Protecting Children with Cancer from Measles

2012
Foreword

Immunising our children against preventable diseases not only protects them but also others in the community, including those who cannot be immunised or have low immunity.

Young people with cancer are particularly vulnerable to illnesses such as measles because chemotherapy greatly reduces their immunity and means their previous vaccinations are generally no longer effective. They cannot be re-vaccinated until their cancer treatment ends. Babies who have not been fully immunised and frail older people are also vulnerable to diseases that can be vaccinated against.

In this booklet, we tell the stories of four young people with cancer and the impact the 2011 Auckland measles outbreak has had on them and their families. Two of New Zealand’s childhood cancer specialists also share their fears for their patients when measles is circulating in the community.
Children with cancer are at increased risk from measles

While measles can be a dangerous illness with long term side effects for any child, it has a more than 50 percent death rate for New Zealand children with low immunity. As well as causing death, measles can cause pneumonia, deafness and brain damage.

In this country, the biggest group of children with low immunity are those receiving cancer treatment. Chemotherapy attacks bone marrow and reduces the effectiveness of the immune system, making people much more susceptible to infection, particularly from viruses such as chicken pox and measles. While there is now treatment available for chicken pox, there is no effective treatment for measles.

These children cannot be immunised

Because the measles vaccine contains a live virus, vulnerable children cannot be immunised but everyone around them needs to be.

Previous immunisations or exposure to illnesses will only partially protect children who have had chemotherapy because the damage done to their immune system erases much or all of the body’s memory that is has seen the virus before.

A child’s immunity continues to drop as they receive more chemotherapy. For patients with leukaemia – the most common type of childhood cancer – their immunity continues to decline over the two to three years’ worth of treatment. It also remains severely impaired until at least six months after treatment has ended.

When children have finished receiving their cancer treatment they are re-immunised, with the measles vaccine the first to be given during a measles outbreak.

What can we do to protect them?

The most important thing we can do to protect children with low immunity is to make sure that we and our children are immunised against measles, so that we cannot spread the illness. It is especially important that extended family members of a vulnerable child, their friends and anyone who comes into contact with them are immunised against measles or they should keep away from them. If they have not been immunised, this should be done as soon as possible. People can worry that they will give a vulnerable child measles from being vaccinated with the Measles, Mumps and Rubella vaccine because it is a live virus vaccine, but this is not a risk.

What do vulnerable children need to do to protect themselves?

If there are measles cases at the child’s school, they need to stay away from school until the risk of getting measles has passed. Information about when it is safe to return to school is given by the local Medical Officer of Health.

Children with low immunity also need to stay away from crowds of people, particularly during a measles outbreak. This means keeping away from places such as shopping malls, movie theatres and big events or going at off peak times.

Regularly using hand sanitiser is important for affected children and those caring for them. Special precautions also need to be taken in hospitals during a measles outbreak to keep measles patients away from others.
Measles keeps Kelcey away from school

Having just missed a year of school through illness and chemotherapy, 10-year-old Kelcey Roberts was unluckily attending Auckland’s Oratia School, when the 2011 measles outbreak started there.

‘We couldn’t believe our bad luck,’ Kelcey’s mother Tracey Roberts says. ‘Kelvin and I suddenly discovered that there were a large number of unimmunised children at our children’s school. That meant the odds were increased that she could contract measles – a disease that could kill her.’

Kelcey was diagnosed with acute lymphoblastic leukaemia in December 2009. The treatment for her cancer, which reduced her immunity to very low levels, meant she was unable to attend school in 2010 except for very brief periods.

She had also had time off school in early 2011 and was just settling in again in term 2 when the first case of measles at Oratia was confirmed. The Roberts family were contacted by the school and Kelcey was immediately removed.

Tracey says her daughter finds it hard to fathom why other children aren’t protected against a disease that could be so dangerous for people like her. ‘Kelcey understands why she can’t go to school because of a low blood count or when she is unwell, but she was feeling great and she couldn’t go because so many pupils at the school hadn’t been immunised.’

Kelcey was away from school for five weeks during the measles outbreak and when she went back she was restricted to only going to her class because of the increased risk of mixing with unimmunised children in other classes.

‘Richard Hoskins [the local Medical Officer of Health] called us every Wednesday to give us an update on the measles outbreak. That way we knew when it was safer for Kelcey to go back to school,’ Tracey says.

‘Every time I take Kelcey out of the house, it’s a risk – we cannot go the mall, McDonalds, the movies or places with lots of people. Measles can live on surfaces for two hours. There was a case in Auckland of a child, with measles who went to the movies, and there was a risk they could have spread it to other children.’

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Unimmunised children a threat to Shauna

Kerry and Niall Manning had just spent four weeks taking their lively four-year-old daughter to meet family from Ireland in Europe when they received the news that rocked their world.

Shauna, their only child, had been diagnosed with acute lymphoblastic leukaemia. ‘We had just got back and were actually moving [house] when we got the call from Starship. It was an awful fright. We just put down the boxes and our friends finished packing and moving for us,’ Kerry says.

