

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



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# 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



# Immunisation Research



- 📄 Aboriginal Community Controlled Health Organisations
- 📄 Strengths-based research



# Immunisation- the opportunity to prevent

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# Some immunisations ... for some diseases

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# A perspective on diseases

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- 📄 Diseases can be very severe
- 📄 Limitations in treatment success



# A perspective on vaccines

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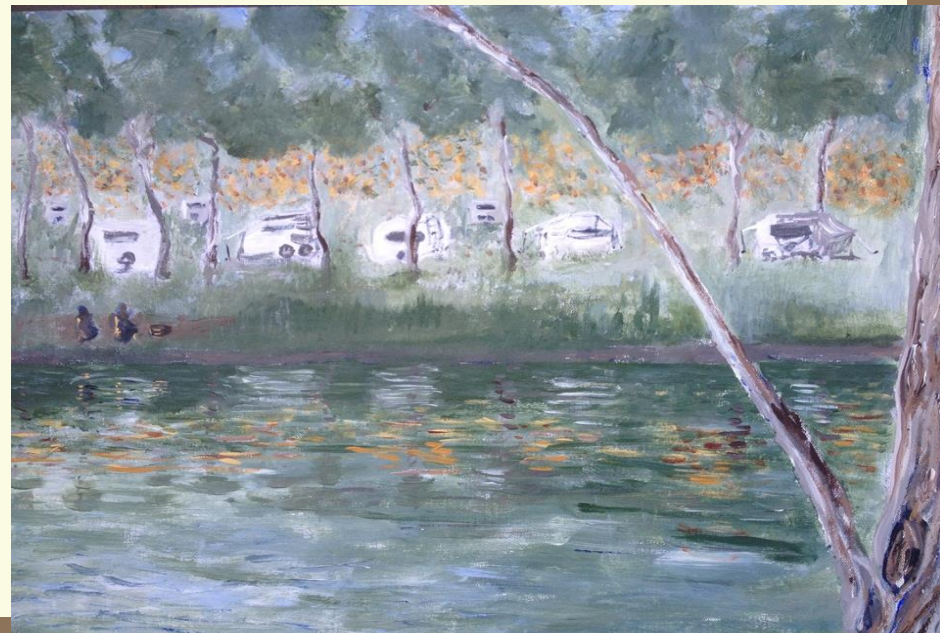
- 📄 The opportunity to prevent
- 📄 The risk of diseases outweighs the risk of vaccine side-effects



# Respect

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- 📄 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

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📄 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

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



# Owning vaccine side-effects

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📄 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...

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☰ 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...

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## Knowledge exchange about diseases

- Neighbours
- Family dinners
- Newspapers
- TV
- Radio





# Now...

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## 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...

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## 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 won't have a rare major side-effect?

## In addition...

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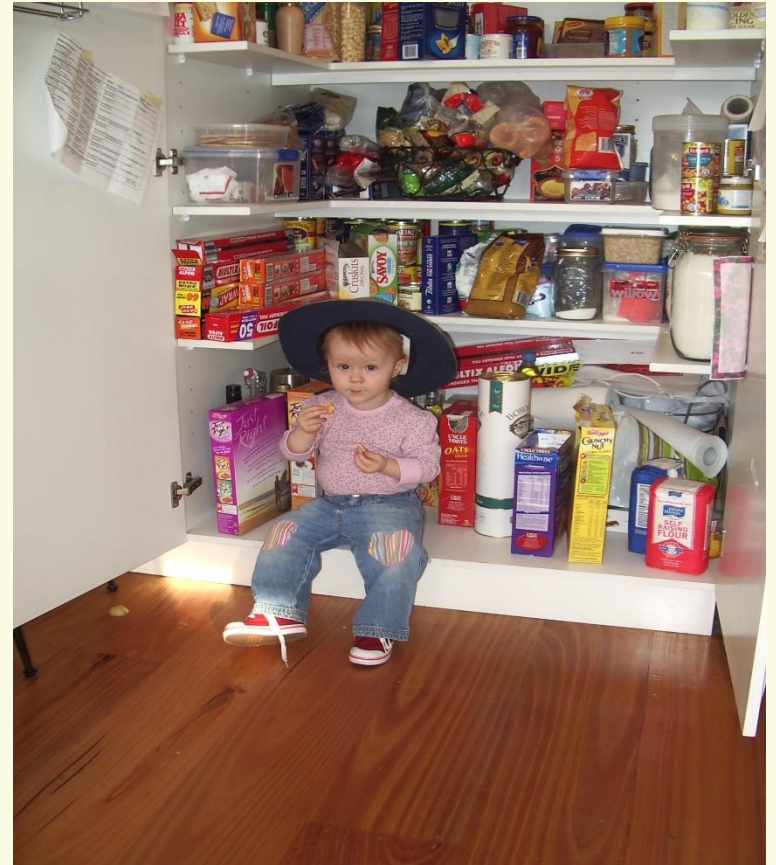
We are not all the same with our approach to medicine

- 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

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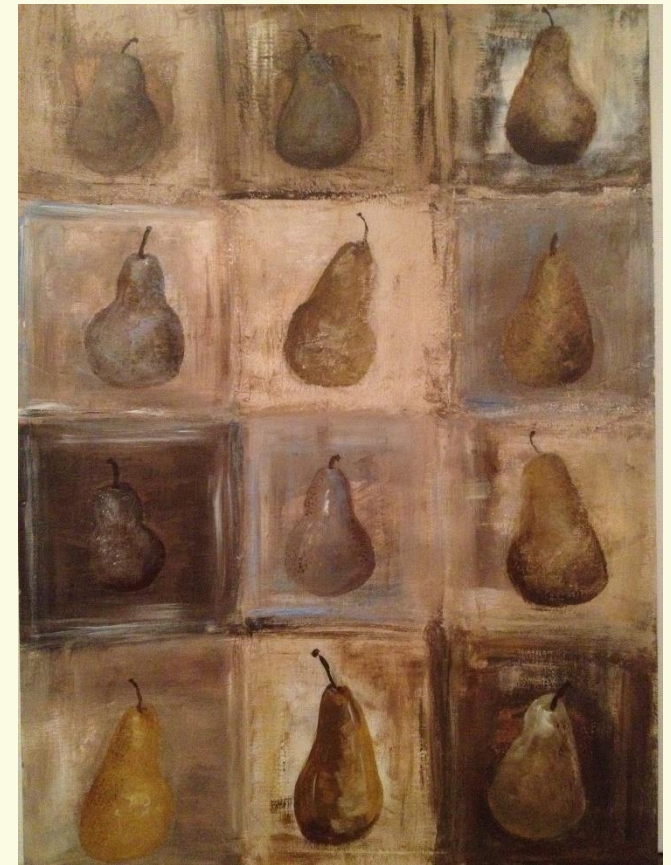
- Don't just answer the question
- Opportunistic immunisation education
- Share narratives



# The M.A.P. - Mutually Agreed Plan

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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


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- ☞ Meet and greet
- ☞ Introduce myself



# Michael - 7 weeks old

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 Mum and grandmother





# Michael - 7 weeks old

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## Mum and grandmother

- We are not anti-vaccine
- We just have concerns about vaccine side-effects....



# Before I start explaining... I ask

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What are their concerns about vaccine side-effects

- ...
- ...
- ...
- ...
- ...



# Specific family concerns

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- 📄 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

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Where are they at?

- (with giving these immunisations)



Do the parents have the same opinion?



## Individual family details, Michael (holistic medicine)

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- 📄 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...

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I am so glad you came to talk with me...

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📄 All medicines have side-effects

📄 All immunisations have side-effects





I am worried about Michael getting ...

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📄 Whooping cough (Pertussis)

📄 Meningitis



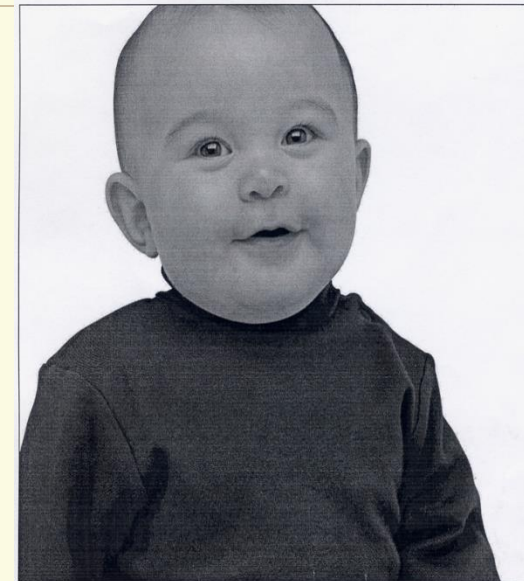
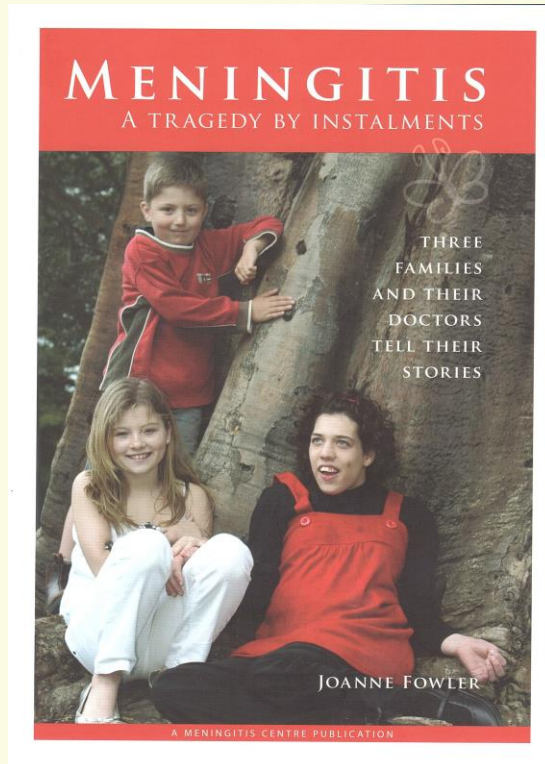
We make different vaccines for different reasons

📄 Whooping cough



# We make different vaccines for different reasons

## Meningitis



**What Meningitis looks like  
the day before it kills.**

**Now is the critical period for Meningitis.  
Don't ignore these symptoms:**

Vomiting, fever, severe headache, stiff neck, change in mood, dislike of bright lights, lethargy, rash, fitting, whimpering. Symptoms may occur in any order.

**Every Second Counts.** Contact your doctor or hospital immediately or Health Direct on 1800 022 222 for 24 hour health advice. Prompt attention will save lives.

The Meningitis Centre  
TfW Telethon Institute for Child Health Research  
Roberts Road Subiaco WA 6008 \* Telephones: 08 9340 8204  
Facsimiles: 08 9382 1028 \* Freecalls: 1800 253 223  
\*Manage the Minutes\* and courtesy of the Meningitis Research Institute and Meningitis Trust (UK)

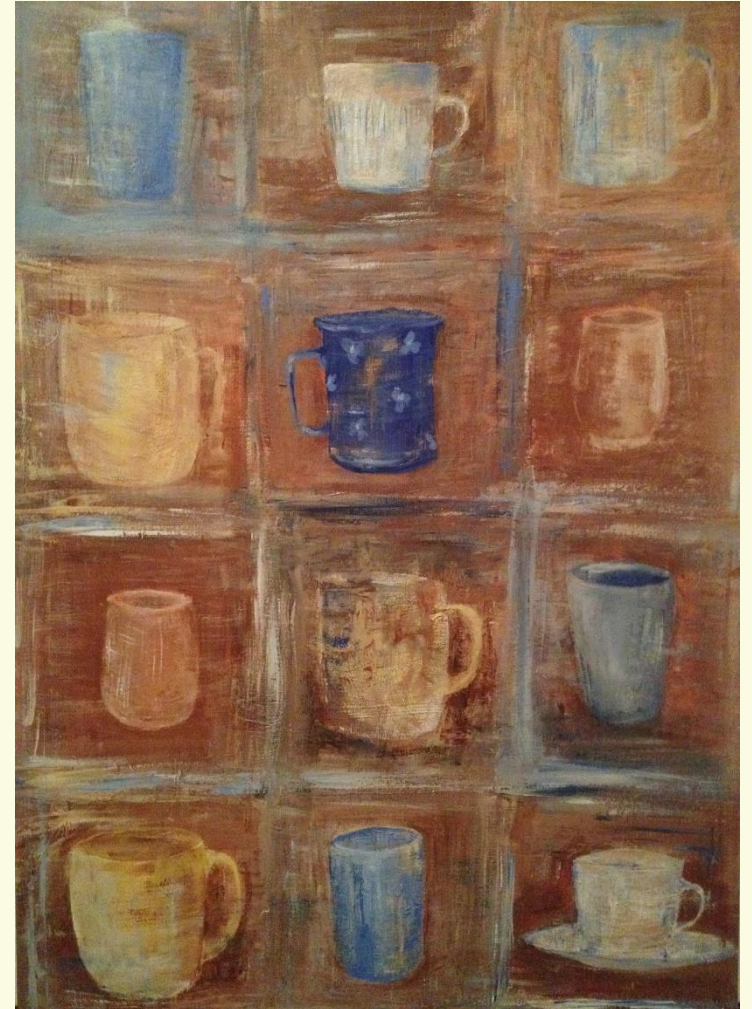
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We make different vaccines for different reasons

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📄 Hepatitis B



We make different vaccines for different reasons

 Rotavirus



# We make different vaccines for different reasons

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## 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?

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


📄 How are vaccines made?

- Tetanus
- Diphtheria
- Pertussis (whole-cell)

📄 The lists of potential side-effects

# Explain- Vaccine symptoms (side-effects)

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 Eg. D-T-Pw (Triple Antigen)<sup>®</sup>

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



# Explain- Vaccine symptoms (side-effects)

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## Minor

- Fever
- Rash
- Local
- Irritability

**DTPw**

40 - 60%

**DTPa**

2 - 5%

## Major

- Seizure
- HHE
- Anaphylaxis

1/1000

1/1000

1/million

1/20,000 - 50,000

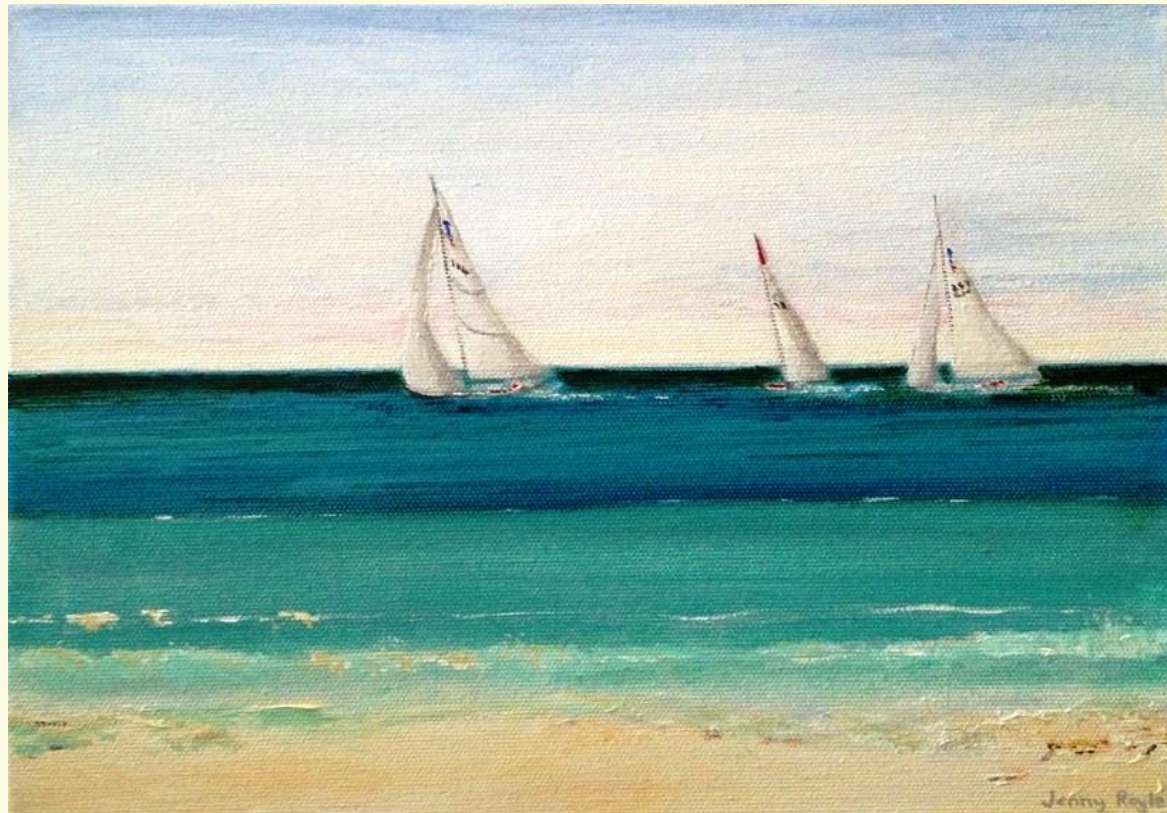
1/20,000 - 50,000

1/million

# Why do we immunise against polio and diphtheria?

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- Important Imported Diseases



## Explain- How are vaccines made?

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

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

# Discussions about the young immune system

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📄 My approach to this ...

- Explain diseases and the young immune system
- Remember
  - We make different vaccines for different reasons



# Discussions about combination vaccines

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## 📄 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



### 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

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📄 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

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📄 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 ...

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- 📄 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'

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 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'

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## 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'

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## Varicella

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

# Helpful advice

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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

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## 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- 5<sup>th</sup> edition 2013

## Table: Effects of diseases and vaccines

- 10<sup>th</sup> Edition Australian Immunisation Handbook
  - Inside back cover

SUMMARY SHEET - COMPARISON OF THE EFFECTS OF DISEASES AND THE SIDE EFFECTS OF NIP VACCINES		
DISEASE	EFFECT OF DISEASE	SIDE EFFECT OF VACCINE
Diphtheria - bacteria spread by respiratory droplets, causes severe throat and breathing difficulties.	Up to 1 in 7 patients die. The bacteria release a toxin, which can produce nerve paralysis and heart failure.	About 1 in 100,000 local swelling, redness or pain at the injection site. About 1 in 100,000 may experience a fever, which is usually completely within a few days. Serious adverse events are very rare.
Hepatitis A - virus spread by contact or ingestion of faecally contaminated water/food or through contact with the faecal material of a person infected with hepatitis A.	At least 7 in 10 adult patients develop jaundice (yellowing of the skin and eyes), fever, anorexia (loss of appetite), nausea, vomiting, hepatic (liver) pain and malaise (tiredness).	About 1 in 5 will have local swelling, redness or pain at the site. Serious adverse events are very rare.
Hepatitis B - virus spread mainly by blood, sexual contact or from mother to newborn baby, causes acute hepatitis (liver inflammation or chronic infection).	About 1 in 4 chronic carriers will develop cirrhosis or liver cancer.	About 1 in 20 will have local swelling, redness or pain at the site and 1 in 100 will have fever. Anaphylaxis occurs in about 1 in 100,000. Serious adverse events are very rare.
Hib - bacteria spread by respiratory droplets, causes meningitis (infection of the tissues surrounding the brain), epiglottitis (inflammatory obstruction), septicaemia (infection of the blood stream) and septic arthritis (infection of the joints).	About 1 in 20 meningitis patients die and about 1 in 4 survivors but permanent brain or nerve damage. Epiglottitis is rapidly and invariably fatal without treatment.	About 1 in 20 will have local swelling, redness or pain at the injection site. About 1 in 50 will have fever. Serious adverse events are very rare.
Human papillomavirus - virus spread mainly via sexual contact, up to 80% of the population will be infected with HPV in a given lifetime. Some HPV types are associated with the development of cancer.	About 7 in 10 cervical cancers worldwide have been associated with HPV-16 and 1 in 5 with HPV-18.	About 1 in 10 will have pain and 1 in 10 will have local swelling, redness or pain at the injection site. Headache, fever, muscle tenderness may occur in up to 1 in 10 people. Serious adverse events are very rare.
Influenza - virus spread by respiratory droplets, causes fever, muscle and joint pain, pneumonia. About 1 in 10 to 1 in 3 persons will get influenza every year.	There are an estimated 3000 deaths in people older than 50 years of age each year in Australia. Cause numerous hospitalizations in the very young (under 5 years of age) and the elderly. Other high-risk groups include pregnant women, people who are obese, diabetics and others with certain chronic medical conditions.	About 1 in 100,000 local swelling, redness or pain at the injection site. About 1 in 10 children aged 6 months to 5 years will experience a fever. About 1 in 100,000 will experience a fever. Serious adverse events are very rare.
Measles - highly infectious virus spread by respiratory droplets, causes fever, cough and rash.	About 1 in 15 children with measles develops pneumonia and 1 in 1000 develop encephalitis (brain inflammation). For every 10 children who develop measles encephalitis, 1 die and many have permanent brain damage. About 1 in 100,000 develop SSPE (slow progressive), which is always fatal.	About 1 in 10,000 local swelling, redness or pain at the injection site, or fever. About 1 in 20 develop a rash, which is self-limiting. Low-grade fever (lasting longer than 3 days) occurs in about 1 in 20 children aged 6 months to 5 years. Serious adverse events are very rare.
Meningococcal infection - bacteria spread by respiratory droplets, causes septicaemia (infection of the blood stream) and meningitis (infection of the tissues surrounding the brain).	About 1 in 10 patients die. Of those that survive, 1 to 2 in 10 have permanent long-term problems, such as loss of limbs and brain damage.	About 1 in 10,000 local swelling, redness or pain at the injection site, fever, irritability, loss of appetite or headache (nausea). About 1 in 200,000 have a fever reaction (pyrexia) after vaccination. Serious adverse events are very rare.
Mumps - virus spread by saliva; causes swollen neck and salivary glands, and fever.	One in 1000 children develop encephalitis. Deafness is permanent. One in 5 males (adolescent and adult) develop inflammation of the testes. