Non-judgmental conversations with parents worried about vaccines side-effects

Nov 3rd, 2017

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UNSW
THE UNIVERSITY OF NEW SOUTH WALES

Multicentre NHMRC Centre of Research Excellence

Immunisation in Understudied & Special Risk Populations

- Closing the gap in knowledge through a multidisciplinary approach

- Stream
  - Aboriginal and Torres Strait Islander vaccination needs

kids research Institute the children's hospital at Westmead

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CIDM centre for infectious diseases & microbiology Public Health

Kirby Institute

THE UNIVERSITY OF SYDNEY

Immunisation Research

- Aboriginal Community Controlled Health Organisations
- Strengths-based research

Immunisation- the opportunity to prevent

Some immunisations ... for some diseases

A perspective on diseases

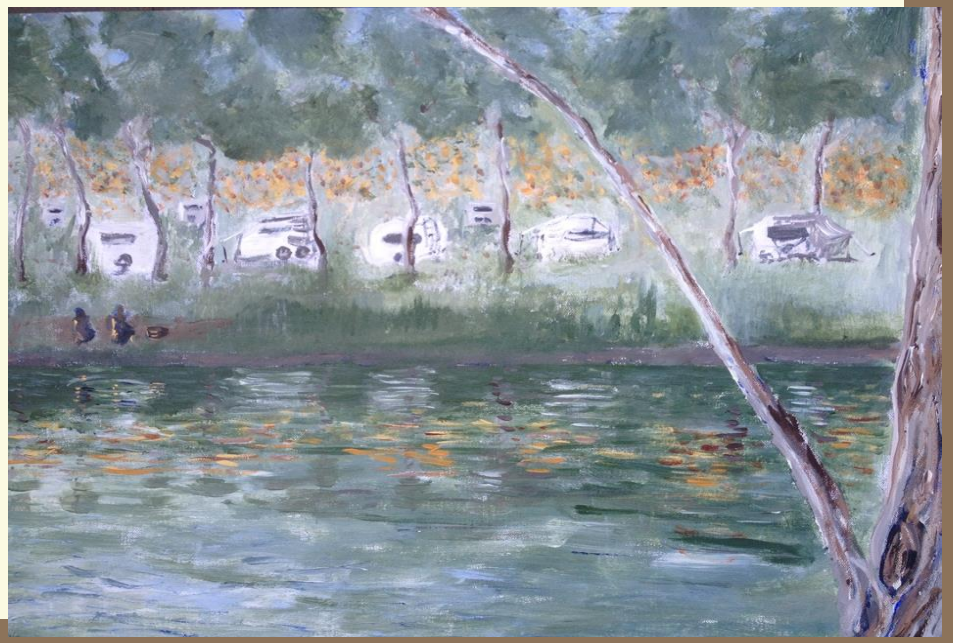
- Diseases can be very severe
- Limitations in treatment success

A perspective on vaccines

- The opportunity to prevent
- The risk of diseases outweighs the risk of vaccine side-effects

Respect

- It's OK for parents to worry about immunisation side-effects
- I have enormous respect for people with concerns about immunisation side-effects



Topics for today

- Understanding the challenges of communication
- Respectful, non-judgmental discussions
  - Active listening
  - Answering questions
  - Providing resources
- Understanding the knowledge gap
  - Diseases
  - Vaccines

Explaining to parents

- Diseases
  - The young immune system
  - Limitations in treatment
  - The relevance to their child
- Vaccines
  - How vaccines are made
  - Vaccine side-effects
  - Conjugate vaccines
  - Important imported diseases
  - Combination vaccines
  - Vaccine additives
  - Live vaccines
  - Options

Owning vaccine side-effects

- All medications have side-effects
  - Just like aspirin and paracetamol
- All immunisations have side-effects

Owning vaccine side-effects

- For each immunisation there is a list of
  - Common side-effects
  - Rare side-effects
- All side-effects are significant

Owning vaccine side-effects

- We weigh-up the risks and benefits

Consider this…

- Plane crash
- It is a valid worry
- Why don't' we demonstrate a respect for all people with worries about vaccine side-effects?
- Why do some people refer to them as
  - 'The worried well' ?

