Meningococcal disease is terrifying because of the incredible speed with which it can kill or maim, and the difficulty of early diagnosis, even by experienced doctors. Stephen, Paige and Amanda all died of meningococcal septicaemia – which was not diagnosed until it was too late.

It was October 1997. Amanda had just returned from a Rowing Regatta in NSW, where one of the other rowers had contracted meningococcal disease. Back in Perth, she spent her Saturday rowing in the State Championships. That evening she complained of a headache and pain in her thigh. She also had cold hands and feet and a fever. After vomiting, she was taken to a hospital where a test confirmed she did not have meningitis. The next morning she had severe diarrhoea and a rash. She died from septicaemia at 5pm.

Paige was about a month short of her third birthday when she became ill with a fever and dept the whole afternoon. Her parents put it down to a virus. Later that night Paige complained of very sore legs, and her mother noticed bruise-like spots. Alarmed, she took Paige to the doctor, but was reassured that it was just "a respiratory virus". Back home, her condition rapidly deteriorated and the bruising spread. Her parents rushed her to hospital – but she died at 3am.

Stephen was perfectly well at school that day, and full of energy when he arrived home. Later he put on a jumper and said he was cold. In fact, he was very hot. That evening his parents took him to the hospital with fever, rapid breathing and severe pain in his joints and chest – they thought he was having a heart attack. He was diagnosed with "gastro-enteritis and flu symptoms". He deteriorated during the night and at 4am his parents rushed him back to the hospital – but he died at 8.40 am.

If your doctor reassures you that it is not meningococcal disease, but it gets worse or you have a gut feeling it’s serious, don’t be afraid to go back, persist, or get an urgent second opinion.

FIGHTING MENINGOCOCCAL DISEASE
A practical guide for parents, teachers, students and health care professionals.  (14 mins)
This award-winning programme tells you everything you need to know about symptoms, risk factors, precautions & vaccination.

FIVE MINUTES TO SAVE A LIFE (5 mins)
Just take 5 minutes from your day to pick up some life-saving tips on how to recognise this disease and what to do. To view, click on ‘Meningococcal Disease’: www.amandayoungfoundation.org.au

EARLY DETECTION & TREATMENT SAVES LIVES
Help us to spread the word. Caitlin, Suzie and Peter are amongst those who contracted the disease, but sought help in time to be treated successfully – thanks to awareness of the disease and its symptoms, and perseverance in seeking urgent medical assistance.

MANAGING MENINGOCOCCAL DISEASE
A valuable guide for doctors, paramedics, nurses and other health professionals.  (24 mins)
Includes many case studies and advice from top Australian experts.

MANAGING MENINGOCOCCAL DISEASE
A practical guide for parents, teachers, students and health care professionals. (44 mins)
Increasing awareness about meningococcal disease in the community
Develop leadership in the community through the Youth Leadership Program
Provide funding for relevant medical research projects
Provide support for survivors of the disease
The Foundation welcomes your support.

The following award-winning Australian-produced programs are available on DVD, and are consistent with the meningococcal disease guidelines set down by the Federal Government.

The Amanda Young Foundation was formed in March 1998 after the tragic death of Amanda from meningococcal septicaemia at the tender age of 18 years.

The Foundation aims to:

• increase awareness about meningococcal disease in the community
• develop leadership in the community through the Youth Leadership Program
• provide funding for relevant medical research projects
• provide support for survivors of the disease

The Foundation welcomes your support.

For more information/previews: www.meningococcal.org
TO ORDER: Either contact The Amanda Young Foundation info@amandayoungfoundation.org.au
TO ORDER:  Call or email The Amanda Young Foundation
TO PREVIEW: Go to: www.mediaone.com.au

This brochure was written, designed and produced as a public service by Meningococcal Education, a division of Media One – health & video communications specialists – in conjunction with this Foundation.
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What is meningococcal disease?

Meningococcal disease is an acute bacterial infection that can cause death within hours if not recognised and treated in time. In Australia it’s classed as a rare disease, affecting approximately 700 people each year. Although the majority will recover fully, 5-10% die, and around 20% will have permanent disabilities, ranging from sight and hearing problems, learning difficulties or depressions to scars from skin damage and loss of fingers, toes or limbs.

Meningococcal disease actually encompasses two different illnesses caused by the meningococcal bacteria: meningitis and septicaemia. Meningococcal disease may take the form of one – or both – of these.

