We discussed sleep hygiene and setting up a regular routine, with some relaxing wind-down preparation, no TV or stimulating activities and going to bed and waking at a regular time (even in the weekends). She received further advice from the Consult Liaison team about relaxation techniques.

Discussion:
Anxiety is the most common psychiatric disorder in childhood and occurs in approximately 5-18% all children and adolescents. As in our case, significant impairment in day-to-day functioning is unfortunately common. EN was exposed to an extremely traumatic event with the loss of her mother. This was further complicated by understandable concern for own health and the future given that she shares the same genetic condition and similar phenotype.

My strategy was first to gather realistic and up-to-date information about her cardiac status. I believe that the cardiology review and reassuringly normal exercise test were extremely helpful to EN and her Aunt. From this they were better able to differentiate the feelings that she experienced during a panic attack from true cardiac symptoms. EN now has therapy to help deal with her feelings anxiety. I expect this to be a long process for her and that ongoing family support will be critical over the next few years.

Developmental cases:

18q Chromosomal Deletion
Case Summary – SS:

Problems:

1. 18q deletion
2. Developmental delay
3. Hypotonia
4. Moderate-severe deafness
    a. Bone conduction hearing aid from 9 months
5. Bilateral congenital medial tali
    a. Surgical correction aged 15 months

SS is a 2-year-old child who regularly attends Endocrine growth clinic. Her chromosomal deletion is rare and thought to affect 4 other children in New Zealand. Her parents instigated growth hormone therapy aged 12 months, in conjunction with her Developmental Paediatrician and the Endocrine team. There are a couple of very small studies suggesting an increase in IQ amongst children with 18q deletions treated with growth hormone. SS's parents initially viewed GH as a "cure" for her condition and I was involved in analyzing the literature with them. Treatment is self-funded at a cost of $5,000 per year and is planned for review aged 3 years.

Impact of diagnosis:
SS is the second child to 2 high-achieving biologist parents. Her 18/40 scan revealed bilateral clubfoot and borderline ventriculomegaly and she was referred to National Women's Hospital for a more detailed scan. No further anomalies were identified but her parents warned of the possibility of a chromosomal defect. They declined amniocentesis but recall the remainder of the pregnancy as an "awful" period of waiting. Her Mother said whenever she imagined SS she saw a child with Down syndrome.

SS was reviewed at birth and her parents provisionally reassured. Routine developmental surveillance was provided through Plunket. In retrospect, SS's mother says that she felt something was wrong by 5/12 - SS was floppy, growing poorly and not developing as fast as their 1st child.

The diagnosis was made aged 7/12, prompted by SS starting at day-care. Within a few weeks of her starting the director warned the parents that she was concerned about SS's hearing and arranged to visit them at home. She brought around a video of SS and other infants her age that clearly illustrated some delay. Her parents took her to see a private Paediatrician who arranged investigations including the karyotype that revealed her chromosome deletion.

They then met with a Geneticist. They recall being told that SS had no major organ problems but was likely to have ongoing mental retardation, hearing problems and a risk of autism. The message that they took home was that there was nothing that

they could do and they recall feeling devastated by this. They went on to conduct their own research and came across the San Antonio chromosome 18 research center – offering options and hope.

General Development:
This is supervised by a Developmental Paediatrician. SS has moderate to severe hearing loss which is corrected to mild with a bone-conducting hearing aid. She attends a local day-care and is considered to be a sociable, playful child without autistic features. Her foot operations were completed aged 15 months and she continues to need support to walk. She has weekly physiotherapy and her tone has improved on growth hormone.

Current impact of family:
SS is the second of 3 children – with siblings now aged 6 years and 2 months. Both parents generally work fulltime. It is usually SS's father who attends her appointments and this entails time off work once or twice a week. Her parents retain a sense of guilt for not picking up on her problems earlier.

A major concern is how she will be treated at school and perceived by society in general. Although SS is not dysmorphic her hearing aid causes people to stare at her. Her parents' response is to make light of enquiries, explaining that SS is deaf and offering to show them "how cool" her hearing aid is. They have made contact with other families through parent-to-parent and the San Antonio society.

Discussion:
Experts agree that the moment in which bad news is broken is recalled in vivid detail and can have a far-reaching impact on parents. SS's parents recall being given very little hope at the time of diagnosis and were initially angry that they had to find out about treatment options for themselves. This has been discussed over time both with the Endocrine team and SS's Developmental Paediatrician. They now accept that growth hormone is not a cure for SS and has unproven results in the long-term, but would not feel that they were doing the best for her by ignoring the opportunity.

It is important for medical professionals to be aware that many parents will conduct independent internet searches about their child's condition. We should thus aim to direct parents to reputable sites and offer to help to interpret the information found. SS's GH injections are well tolerated and expense manageable for the family and it is a decision that her medical teams have been able to support.

Down syndrome
Case Summary – JB:

Problems:

1. Down syndrome
2. Bilateral cataracts
    a. Lensectomies
    b. Uses contact lenses
3. Moderate ASD
4. Type I diabetes
5. Transient myeloproliferative disorder
6. Ex-premature at 34 weeks

I first met JB and family when she was diagnosed with Type I diabetes aged 9 months. JB has Down syndrome and multiple medical co-morbidities to which her diabetic care has added a further layer of complexity.

As in the earlier case, I did not know JB's family at the time when Down syndrome was diagnosed but have had the opportunity to discuss this subsequently.

Response to initial diagnosis:
JB's Mother was 35 years old during her pregnancy with sons aged 12 and 8 years. Routine scans were unremarkable and JB was induced at 34/40 for oligohydramnios. She was taken to SCBU at birth and the provisional diagnosis of Down syndrome made by a Paediatrician several hours later.

In hindsight, JB's parents acknowledge that their initial response was one of denial and rejection – thinking "we don't want her", "we can't cope", and that it would be "too much for the boys." They were reluctant to tell people about JB's birth and were surprised to meet with positive reactions rather than pity – in particular they recall being told that they were lucky and that she was "a gift".

Medical progress:
JB required highly medicalised care for the first few months of her life. She spent 6 weeks in SCBU and had significant difficulty in establishing feeds. She required intensive support from the Homecare nurses after discharge.

Bilateral lensectomies were also performed prior to discharge. JB now wears daily contact lenses. Her blood disorder has resolved. She will also require surgery for closure of her ASD in the next couple of years.

Development:
JB is under the care of a Developmental Paediatrician and accesses services provided through Wilson Home. The team includes an SLT, physiotherapist and social worker. Her Mother believes that her motor development is average for a Downs infant and language skills slightly advanced. They are able to provide her with lots of

stimulation at home and generally report feeling well supported and positive about her progress.

Diabetes:
JB presented to ED aged 9 months with what her parents thought was a viral illness. When they were told that she actually had diabetes they found it hard to accept that she had a further serious problem. They were angry with the staff in ED and wanted to take her home. JB was left in hospital with the nurses on the first night of her admission and this pattern continued throughout her stay - Grandma was there for most of the day and JB's parents came in for short periods only.

We were concerned about their response and reluctance to stay with JB and involved both JB's Developmental Paediatrician and the ward Social Worker. Both spent a considerable amount of time helping JB's parents adjust and were able to reassure us about the level of care provided at home.

Her stay was longer than usual in order to ensure that both parents and JB's Grandma were fully educated and prepared to look after her at home. Since then her diabetic cares have been performed conscientiously. Their attendance at outpatient follow-up has been reliable and appropriate.

Current impact family:
JB's Mother recalls that the impact on her sons was one of her major focuses when JB was diagnosed with Down syndrome. Until she became attached to JB she saw her sons as top priority and felt as though she couldn't accept another child at their expense. The boys were initially upset but have come to "adore" SS. Their mother actively tries to normalise her in their eyes by highlighting their similarities and relating anecdotes from their own babyhoods.