Vaccine Preventable Diseases

- Why do we immunise against…..
  - Tetanus
  - Diphtheria
  - Pertussis
  - Polio
  - Haemophilus influenza type B
  - Hepatitis B
  - Measles
  - Mumps
  - Rubella
  - Meningococcal C
  - Varicella
  - Influenza
  - HPV
  - Meningococcal W

Previously…

- Knowledge exchange about diseases
  - Neighbours
  - Family dinners
  - Newspapers
  - TV
  - Radio

Now…

- Knowledge transfer gap about diseases
  - What are these diseases?
  - How bad can they be?
  - Can we treat them?
  - How likely is it my child will get the disease?
- Knowledge exchange about vaccine side-effects

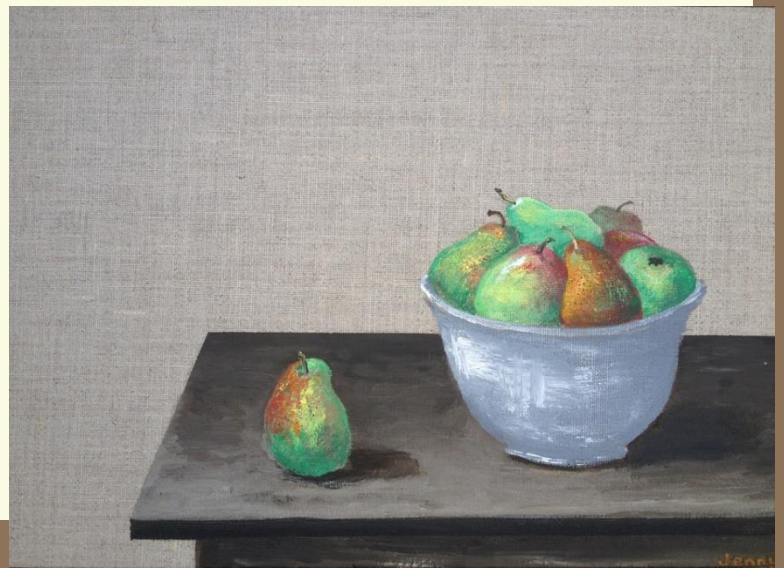
Now…

- Knowledge transfer gap about vaccines
  - How well do vaccines work?
  - Why are there so many at the one time?
  - Why are they given so young?
  - Why do we give vaccines for diseases we don't have in Australia?
  - Why do we give hep B vaccine at birth?
  - How do I know my baby wont have a rare major side-effect?

In addition…

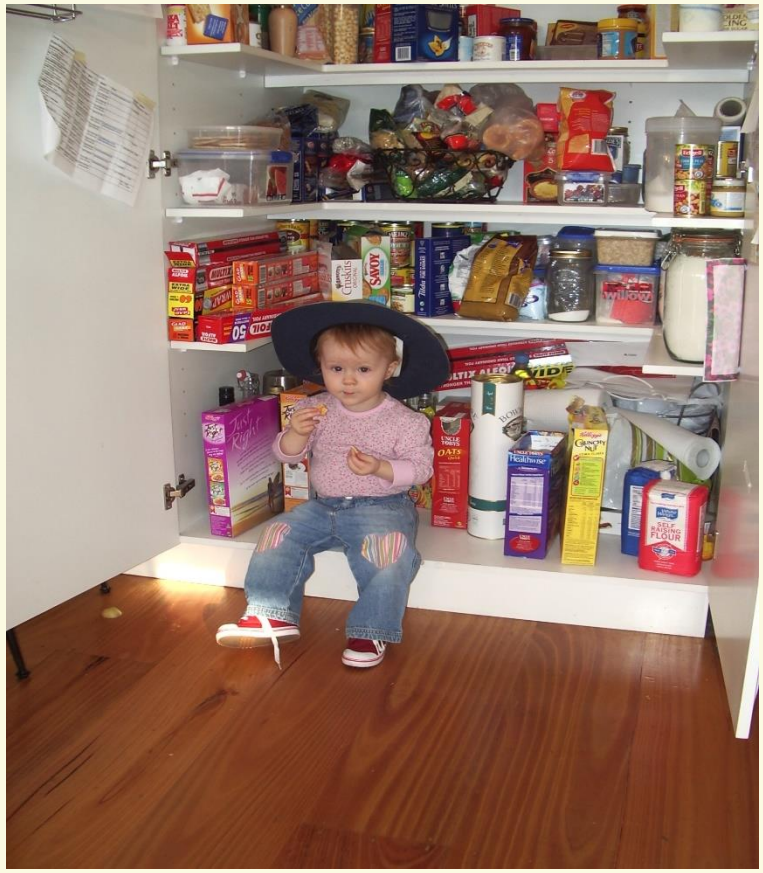
We are not all the same with our approach to medicine

- Background beliefs in medicine
- Experience with the health system
- Experience with vaccines



Public Health Promotion

- Educate about diseases
- Educate about vaccines
  - How well they work



Education

- Don't just answer the question
- Opportunistic immunisation education
- Share narratives

The M.A.P.- Mutually Agreed Plan

1. **Non-judgmental** approach
2. **Specific family concerns** considered
3. **Explanation-** don't just answer the questions
   - Local disease data
   - Acknowledge vaccine side-effects

A Patient at my 'NEST' Family Clinic Elsternwick

- Meet and greet
- Introduce myself

Michael - 7 weeks old

- Mum and grandmother

Michael - 7 weeks old

- Mum and grandmother
  - We are not anti-vaccine
  - We just have concerns about vaccine side-effects….

Before I start explaining... I ask

- What are their concerns about vaccine side-effects
  - …
  - …
  - …
  - …
  - …

Specific family concerns

- Why do we immunise against polio and diphtheria?
- The young immune system
- Combination vaccines
- Vaccine ingredients
- Vaccines and developmental conditions
- Vaccines 'not working very well'

Before I start explaining...

- I actively listen and respond to their person stories
- "That must be really difficult"
- "I can see you would be worried about that too"
- "Do you mind telling me a bit more about that"
- "I am really sorry to hear that"
- "That must have been awful"

Before I start explaining... I ask

- Where are they at?
  - (with giving these immunisations)

- Do the parents have the same opinion?

Individual family details, Michael (holistic medicine)

- Pregnancy
  - (pertussis vaccine history)
- Delivery
- Birth hep B vaccine
- Feeding / sleeping
- Coping / enjoying
- Infant development

I am so glad you came to talk with me…

I am so glad you came to talk with me…

- All medicines have side-effects
- All immunisations have side-effects

I am worried about Michael getting ...

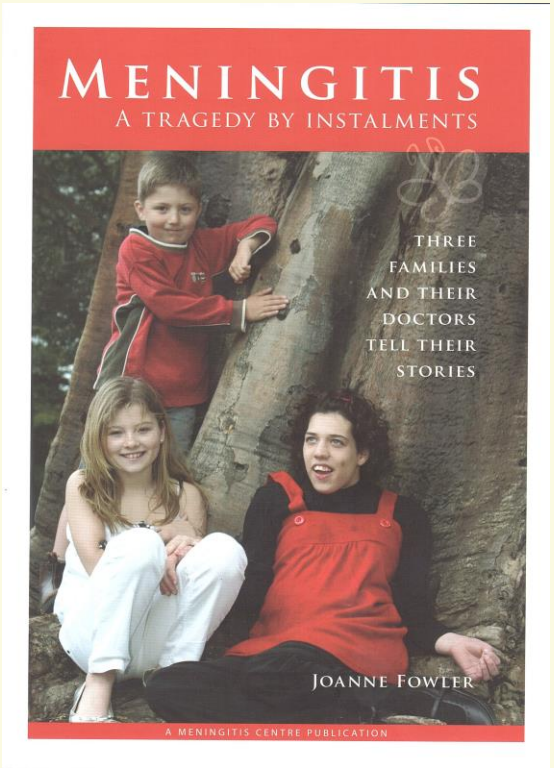
- Whooping cough (Pertussis)
- Meningitis

We make different vaccines for different reasons

- Whooping cough

We make different vaccines for different reasons

- Meningitis



We make different vaccines for different reasons

- Hepatitis B

We make different vaccines for different reasons

- Rotavirus

We make different vaccines for different reasons

1. **No treatment**
   - Pertussis, measles, mumps, rubella

2. **Treatment can't guarantee a good outcome**
   - Hib (Haemophilus Influenzae type B)
   - Pneumococcal
   - Meningococcal C (B, W…)
3. **To prevent cancer**
   - Hepatitis B
   - HPV

4. **To prevent the disease complications**
   - Rotavirus, chicken pox (varicella), influenza

Explain- How are vaccines made?

'Killed' tetanus (toxoid) + water + binder or stabilizer (vaccine components)

- How are vaccines made?
  - Tetanus
  - Diphtheria
  - Pertussis (whole-cell)
- The lists of potential side-effects

Explain- Vaccine symptoms (side-effects)

- Eg. D-T-Pw (Triple Antigen)®

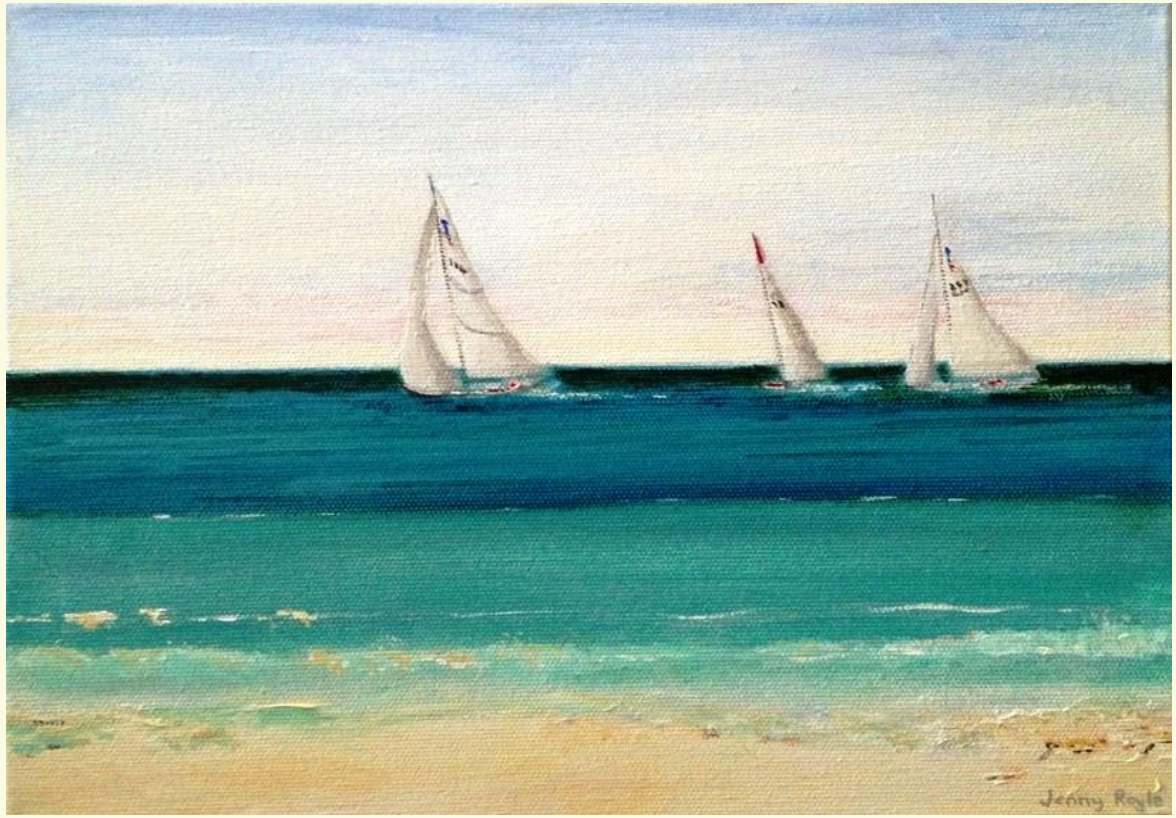
Minor 50%	Major 1/1000
Fever	Seizure (fit)
Rash	Hypotonic hyporesponsive episode
Local	Anaphylaxis (1/million)
Irritability	

Explain- Vaccine symptoms (side-effects)

	DTPw	DTPa
Minor	40 - 60%	2 - 5%
• Fever		
• Rash		
• Local		
• Irritability		
Major		
• Seizure	1/1000	1/20,000 - 50,000
• HHE	1/1000	1/20,000 - 50,000
• Anaphylaxis	1/million	1/million

Why do we immunise against polio and diphtheria?

- Important Imported Diseases



Explain- How are vaccines made?

'Killed' tetanus (toxoid) + water + binder or stabilizer **(vaccine components)**

'Killed' **Hib** + a piece of tetanus or diphtheria + water + binder or stabilizer **(vaccine components)**

Discussions about the young immune system

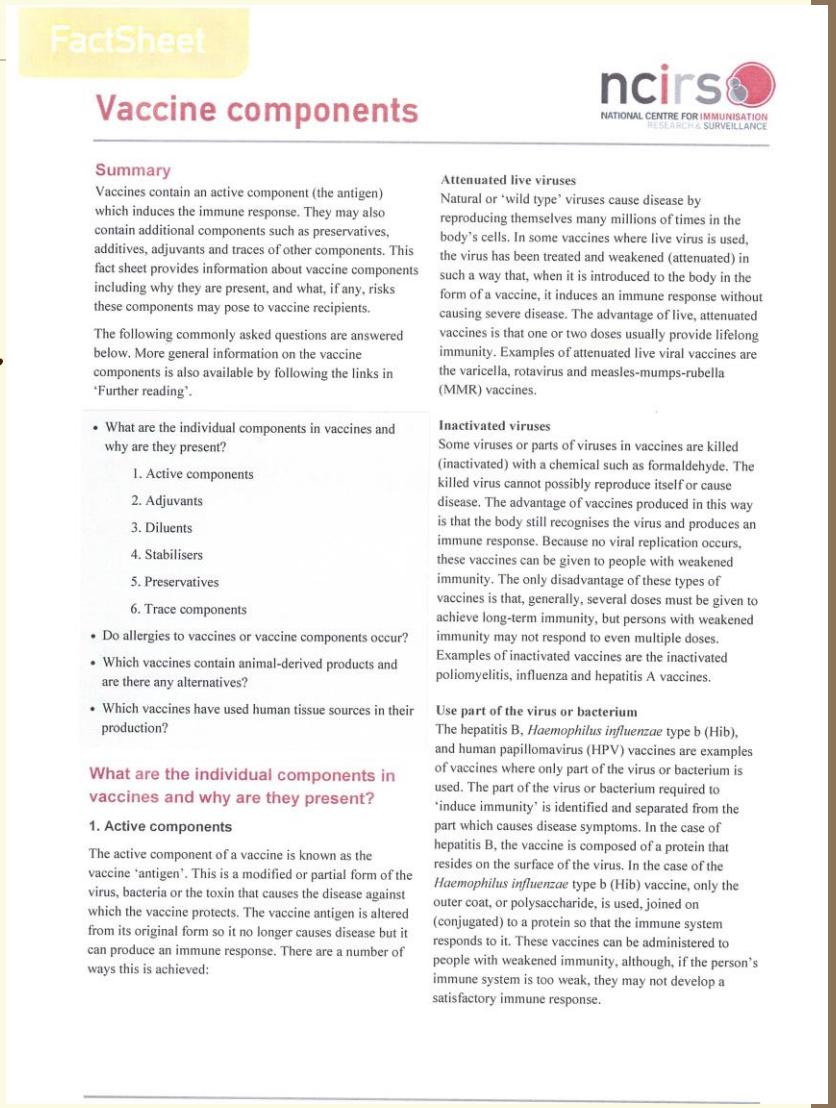
- My approach to this …
  - Explain diseases and the young immune system
  - Remember
    - We make different vaccines for different reasons

Discussions about combination vaccines

- My approach to this
  - Explain how combination vaccines are made
  - Explain the potential advantages of combination vaccines
  - This is what I have available (apologize for limitations, discuss options)

Discussions about vaccine components

- My approach to this…
  - Explain how the vaccines are made
  - This is what I have available
  - Provide resources



FactSheet

Vaccine components

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Summary

Vaccines contain an active component (the antigen) which induces the immune response. They may also contain additional components such as preservatives, additives, adjuvants and traces of other components. This fact sheet provides information about vaccine components including why they are present, and what, if any, risks these components may pose to vaccine recipients.

The following commonly asked questions are answered below. More general information on the vaccine components is also available by following the links in 'Further reading'.

- What are the individual components in vaccines and why are they present?
  1. Active components
  2. Adjuvants
  3. Diluents
  4. Stabilisers
  5. Preservatives
  6. Trace components
- Do allergies to vaccines or vaccine components occur?
- Which vaccines contain animal-derived products and are there any alternatives?
- Which vaccines have used human tissue sources in their production?

What are the individual components in vaccines and why are they present?

1. Active components

The active component of a vaccine is known as the vaccine 'antigen'. This is a modified or partial form of the virus, bacteria or the toxin that causes the disease against which the vaccine protects. The vaccine antigen is altered from its original form so it no longer causes disease but it can produce an immune response. There are a number of ways this is achieved:

Attenuated live viruses

Natural or 'wild type' viruses cause disease by reproducing themselves many millions of times in the body's cells. In some vaccines where live virus is used, the virus has been treated and weakened (attenuated) in such a way that, when it is introduced to the body in the form of a vaccine, it induces an immune response without causing severe disease. The advantage of live, attenuated vaccines is that one or two doses usually provide lifelong immunity. Examples of attenuated live viral vaccines are the varicella, rotavirus and measles-mumps-rubella (MMR) vaccines.

Inactivated viruses

Some viruses or parts of viruses in vaccines are killed (inactivated) with a chemical such as formaldehyde. The killed virus cannot possibly reproduce itself or cause disease. The advantage of vaccines produced in this way is that the body still recognises the virus and produces an immune response. Because no viral replication occurs, these vaccines can be given to people with weakened immunity. The only disadvantage of these types of vaccines is that, generally, several doses must be given to achieve long-term immunity, but persons with weakened immunity may not respond to even multiple doses. Examples of inactivated vaccines are the inactivated poliomyelitis, influenza and hepatitis A vaccines.

Use part of the virus or bacterium

The hepatitis B, *Haemophilus influenzae* type b (Hib), and human papillomavirus (HPV) vaccines are examples of vaccines where only part of the virus or bacterium is used. The part of the virus or bacterium required to 'induce immunity' is identified and separated from the part which causes disease symptoms. In the case of hepatitis B, the vaccine is composed of a protein that resides on the surface of the virus. In the case of the *Haemophilus influenzae* type b (Hib) vaccine, only the outer coat, or polysaccharide, is used, joined on (conjugated) to a protein so that the immune system responds to it. These vaccines can be administered to people with weakened immunity, although, if the person's immune system is too weak, they may not develop a satisfactory immune response.

Discussions about vaccines and developmental problems

- Why is this particular family concerned about developmental issues?
- My approach to this …
  - Explain
    - Developmental issues
      - What are they
      - There are a lot of unknowns
      - Rare regression
  - Acknowledge concerns about developmental issues and vaccines
  - Discuss
    - Live-attenuated vaccines

Owning MMR vaccine side-effects

- Draw a graph of the
  - Timing of symptoms after the live-attenuated MMR vaccine
- NCIRS Resources
  - Factsheet: 'MMR vaccine, inflammatory bowel disease and Autism'

The explanation …

- The level of worry about the vaccine doesn't need to be zero
- They can still feel a very real element of risk
  - Because
    - All medicines have side-effects
    - Just like aspirin and paracetamol

Discussions about vaccines 'not working very well'

- My approach to this …
  - Explain
    - The balance between the strength of the vaccine and minimising side-effects
    - Pertussis vaccine
      - Draw a graph of the immune response
    - Varicella vaccine

Discussions about vaccines 'not working very well'

- Pertussis
  - Minimising the chance of severe disease
  - The importance of the first dose
  - Immunise the baby on-time
  - Immunise the mother during the pregnancy

Discussions about vaccines 'not working very well'

- Varicella
  - Low-strength vaccine
    - "Your child can still catch mild chicken pox"
  - Advocate for 2-dose schedule

Helpful advice

1. Tetanus prone wounds

2. Meningitis
   - Present early with high fevers and unwell
   - Tell staff your child hasn't yet had any meningitis vaccines

