KNOW MENINGOCOCCAL

A PARENT’S GUIDE TO UNDERSTANDING MENINGOCOCCAL DISEASE:
facts and advice you need to know to help protect your child
“I can’t believe it’s been almost two years of being a mum to my precious baby girl, Kelsey Lee. I never knew the true depth of love until I saw her beautiful face, and she is truly mine and Michael’s life. My job as ‘mum’ feels like the most rewarding one yet.

Kelsey Lee spent her first few days of life in an incubator. I’ll never forget the fear, and sense of helplessness I felt in that first week, worrying what effects this may have on her future health and if she would be 100% ok. Thankfully, she’s since grown into a happy, healthy child, but I know so many other Australian families are not this lucky.

Now that I’m a mum, I understand the overwhelming need you have as a parent to protect your child, the strong desire to make sure they’re happy and healthy, but we cannot know everything. Meningococcal disease is devastating, but so many parents, including me until recently, don’t know how serious it can really be. I’ve had the opportunity to meet with families affected by meningococcal to gain a better understanding of this rare yet horrible disease. It is with this compassion that I hope to help every parent in their child’s health journey, by supporting meningococcal disease awareness through KnowMeningococcal.

Because of KnowMeningococcal, I now know there is more than one strain of meningococcal and I now know that routine childhood vaccinations don’t protect against every type of meningococcal disease.”

With love,

Kathy Clarke

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**KNOW THE FACTS**

**WHAT IS MENINGOCOCCAL?**

Meningococcal disease is a bacterial infection of the blood and/or membranes that line the spinal cord and brain. While rare, the disease is potentially life-threatening.

Meningococcal disease can lead to death within 24 hours if not recognised quickly and treated in time.

Most children survive meningococcal, but once parents know about it, it’s unlikely they will want to take the risk.

Up to one in ten of those infected with meningococcal disease may die, and around one in five will suffer from serious long-term disabilities, including brain damage, deafness, and limb loss.

Globally, there are 13 different strains of meningococcal bacteria, of which, there are six main strains that most commonly cause disease (A, B, C, W, X & Y). In the early 2000s, meningococcal C was the second most common strain in Australia. The inclusion of a vaccine against the C strain on the government funded program led to a drastic reduction in cases. However, there are other strains that can cause meningococcal disease that are not currently included as part of routine childhood vaccination. In Australia, strains B, W and Y currently cause the majority of meningococcal cases.

In 2016, reported cases of meningococcal disease in Australia were caused by:

- **Strain B**: 35%
- **Strain W**: 42%
- **Strain Y**: 16%
- **Other**: 6%
“Riley was one when he went into hospital. He spent his second birthday unconscious.

It was the day before Mother’s Day, Riley woke up vomiting and had a temperature - symptoms I thought were typical of a one year old getting sick. Riley’s dad took him to the local hospital and the doctors there asked us to take Riley to the hospital in Adelaide, just for precaution. I knew something was seriously wrong during the drive from Ardrossan to Adelaide. As more time passed, Riley continued to get worse and worse. He could hardly move a muscle. I just thought, this isn’t right, this isn’t the Riley I know, the boy he’s grown up to be. No matter how sick he gets normally, he’s usually the happiest, bubbliest little boy. He’s never looked at me before and wanted to go back to sleep.

Riley didn’t have any rash at all when he went to the hospital in Ardrossan that morning, but not long after we’d hit Adelaide, he was covered in a head to toe purple rash – a sign, I now know, means the disease was very advanced in his small body.

The doctors took one look at him and he was quickly rushed out the back, where he was sedated, put on a breathing tube and pumped full of antibiotics. Once he was stabilised, that’s when we were told it was meningococcal.

Riley surprised everyone with how strong he was and how hard he fought for his life – and he did. He won his battle against meningococcal, but not without sacrifices. Both of Riley’s hands and legs have now been amputated, he may be a little different in his physical appearance, but he’s still Riley, he’s still my little boy.

I hope by sharing my family’s story, I can help build greater awareness around meningococcal and help other families, even if it’s just one family, not go through what we’ve been through.”
WHEN IT COMES TO MENINGOCOCCAL DISEASE, DON'T ASSUME YOU KNOW.