JB's parents say that they have moved from shock to acceptance and now feel glad to have JB – that she is not necessarily harder work than other kids, just different. They actively focus on the positive – saying that "you must look for the light or you'll get depressed." This adjustment has likely been made easier by her sunny, affectionate and content nature. They are well supported by family and friends, especially JB's maternal Grandmother.

Her parents report feeling sad about "lost things" – future opportunities for their daughter that people generally take for granted. They dislike people staring at JB and feeling as though they are pitied. Fortunately they have been able to discuss their concerns in a relatively open manner with staff and parents at Wilson Home, and have found that many others feel the same.

Discussion:
JB's parents reacted with shock and denial to the news that she had Down syndrome. They acknowledge great difficultly in moving beyond their preconceived idea of having a handicapped child. This has been made easier by positive responses

from family and friends and the level of ongoing support that they receive. They are also relieved by what now seems to be a positive impact on their other children.

As medical professionals I believe that one of the most important things we can do for families like JB's is to encourage them to take things a step at a time – resisting the urge to forecast too far ahead – and to remember to emphasise the positive along the way.

At the time that I got to know the family JB had just been diagnosed with diabetes and it was clearly very difficult for her parents to accept a further medical diagnosis. It was a challenging situation to negotiate – we needed to ensure the care and protection of JB foremost but were sympathetic and conscious of our need to build a future working relationship with the family. It was extremely valuable to involve JB's usual Paediatrician and the ward Social Worker, both to provide us with reassurance that this was a family that were capable of dealing with diabetes and to assist the family in accepting the news.

Prader-Willi Syndrome
Case Summary - JM:

Problems:

1. Prader-Willi syndrome
2. Short stature
3. Scoliosis
4. Challenging behaviour with very high anxiety

JM is an 11-year-old boy who regularly attends Endocrine growth clinic. He was commenced on growth hormone therapy aged 5 years. He is also under the care of a Developmental Paediatrician and Child Psychiatrist.

His mother is very open about the difficulties they face. She is heavily involved with the Prader-Willi association and as wants to increase knowledge of the syndrome. JM currently functions at a similar level to his 5-year-old brother and has just learnt how to read. He is articulate and enjoys contact with medical professionals - giving the superficial impression that his cognitive level is above what it truly is.

Response to diagnosis:
JM is the product of an unplanned teenage pregnancy. His mother recalls warning signs during the pregnancy – he was growth restricted and rarely kicked – but did not feel that she appreciated the seriousness of this. He had poor Apgars at birth and was admitted to the NICU where he continued to be floppy with feeding difficulty. A formal genetic diagnosis of Prader-Willi made on day 10 of life.

She recalls being devastated by the news. She had some experience of Prader-Willi as she grew up with an affected family friend who was teased and treated badly at school. She felt that, as a young mother, she was given minimal information about the syndrome and was left to seek this from books – which terrified her even more as they presented shocking cases of mental retardation and morbid obesity. In retrospect she says that she was fortunate to have her son diagnosed early as she has met other parents who went through years of uncertainty and developed patterns of overfeeding that were then very difficult to break.

At this stage she lived with JM's father and his family. JM's father "brushed over" the diagnosis and she felt very alone in dealing with their child. The relationship collapsed several months later. She then moved back in with her own parents who were supportive and enabled her to complete her high school education.

Obsessive behaviour:
She has found the most difficult issue to be JM's obsessive behavior. By 2-3 years of age he spent hours each day involved in repetitive activities such as ripping paper and playing with shoe laces. He became anxious and aggressive if not allowed to do this and would wake at night wanting to pursue these activities. By 5 years of age his Mother says that she had come to feel "trapped" and "isolated" by his behavior.

They were referred to Starship psychiatric liaison and JM started on Risperidone. The medication made him less anxious and, given at night, improved his nighttime settling considerably. Aropax was added a couple of years later and unfortunately led to a dramatic deterioration. He became aggressive and violent – breaking furniture at home and threatening his parents and younger brother – and was admitted to Starship for respite. The aggression resolved when Aropax was withdrawn.