3. Reducing the chance of pertussis
   - Seek medical advice if the child has a known contact

Additional vaccines to consider

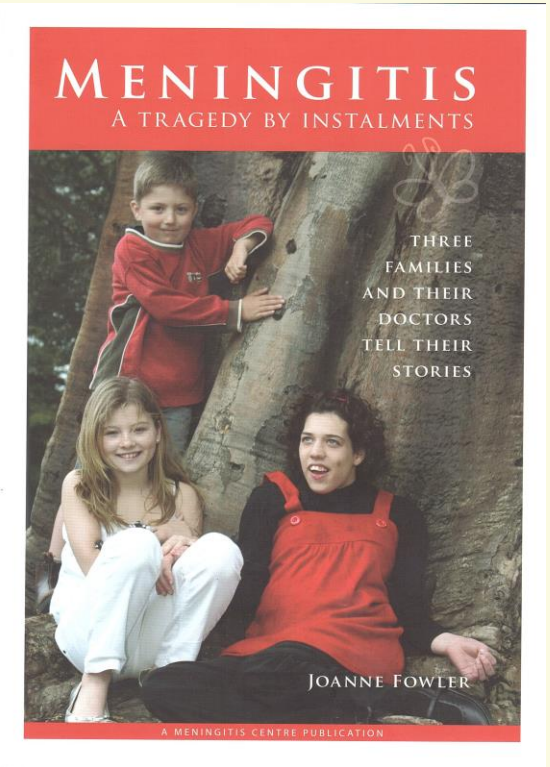
- Meningococcal
  - Men ACWY
  - Men B
    - Check number of doses required depending on the age
- Varicella
  - Second dose
- Influenza vaccine
  - From 6 months

Resources

- NCIRS website
  - National Centre of Immunisation Research & Surveillance
  - Fact sheets
    - Vaccine components
    - Rotavirus vaccine
    - MMR vaccine, inflammatory bowel disease and Autism
    - Others
- Myths and Realities handbook- 5th edition 2013
- Table: Effects of diseases and vaccines
  - 10th Edition Australian Immunisation Handbook
    - Inside back cover

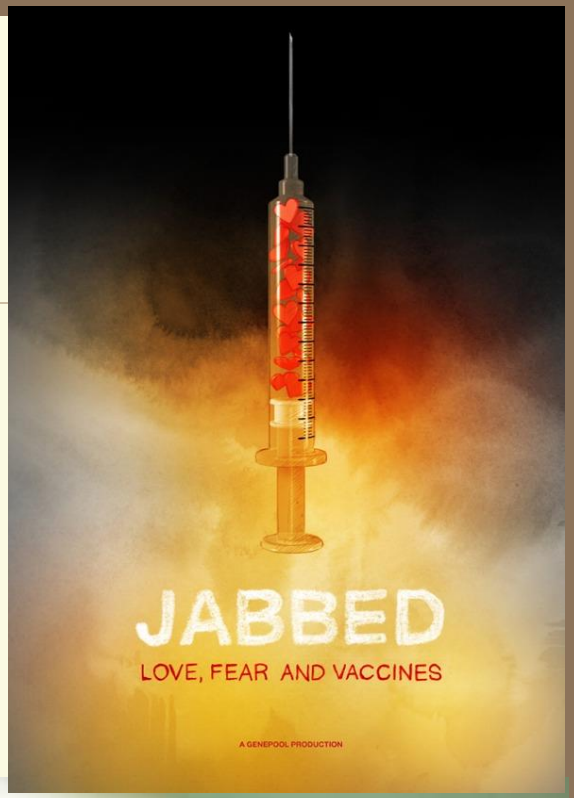
Resources on Meningococcal

- 'The Meningitis Centre'- *Every second counts*
  - Website- videos
  - Book
- Meningococcal resources
  - ATAGI MenB advice summary 2014
  - NCIRS
    - Meningococcal fact sheet
    - Meningococcal Q and A
      - up-dated Sept 2017
  - DHHS
    - Immune hero, FAQ fact sheet
    - Better Health Channel- website



'JABBED - Love, Fear and Vaccines'

- Science documentary
  - Available on line: 'SBS on demand'



Organise another appointment to discuss immunisations

- Maternal and Child Health Nurse
- Council Immunisation Clinic Staff
- Aboriginal Community Controlled Health Organisation staff
- Doctor
- GP Practise nurse

Acknowledgments

- Immunisation CRE, Sydney
  - Raina Macintyre, Telphia Joseph, Julie Leask and the Aboriginal stream team
- Research Advisors and co-investigators
  - Brendon Kelaher, Robert Menzies, Peter McIntyre, Amy Creigton, James ward, Kate Russo, Wendy Bissenger
- Research Community Advisory Group
- *'Learnmed' research grant*
  - On-line physician exam programs
- NEST Family Clinic
  - 289 Kooyong Rd, Elsternwick, 3185
  - Bronwyn Allen and staff
- City of Stonnington: Immunisation Team
- Yarra Ranges Council: Immunisation team
- Catherine and Greg Hughes
- Victoria Dept of Health and Human Services: Immunisation team