Meningococcal C has been successfully controlled through the government immunisation program, but nearly one in two Australian parents (46%) incorrectly believe that all strains of meningococcal are covered by routine childhood vaccination.

96% of parents understand meningococcal disease is life-threatening.

Nearly a quarter (24%) of parents do not know there is more than one strain causing meningococcal disease in Australia.

Almost half (43%) of parents with a young child rely on their doctor for information about vaccinations – yet over a third (36%) had no idea if additional vaccination to those provided by the government were available for their child or not.

Information derived from an online questionnaire of 1,000 parents with children under the age of four, conducted by Ipsos on behalf of GSK on 5-12 May 2017. The purpose of the questionnaire was to collect information on Australian parents’ habits and perceptions on vaccinations, meningococcal disease and general child health concerns.

KNOW THE FACTS

DIFFERENT FORMS OF MENINGOCOCCAL DISEASE

Meningococcal disease can appear in different forms, depending on which part of the body the bacterial infection occurs. Septicaemia and meningitis are the most common outcomes of meningococcal infection (see below). It’s also possible to contract a combination of both forms.

Meningococcal septicaemia (affecting the blood)

Septicaemia is the medical term for blood poisoning. Very serious cases of septicaemia can result in scarring or amputation of affected limbs, fingers or toes. The disease can also cause blood clots within vital organs, leading to life-threatening organ failure.

Meningococcal meningitis (affecting the brain and spinal cord)

Meningitis is an inflammation (swelling) of the protective membranes covering the brain and spinal cord. In serious cases, meningococcal meningitis injures or destroys nerve cells and causes brain damage.

HOW IS IT SPREAD?

Meningococcal bacteria can be spread through sneezing and coughing, close contact and activities such as sharing food and drink.

WHO’S AT RISK?

While the meningococcal bacteria can infect anyone – infants less than one year and children (under five) are most at risk, followed by adolescents.

During the early years of life, children have an undeveloped immune system, meaning they are more likely to pick up a strain of meningococcal they are not immunised against or don’t have any natural immunity to.

Babies and children up to the age of five accounted for 20% of meningococcal cases in Australia in 2016.

In fact, 20% of people will carry the bacteria at any one time, without ever becoming ill.

Meningococcal bacteria can live harmlessly in our throat and nose.
“When Jenna got unwell, we really didn’t think much of it at first. After her bath in the evening, she started to feel quite chilly and was feverish, but we thought it was just a flu that was coming on.

As the night progressed, she started to vomit and then had diarrhoea. I googled her symptoms but not knowing what meningococcal does or how it works, and thinking that Jenna had already had her vaccination against meningococcal and was protected, I didn’t look into it. The vomiting had stopped by this stage, so I thought she was over the worst of it.

In the morning, Jenna woke up and wanted some breakfast. I thought, I better just check and make sure there’s no rash - because I knew that was a sign of meningococcal. I wasn’t expecting to see a rash, so when I lifted up her top, it was a shock to see the purple, spotty rash over her tummy and back.

I called the ambulance and not long after we heard the sirens racing down our street. I remember the ambulance driver saying to me, “you do realise this could be meningococcal?” But I was in shock. They knew the seriousness of what it could be, but I didn’t. It was the total unknown for me.

In the hospital, they took us in to see her in intensive care and she didn’t even look like our child anymore. Her body was so swollen, the rash had gone from a few spots to just a purple rash covering her whole body.

I feel like I didn’t have a chance to be told about what meningococcal is, the early signs, and I wasn’t informed about vaccines before this happened to our family. This is what makes me so passionate to educate other people and make them aware of meningococcal disease.

We can’t be complacent and just think it’s never going to happen to us. If there is one thing I want people to take away from hearing our story, it’s to just appreciate what you have, and try and do your best to protect your family.