His Mother describes his current state as anxious and obsessive. He asks for reassurance in the form of constant questions and his parents have to be careful to give the same answers. They have learnt that he needs firm, consistent boundaries and a regular routine. He responds to the use of time-out for tantrums. They receive ongoing support from Marinoto House – JM has learnt relaxation techniques but his mother believes that the most benefit comes from his being on Risperidone.

He attends the Endeavour unit at Mt Roskill primary school. He is well known to the staff there and they follow a similarly structured routine to home. At this stage a major difficulty is getting JM to and from school. Although he is funded for a taxi many of the regular drivers refuse to drive him. This is because he screams shouts and has even jumped out of moving taxis. This is a big concern for his parents as responsibility for school transfers would have a major impact on their own jobs.

Weight management:
JM has a healthy BMI of 17kg/m2. His parents work hard to maintain this and apply a similar healthy eating regimen to the whole family. They understand that JM is always hungry and is unable to control his impulse to acquire food. He is fed 5 small meals a day at regular times and knows that there is "no negotiating" for food in between. In the past JM has taken food from the rubbish bin, other children at school and straight from the freezer. He is encouraged to be open about "sneaked treats" and these are deliberately met with a calm, accepting response, with his next meal portions decreased accordingly.

JM's body habitus changed dramatically with the introduction of growth hormone – fat seemed to "melt away" over the first couple of years as his height increased from the 1st to 25th centile. As he became stronger he was also more inclined to be physically active. He currently swims with a special needs group once a week and has a netted trampoline at home.

Current impact on Family:
The household is busy and consists of JM, his mother (currently 25 weeks pregnant), stepfather and 5-year-old half brother. Both parents work full time and JM's mother feels that it is essential for her to have the break of work time. They try to continue with "life as normal" and go on family outings and holidays. These are often disrupted by JM's behaviour. JM finds it difficult to play with other children and is easily upset but plays well with his brother. Both parents feel highly protective of him as a child with special needs.

JM currently receives a complex needs package from Taikura Trust. His mother previously took the Trust to the Health and Disability Commissioner in order to achieve recognition of his needs. They use his 28 days of carer support on recreation and holiday programmes. It is an ongoing struggle to find suitable activities as many providers are poorly equipped or unwilling to deal with JM's behaviour. He has respite for one weekend per month at Oasis Trust, a relatively new facility that specifically caters to able-bodied but behaviourally difficult children.

Discussion:

JM has complex and difficult needs. His obsessive behaviour can be difficult, disruptive and often unpleasant and is something that his parents have found far harder to deal with then standard Prader-Willi issue of over-eating. They freely acknowledge times of "crisis" over the years and are pro-active in seeking assistance.

They have learnt to apply firm and consistent boundaries with considerable success. It is likely that an important part of their ability to cope with JM is that they understand that his behaviour is internally driven - and not done deliberately to "wind up" or punish them.

They have a strong belief that JM is a valued member of the family and are appreciative of his positive traits. They work hard to strike a balance between meeting his needs and those of the rest of the family – by continuing with "life as normal", work and family life.

JM's mother believes strongly in the rights of people with special needs to be part of society. Over the years she has taken on both medical services and the Needs assessment agency in order to advocate for her son. She takes an active role in raising community awareness of Prader-Willi and hopes that in the future that growth hormone will continue to become more available to affected children.

Global Developmental Delay
Case Summary - SW:

Problems:

1. Global developmental delay
2. Obsessive picking behaviour
3. Chronic non-healing forehead ulcerative lesion
4. Iron deficiency secondary to above
5. Obesity
6. Type II diabetes
7. Fatty liver

SW is a 9-year-old girl who is well-known to the diabetic service. She has developmental delay with a cognitive age of approximately 4 years and no unifying diagnosis. She is cared for by her mother and attends a mainstream class at school with ORRS funding for 10 hours per week.

She has had a large ulcer present on her forehead for the last 2 years. This is unable to heal as SW picks at it constantly. Chronic blood loss from the lesion has led to iron deficiency anaemia. I was involved in an elective admission to facilitate wound healing, with input from dermatology, psychiatry and developmental paediatrics.