Shauna has since had 13 months of cancer treatment and at the time of writing there was still 13 months to go. Because the chemotherapy has at times reduced her immunity to zero, she has not been able to start school. Family life is also complicated as Kerry’s mother, who lives in a flat behind the Manning home, has bronchiectasis and is often sick with infections, requiring her to wear a mask or keep her distance from Shauna.

While even a cold could make Shauna very unwell, this year’s Auckland measles outbreak has made the prospect of sending the five-year-old to school too dangerous for Kerry and Niall.

‘Measles has been a real worry,’ Kerry says. ‘We can send a letter to all the parents of children in the class asking them to let the school know if their child is sick but with the measles outbreak at the moment we are not prepared to take the risk that she could be exposed.’

‘We have cancelled so many outings because people have been in contact with chicken pox or measles that we don’t tell Shauna if we are planning to go somewhere to stop her from being disappointed if we have to call it off.’
‘Even when she does get to school she won’t be able to take part in all school activities like swimming or travelling on a bus because of the risk of infection. I thought schools wouldn’t let children start unless they were immunised but it’s just not the case.’

Some ordinary activities such as visiting the supermarket and going to the movies with other children are also off the agenda for Shauna because of the risk of infection. ‘One of us has to stay home while the other gets the groceries and we take her to the movies when everyone else is at school,’ Kerry says.

‘We have cancelled so many outings because people have been in contact with chicken pox or measles that we don’t tell Shauna if we are planning to go somewhere to stop her from being disappointed if we have to call it off.’

Thankfully the Mannings have friends and family that understand Shauna’s condition and Shauna has friends that come to play with her regularly. Her best friends Dylan and Meg are like members of the family and she even goes for sleepovers there. We have also bought her a puppy that we take to the park,’ Kerry says.

The Mannings say they have got through one year and know they will get through another if they can keep Shauna away from any unwanted bugs. ‘She’s a strong wee girl. We’ve only had two extra stays in hospital. That is not a lot compared to other families we have met through clinic. The care that Shauna receives at Starship is fantastic but we really don’t want to see them unless it’s a clinic day.’

Tracey says, even though the rest of their school community knows about Kelcey, she doesn’t think they understand how dangerous measles would be for her. ‘Because she looks quite well, people might think she is out of danger but if Kelcey got measles she could die.

‘When I had Kelcey immunised as a preschooler, I did it to protect her and for the greater good. We need the majority of our population immunised to make it safer and healthier for everyone. I thought about the elderly and newborn babies but it wasn’t on my radar to think about kids with cancer.

‘I know that people who choose not to immunise their children have their reasons and those reasons centre around doing the best thing for their child. I get that. The problem is that there are people in our community who do not have the luxury to choose whether to immunise or not. Kelcey cannot be immunised for anything because of her treatment, yet prior to her diagnosis she was fully immunised.’

Kelcey is one of two children in the Roberts family. Her Mum, Dad and seven-year-old brother Maclain have all been immunised. Kelcey’s immunisations no longer work because of the impact of chemotherapy on her immune system.

Although Kelcey hasn’t been able to go to school for much of this year she has taken part in Camp Quality for kids living with cancer and loves emailing and skyping her friends.
Social isolation takes its toll on three-year-old

After seeing the effect of chicken pox on their immune-compromised son, James and Karen Alden have been terrified by the recent Auckland measles outbreak.

Cooper (now three-and-a-half years old) was diagnosed with acute lymphoblastic leukaemia when he was 20 months old. He started chemotherapy on the day he was diagnosed and will finish just before his fifth birthday.

At the moment his treatment includes daily chemotherapy tablets, intravenous chemotherapy and steroid courses monthly, intrathecal chemotherapy into his spinal fluid every three months and a trip to hospital for intravenous antibiotics whenever he has a fever and very low neutrophils (white cells that fight bacterial infections).

While Cooper’s immunisations were up to date before he became sick, his immune system now doesn’t recognise that he has been vaccinated.

‘The chemotherapy that is killing off the cancer cells in his bone marrow has also wiped out his immune system’s memory and he has about a quarter of the immunity of a healthy child,’ Karen says.

‘What’s left is enough to deal with coughs, colds and run-of-the-mill bugs but unfortunately he came across someone with chicken pox and his system couldn’t cope with it on its own,’ she says.

For six months, Karen says Cooper would have a new bout of chicken pox every 28 days. ‘He would have a rash and runny nose for about five days. His system would forget he had had it when his steroids started again and it would come back.’

While he was given immunoglobulin to help fight the illness and it eventually passed, Karen was told ‘It made James and I feel physically sick. The worry is hard to describe but you cannot get used to the fear of losing your child.’
measles is much harder to treat. ‘The only thing we can do to protect him is to keep him away from children that haven’t been immunised.’

At three-and-a-half Cooper is ready to start Kindy but won’t be able to go unless all of the children in his session have been immunised. Until now he has played mainly with his cousins, his six-year-old sister Mikayla and 16-month-old baby sister Hollie who are up to date with their immunisations, including chicken pox.

‘Any play dates are well checked and we keep him away from crowded places like shopping malls. Sadly it’s a case of lots and lots of isolation,’ Karen says.

‘People take it seriously if they know us but for a lot of people it seems ignorance [about the impact of measles on immune-compromised children] is bliss,’ she says.

After this story was written, it was thought Cooper had come in contact with measles and he was treated with immunoglobulin. Karen Alden says, ‘It made James and I feel physically sick. The worry is hard to describe but you cannot get used to the fear of losing your child.

‘It [his possible connection with measles] has shown us how hard it is to keep him safe from this threat. No child wears a note to say they are vaccinated, and measles can live on a surface for two hours.’

The Aldens were also worried that Cooper’s isolation was beginning to affect his social development and he was reflecting their worries about young children he didn’t know.

New Zealanders underestimate measles

South African trained paediatric oncologist Dr Rob Corbett has sadly seen first hand what measles can do to children with low immunity and worries about the children under his care when measles is circulating in the community.

‘The effect of measles on people who are immune compromised is truly horrible,’ he says. ‘Like children receiving cancer treatment, people who are severely malnourished are very vulnerable and I have seen numerous children die [in South Africa] because of the virus.’

In otherwise well children, measles doesn’t invade the body organs but in immune compromised children the virus gains access to the lungs and they often die from progressive pneumonia or it can attack the brain.

Dr Corbett, who is Clinical Director of Paediatric Oncology for the South Island Child Cancer Service says measles is an incredibly serious illness, which is under recognised in New Zealand.

‘People in developing countries have a very different perspective on it. I do a lot of work in the Pacific Islands and we don’t see any reluctance there to protect children from diseases that you can be immunised against. Here, there is some sort of misplaced belief that immunisation is harmful, when it has done so much good for the world’s children.’
At 16 years of age, Leroy Beckett has learnt something that takes many more years for most people to discover. He knows he isn’t bullet proof.

In Easter 2009 Leroy almost died as a result of undiagnosed acute lymphoblastic lymphoma. He is now midway through three and a half years of cancer treatment, which has reduced his ability to fight off everyday illnesses to almost zero. More serious illnesses like measles are lifethreatening for him.

Leroy’s mother Sue says that while she encourages her son to lead a normal life, the recent Auckland measles outbreak has been terrifying. ‘People just don’t take measles seriously or they would immunise against it. They don’t think it is as awful as it is and don’t understand what it can do to people with low immunity,’ she says.

‘Leroy is responsible about his health but most of the time he is just a normal 16-year-old kid who likes to do normal teenage things. It would be so much better if everyone in the population had been vaccinated and we didn’t have this to fear.’

To help protect himself from getting sick Leroy goes to the movies and shopping malls at times when there are few people there, avoids being near young children, uses hand sanitiser regularly and drives himself to school to avoid prolonged contact with others on the school bus. He also has the same food restrictions as pregnant women and has intravenous antibiotics every month to guard against pneumocytis pneumonia – caused by a common yeast organism that Leroy has been told could be more harmful to him than lymphoma.

‘You could get really paranoid about an illness like measles getting you because it could happen anytime but I don’t want to live my life like that,’ Leroy says.

Aside from one week, Leroy has continued going to school throughout the measles outbreak but the school nurse has been asked to alert the family immediately if a case is identified at his school.

‘I have checked that all my friends have been vaccinated and all of our family has been so I have a bit of a buffer around me. At any family dos, it’s the rule that there are no kids that
have been sick and I’m lucky that there is just Tyson [his 21-year-old sister] and me in the family,’ he says. ‘I definitely want to encourage people that it is a good idea to get their kids immunised but I’m rather biased because I don’t want to die. I don’t see any negatives to it as far as pros versus cons: there is no question for me.’

Sue says the need for people to immunise their two-year-olds could seem very removed from protecting young people like Leroy but it is a reality. ‘If people haven’t had their children immunised or been immunised themselves they can do it at anytime to help look after people who can’t be [immunised],’ she says.

After writing this story: One of Leroy’s classmates became sick with measles and Leroy was confined to home, missing the last few weeks of school before his end-of-year exams. He did however, much to his delight, manage to attend the first All Blacks vs France World Cup match wearing a mask.

Measles outbreak increases families’ fears

Starship Hospital paediatric oncologist Scott Macfarlane says the 2011 measles outbreak has had a major impact on the lives of Auckland children with cancer and their parents.

‘Anxiety levels have increased enormously and there has been a major change in the level of confidence of families and children mixing in the community,’ he says.

‘At Starship we have grave concerns about these kids as they go about their daily lives. We are always concerned that they don’t come in contact with measles as internationally deaths from the disease are common amongst them,’ he says.

Dr Macfarlane said his greatest concern was for children who had finished intensive cancer treatment, were now on maintenance therapy and were spending more time in the community. ‘Their immunity is still low and they are spending much more time out and about with friends and their families.’

The disruption caused by the measles outbreak is also significant for parents of these children, who may have just returned to work and suddenly find the children can no longer go to school. ‘It has a high impact on their lives and anxiety levels.’