We just take each day as it comes. It’s hard and it will be a long road ahead for Jenna, but we just take one step at a time.”
Symptoms of meningococcal disease can be difficult to recognise, and can easily be mistaken for a common cold or virus. Common symptoms of meningococcal amongst babies and young children may include:

- **High fever**
- **Refusal to eat**
- **Difficulty waking or extreme tiredness**
- **High-pitched, moaning cry**
- **Vomiting**
- **Pale, grey or blotchy skin**
- **Sensitivity to light**
- **Cold hands and feet**
- **A bulging fontanelle (soft spot on top of the head)**

**KNOW THE SIGNS & SYMPTOMS**

**MENINGOCOCCAL RASH**

The meningococcal rash is an advanced symptom of meningococcal septicaemia (blood poisoning). The rash may start with a simple spot or blister, which may quickly progress to red pinpricks like small mosquito bites, and/or spread rapidly into purple like blotches. The rash is non-blanching, meaning that it does not fade when you apply pressure to the skin (for example by pressing a clear drinking glass against the skin).

It’s important that you don’t wait for the purple rash to appear. If you suspect your child may be suffering from meningococcal, or if you’re concerned about your child’s health, seek medical attention immediately.

**WHAT I WANT PARENTS TO KNOW**

"Meningococcal disease is rare, but it can be such a devastating disease that it’s something we need to think about in any sick child. What’s tricky is that it’s so difficult to detect. A child can begin with what seems like a common cold, but can rapidly progress to being critically unwell. It’s often not until a child develops more significant signs of meningococcal disease that it becomes more obvious. And unfortunately, by then, it’s sometimes too late to prevent the severe consequences."

If a child has a fever and rash, parents should take him or her to the doctor. But they should also ask their doctor about meningococcal vaccination. The most common strains of meningococcal disease can be prevented by vaccination.

"The routine immunisations can protect against one strain and there are other meningococcal vaccines available that can protect against more strains. Meningococcal disease can be extremely difficult to spot – even for doctors. And it’s potentially preventable. This is why I’m supporting KnowMeningococcal, so we can all know more and do more to stop this devastating disease."

Prof Mike Starr
Paediatrician, Infectious Diseases Physician, Consultant in Emergency Medicine, The Royal Children's Hospital, Melbourne.
"When the doctor first told me that he suspected Jazzy had meningococcal, I wasn’t too concerned because I presumed Jazzy was covered. I said, she’s covered, she’s up to date with her vaccinations, she can’t get it bad. It was a huge shock when we found out there were other strains of meningococcal. I was baffled, why weren’t we told about the other vaccinations? Why didn’t we know? Time matters when it comes to meningococcal. In Jazzy’s case, it was caught very early, which means it was diagnosed very early and they could start treatment quicker. Jazzy survived without amputation but she does have neurological nerve damage. She is in pain every day with her legs and we’ve been doing more tests to try and find out why she’s in so much pain – but the outcome could have been far worse. We’re so lucky with Jazzy’s outcome and I kind of feel like because of that, it’s my job to let other families know about meningococcal disease. My advice to other parents is speak to your doctor and find out as much information about meningococcal as you can. If you’re not happy with the information you’re receiving, go see someone else. Try to find as much information as possible. I hope our story can help other families. Parents need to know that just because their child has had all of their routine vaccinations, it doesn’t necessarily mean they’re protected."

KnowMeningococcal before it’s too late. Get the information you need to help protect your child – visit www.knowmeningococcal.com.au
TREATMENT & PREVENTION

TREATMENT

Early recognition and treatment of meningococcal offers the best chance of recovery.

As a parent, no one knows your child better than you do. If you’re concerned about your child’s health, monitor for signs and symptoms, and always seek advice from a healthcare professional if your child’s condition continues or gets worse.

PREVENTION

While practicing good hygiene can help to protect against the spread of germs, vaccination is the only truly effective way to help prevent meningococcal disease.

But did you know that even with their routine vaccinations, your child may still be at risk from common strains of meningococcal?

There’s no single vaccine that protects against all types of meningococcal disease.

There are now vaccines available for the five most common strains of the disease in Australia (A, B, C, W & Y), however not all of these strains are immunised against on the National Immunisation Program.

Children who receive their routine vaccinations in Australia are protected against one type of meningococcal disease (meningococcal C) and can still be susceptible to other types.

Make an informed decision when it comes to meningococcal disease. Speak to your doctor about your child’s options for meningococcal vaccination.
References:
1. WHO Meningococcal Fact Sheet. www.who.int/mediacentre/factsheets/fs141/en/
3. Lahra and Enriquez, CDI 2016; 40(2): E221-228