Her other medical issues include obesity, type II diabetes and fatty liver. The diabetes is managed with bd penmix and is generally well controlled.

Behavioural issues:
SW presents as a cheerful, out-going child. The major behavior of concern is picking at her forehead lesion. This is dressed once a week by the district homecare nurses and twice daily by her mother. SW removes the dressings and has previously removed gloves, mittens and tapes to her hands. SW picks at her wound in all situations and with all caregivers and becomes verbally abusive when prevented from removing the bandage.

Her mother had tried all sorts of behavioural and environmental strategies to discourage picking (including stickers and positive reinforcement). The picking is particularly prominent overnight and SW wakes with her pillow and pyjamas soaked in blood. Her mother generally wakes and showers and changes her at least once per night.

Management strategy:
During her week as an in-patient SW was treated with oral antibiotics, overnight vallergan forte and various attempts to increase the physical barrier to picking. Unfortunately, Tubigrip balaclavas were easily removed and she did not tolerate an orthotically fitted helmet. There was little improvement to the lesion over this time.

The psychiatric service suggested an intensive behavioural approach to be used at home for several weeks. This plan included an instant reward (toy or story) in the

morning for SW keeping her bandage on. Her mother was advised not to shower and change SW and to simply re-bandage her lesion in the night to avoid unintentionally rewarding the behaviour. Unfortunately there was little benefit from this alone.

SW has recently commenced a trial of low dose SSRI, in an attempt to reduce the obsessive aspect of her picking behaviour. She will receive regular out-patient review from the child psychiatric service.

Social impact:
SW's mother cares for her with the assistance of a sister. She has no other children and has been unable to work as a result of the demands of caring for SW. She receives a child disability allowance, carer support and 28 days respite per year but, understandably, admits to feeling overwhelmed and worn down. We have applied for further radical respite at the Wilson centre, whereby SW could receive overnight nursing care for her wounds.

Discussion:
The forehead lesions have had a profound impact on SW and her mother's day-to-day life. The picking behavior is likely to be multifactorial in origin - with a component habitual motor action, a component obsessional, a component related to sensation (itching in a healing wound), and partly perpetuated by the (negative) attention received for picking.

The behavior has proven remarkable resistant to intervention and it is likely that a successful management strategy will need to encompass all of the above facets, as well as supporting an extremely tired and disheartened mother. SW's case has proven extremely challenging to all of the medical staff involved, as evidenced by the need to involve multiple teams, and the issue remains to be resolved.

Behavioural cases:

Infantile Colic

Case summary – AK:

I met AK as a 3-month-old baby, brought into ED by exhausted parents with inconsolable crying. They described at least a month of frequent, persistent crying lasting for hours at a time, especially late in the day. AK's posture and facial expression suggested to his parents that he was in pain and his parents felt unable to soothe him and concerned that he had a physical problem. His examination, urine specimen and ECG were all normal.

AK was the first child to a busy working father and relatively isolated mother. They lived rurally and his Mother admitted to having little support. She had never been depressed before but was concerned that she might be becoming so. They were also considering a switch from breast milk to hypoallergenic formula.

Management:

My first step was to offer empathy and information. I reassured AK's parents that colic is a common and difficult problem that is not due to serious illness and that, fortunately, resolves in most babies by 4 months. I advised them that changing to formula was unlikely to help and might make his Mother feel even worse. I also provided them with written information on colic from the RCH Melbourne website.)

They had already been given a lot of suggestions by family and friends and were feeling overwhelmed. I acknowledged that we don't know why some babies cry more than others and that there is no definitive fix. We talked about possible modifications to his routine. The RCH handout contained a list of things to try "on the spot" - like music, rocking, a stroller or car ride. They planned to make further contact with their Plunket Nurse.

The other important aspect was to look after AK's mother and strengthen her supports. AK's Father planned to draw up a roster of available friends and family. I advised AK's Mother to see her own General Practitioner to discuss the way she was feeling. We talked about the importance of having a person to call if it all became "too much" and the risk of shaking a baby.

Discussion:

Infantile colic is a normal but exhausting pattern of behaviour. AK's parents found it to be very demoralizing, especially because they were unable to soothe him and were worried that he had a physical problem. My management strategy was to change the way they viewed his crying and strengthen their own coping mechanisms. On phone review 2 weeks later AK's Mother reported a marked improvement, which may have either reflected the natural history of the problem or their improved ability to cope with it.

Feeding Aversion
Case Summary – DK:

I met DK as a 5-year-old boy referred to General Paediatric Clinic with feeding difficulty. He was the first child to Philippino parents and had been a difficult feeder since the introduction solids. There was no evidence of oro-motor dysfunction or reflux. Both his height and weight were around the 10th centile for age.

At home DK displayed strong food preferences and, although he would usually start to eat, he then refused until physically spoon-fed by his Mother. His mother reported that mealtimes were prolonged (up to an hour) and distressing and that she often resorted to bribery with toys. DK had started school several months prior. His teachers commented that he was a very slow eater but ate a similar amount to the other children.

DK's mother was afraid that if she backed off from feeding and cajoling DK to eat he would lose weight and become sick. There was also a new baby in the household, and DK's mother no longer felt able to devote as much time to feeding DK.

Management:
We discussed the fact that DK was currently a very normal size and that short-term weight loss would not make him sick. I reassured her that his appetite was normal and that he will eat – as evidenced by his behaviour at school – eventually.

We discussed the secondary gain of her attention that DK received by refusing food. I suggested that she keep a record of his diet for her own benefit but should not comment on this to DK. This and his weight could be reviewed intermittently with the family doctor.

The basic strategy that we discussed was that of maintaining a pleasant, unhurried mealtime routine. DK should have the opportunity to model the mealtime behaviour of his parents at home and other children at school. He should be offered small servings of nutritious food, including at least one of his favoured foods, and then left to feed himself within limited time interval (initially 45 minutes, reducing to 30 minutes). The meal should be terminated if significant misbehaviour or a tantrum occurs – with his mother advised to withdraw her attention. The same food or a healthy snack could then be re-offered an hour later. I recommended that his mother create a star-chart with rewards (watching a video, time with her doing something he likes etc) dependant on mealtime eating.

We discussed the fact that he needed to receive positive attention for non-food related behaviour, especially with a new sibling present in household. I made a referral to Consult Liaison for additional support, as well as to look at other areas of parent-child interaction.

When I saw him again in clinic 3 months later there had been significant improvement. He was no longer physically fed by his mother and mealtimes had

become much more relaxed. He had had an initial small weight loss with weight that remained just below 10th centile for age.

Discussion:

DK's mother was aware that she was supporting an unacceptable pattern of behaviour but found the situation so distressing that she was unable to step outside of it without significant support and reassurance. It was important to address her feelings of DK's vulnerability to weight loss as well as her sense of failure as his caregiver. Fortunately he responded well to a simple behavioural management plan.

Overeating and Obesity
Case summary – BB:

BB is a 13-year-old Samoan girl who was I saw in Endocrine clinic for assessment of obesity. She had been a large child throughout her childhood and increasingly overweight over the past couple of years - BMI 34kg/m2 on initial assessment. She had a poor pattern of eating (lots of junk food bought from the dairy, daily soft drinks) and was not interested in exercise. Other family members were also overweight with a strong history in the extended family of type II diabetes and complications from this.

BB's parents were concerned about her weight and future health but BB herself seemed ambivalent. On HEADS assessment it became clear that she was very sociable and outgoing – school was OK, she liked TV and relaxing but mostly hanging out with her friends from school and church. She had been involved with kapa haka in the past and liked to play basketball with her friends. She recognised that she was bigger than her peers and had experienced some teasing at school although she felt "able to stick up for herself."

Management:
I provided BB and her family with basic "green prescription" information about diet and exercise for a healthy lifestyle. In regard to BB's diet I advised that the whole family make an effort to eat more healthily and to change the sort of food available in the house. BB was given less access to money for treats and some input into the meals that she would like. I referred BB and her family for dietician review. In our institution the dietetic service is poorly resourced to deal with obesity and they were able to see a dietician for an initial consult only.

I recommended daily exercise for 30 minutes minimum – whether walking with a friend or family, basketball or kapa haka. I encouraged the family to do this together when possible, and to keep a daily activity chart for all family members up on the fridge. I referred BB to "Kidz in Action." This is a South Auckland initiative that encourages activity within a peer group and includes a large proportion of Maori and Pacific Islander children.

When I saw BB 6 months later she had a sustained weight loss of 2kgs. Her diet was generally improved and the family more "health conscious." BB was engaged in a more active lifestyle and had a positive attitude towards this. I was very encouraged, as I believe it represented a significant, sustained effort on her part.

Discussion:
Childhood obesity is a growing public health issue. There is little evidence for the long-term efficacy of any particular management strategy. Experts recommend a behavioural approach embracing both diet and exercise. It is acknowledged that making these lifestyle changes is extremely hard, and that most successful programs involve the whole family with parents who are prepared to motivate and act as a "coach" for their child.

Unfortunately, the majority of obese children that I have followed through clinics have not managed to maintain their weight as successfully as this subject. I believe that her success is likely attributable to great support from her family (who have also committed to changing to a healthier lifestyle) and a generally positive self esteem.

The basic principles that I employ with obese adolescents are to involve families and encourage activities that are appealing and relevant to them. Kidz in Action is a particularly successful program in our area. When I see adolescents I try to separate their concerns from those of their parents. Adolescents need lots of feedback and are better motivated by achievable, short-term goals. When we discuss plans I have learnt to ask them to reflect the ideas back to me to check both that they have understood and that it seems realistic to them.

Preschool sleep problems
Case Summary – AG:

AG is a 3-year-old girl referred to Paediatric clinic with sleep disturbance – both bedtime struggles and persistent night waking. She was an otherwise healthy child, reported by her parents to be tired and fractious during the day but with normal development and growth. Bedtime was set at 8pm but was typically a struggle with persistent requests for drinks of water, another story etc that generally continued for more than an hour. Overnight AG woke approximately hourly and often secured a spot in her parents' bed. She eventually woke for the day at 0500-0600 and had a 2-3 hour nap during the day in her own bed.

AG's parents were both extremely tired. They recognised that there was a problem, and had watched enough "Supernanny" to know that their responses weren't helping, but felt as though they lacked the energy to deal with it in any other way. They were conscious that chronic sleep deprivation had had an impact on their relationship and on general family life. AG had 2 older siblings aged 7 and 10 years – both good sleepers.

Management:
My first step was to provide information about sleep disorders in toddlers. We discussed the fact that all children wake in the night and all need to learn to settle themselves. Night waking can be made worse by positive reinforcement such as prolonged parental attention and gaining a spot in the parental bed.

We planned a program for her beginning with a pleasant, calming bedtime routine. For AG this began after dinner (around 6:30 pm) and involved bathing, changing for bed and an agreed story. Further bids for attention were to be handled in a firm but neutral fashion – no eye contact, just put back to bed. AG's parents were most comfortable by initially responding to night waking with verbal reassurance and placing her back in her bed, followed by silently putting her back. She was no longer offered a place in her parents' bed. I advised them to expect a few really awful nights followed by gradual improvement.

On phone review several weeks later I found that she still had some night waking but this was less persistent and she was more easily directed back to bed. Bedtime had become a much simpler process. She was mostly achieving a 9-hour plus nighttime sleep with improved daytime behaviour.

Discussion:
Sleep programs must be appropriate to the age of the child and acceptable to their parents. Such programs need a firm and consistent approach and both parents must be motivated and in agreement to apply them successfully. The difficulty that AG's parents had was that they were so tired they did what seemed easiest night by night and felt unable to do otherwise without guidance and support.

Sleep Walking
Case Summary - JH:

JH is a 7 year-old girl referred to General Paediatric clinic with sleepwalking. This had occurred once or twice a week over several months, usually around midnight. Her parents described her coming downstairs, apparently confused, on several occasions and had also heard her moving around her room. They were very concerned following a recent attempt to leave the house whilst sleepwalking. She was an otherwise healthy child, well and full of energy during the day. There were no recent stressors identified. Her father recalled sleepwalking as a child and thus was mostly concerned with ensuring JH's safety.

Management:
I provided the family with information about sleepwalking, including an information sheet from Melbourne Royal Children's Hospital website. I reassured JH and her parents that sleepwalking occurs in nearly one third of healthy children, does not indicate emotional or psychological problems and that most children grow out of it as their sleep patterns mature.

My advice was that JH maintain a regular sleep routine, as sleepwalking is more likely when children are overtired. She should be calmly redirected back to bed when found sleepwalking. I agreed that the most important thing was to ensure a safe environment – specifically by clearing the bedroom of objects that she could trip up on, and locking windows and doors. We talked about sleepovers and the need to discuss JH's sleepwalking so that other parents can ensure her safety.

Discussion:
JH's parents already understood that sleepwalking is a common problem and usually self-resolves. JH herself was aware of the issue but not embarrassed on concerned. I offered the family some practical tips on making the house safe and dealing with sleepovers.

Nocturnal Enuresis
Case Summary - LR:

LR is a 9-year-old boy seen in General Paediatric Clinic with primary nocturnal enuresis. He had never been reliably dry at night and was wet on average 3-4 times a week. He had no problem with daytime wetting and had a regular bowel habit. His neurological examination was normal. Previous investigations included a series of urine specimens screening for UTI and a normal renal ultrasound scan. The family had tried restricting drinks in the evening and LR emptying his bladder just before bed with limited success.

Bedwetting was causing significant distress and embarrassment for LR. His 13-year-old brother teased him mercilessly about it and his Mother was clearly frustrated with the problem. The older brother had a history of nocturnal enuresis that had resolved aged 5-6 years. His Mother felt that LR was too old to be wetting the bed and insisted that he change his own bed linen in the morning. LR was nervous of staying over at friend's houses or going to school camp, as he was worried that he might wet the bed and be teased by his peers.

Management:
My first step was to offer reassurance about how common the problem is in LR's age group. I explained that bedwetting affects around 5% of children at age 10 and has a spontaneous resolution rate of 15% per year. I reinforced the fact that this is not something that LR is doing on purpose and that he is likely to be a "late developer" in terms of bladder awareness overnight and probably a heavy sleeper. Thus it was important that the family, including LR's brother, does not punish or make fun of LR.

LR was highly motivated to be dry at night and I was able to quickly enroll him in the local enuresis alarm program. At Christchurch Hospital this is run by a Nurse Specialist, providing regular contact and support for families. She encouraged them to use a star chart for dry nights. We agreed that DDAVP was reasonable in the short-term for sleepovers.

LR had some difficulty waking to the alarm and initially needed help from his mother. However, by 8 weeks (of which 2 weeks were alarm free) he was reliably dry.

Discussion:
Enuresis can have a huge impact on a child's self-esteem and limit their social interactions. The consequences for the child can vary a lot depending on how the family perceives and responds to the problem. Simple information about the condition provides considerable relief to families and may be all that is required. Behavioural treatment with an enuresis alarm requires motivation on the part of the child but can be highly rewarding.

In contrast to this, I recently saw a 12-year-old diabetic boy (HT) in clinic with secondary enuresis. His glycaemic control was very poor, especially overnight when he tended to "raid the fridge" and snack on sugary foods and drinks that he wasn't

normally allowed. His family was very angry about this behaviour, which they perceived as deliberately oppositional and felt unable to control. HT was embarrassed about wetting the bed and tended to conceal it by leaving wet sheets on the bed and bundling wet clothes into his closet. This was also very frustrating for HT's parents, as they had had to buy 2 new mattresses and replace clothes.

My approach to this case was very different, as I believed that the primary problem was difficulty that HT was having in accepting the diagnosis of diabetes, and poor family relations as a result of this. I referred the family for psychologist input through the Starship Hospital Consult liaison team.