- **Meningococcal meningitis** (bacterial meningitis)
  - Meningitis is inflammation of the lining of the brain and spinal cord (the ‘meninges’). There are many different types of meningitis – including fungal, viral and bacterial. The bacterial ones, such as meningococcal meningitis, are the most serious. This illness can result in permanent disabilities – such as deafness or brain damage – and even death.
  - Symptoms may include a severe headache, fever, fatigue, stiff or painful neck, sensitivity to light or convulsions.

- **Meningococcal septicaemia** (blood poisoning)
  - This is the more dangerous and deadly of the two illnesses. It happens when the bacteria enter the bloodstream and multiply uncontrollably, damaging the walls of the blood vessels and causing bleeding into the skin. Septicaemia can lead to death within hours, or permanent disabilities such as scars and limb loss. Early symptoms often include cold hands and feet, severe aches or pain in the legs and abnormal skin colouration, and possibly fatigue, fever or vomiting. The characteristic pinprick or purple rash does not usually appear until much later.

Meningococcal bacteria live naturally in the throat and back of nose. About 10-20% of people will be carrying them at any one time without ever becoming ill (“healthy carriers”). There are many different strains of meningococcus: the most common in Australia are B and C. The bacteria may be spread in saliva – via activities such as sneezing, coughing or kissing, and perhaps shared food or drinks. Places where people are in close contact, such as day-care centres, school camps, parties and nightclubs, make it easier for the bacteria to spread.

But even if you pick up the bacteria, it doesn’t mean you’ll become ill. The danger only occurs if you pick up a strain you’re not immunised against, or don’t have any natural immunity to – or your immune system is too strong for whatever reason and cannot cope.

Risk factors

- babies and children up to the age of 5 years are more at risk due to their less mature immune system and reduced hygiene awareness.
- teenagers and young adults from 15 to 25 years are also more at risk, in part because of the social lifestyle they lead.
- multiple ‘intimate kissing’ partners heightens the risk of exposure.
- exposure to smokers – who are more likely both to carry the bacteria, and to spread it by coughing.
- a recent viral infection. Winter/early spring are higher risk times.

Cautionary measures include not sharing:

- food, dips, beverages – drinks, bottles, straws
- lipstick or lip gloss
- toothbrushes
- mouthguards, cigarettes
- musical instruments with mouth pieces

*Note there is no firm evidence to show these measures are effective.*

Vaccination

The vaccine for C-strain introduced in Australia in 2003 has been very effective, and the incidence of C-disease is now very uncommon. In 2014 a vaccine was licensed for the equally deadly B-strain, and effective, and the incidence of C-disease is now very uncommon.

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Additional symptoms may include:

- being floppy or lethargic: aching of the body or neck
- tense or bulging fontanelle (the soft spot on baby’s head)

In babies:

- Baby Dylan died of meningococcal disease, aged 3 months.

- If someone becomes ill, it’s important to monitor them carefully for any early signs of a rash as it can easily be missed or mistaken for something else. The septicaemic rash usually does not fade (like a harmless rash does) if pressed with a thumb or clear glass.
  - *However this test is not always reliable, especially in the early stages.* If a distinctive rash appears, immediate medical treatment is vital.

The rash, which usually appears in the final stages of septicaemia, is actually blood leaking from damaged blood vessels into the skin.

- It could start off just as a faint pink rash, as a red or purple spot, blisters or blotch, or as pinpricks on the skin. In the final, critical stage, it spreads rapidly into purple bruises, or haemorrhages, which cover the body. The person can go into shock, their blood pressure falls and circulation fails in the body extremities – the fingers, toes and limbs.

Action to take

Recognising the disease in the early stages is critical, but can be very difficult, because it can easily be mistaken for common ailments such as gastroenteritis, the flu, a hangover or even muscle strain. Even experienced doctors can make mistakes in diagnosis – so it’s vital to closely monitor the patient and see your gut feelings to decide whether the illness is in any way different or progresses more rapidly than what you’d normally expect. Watch out for any sign of a rash.

If you suspect meningococcal disease, rush the patient to a doctor or hospital. Don’t wait for a rash to appear – it may not. Insist on seeing someone straight away, and clearly list all the symptoms. If it is meningococcal disease, antibiotics must be given as soon as possible.

The incubation period (time between picking up the strain and when the symptoms appear) is between 2-7 days. Anyone who’s had close contact (kissing contacts and those sleeping in the same house) with the patient in the 7 days prior to symptoms appearing should be treated with antibiotics to kill any bacteria in their throat and nose. They should still watch carefully for any signs of the disease.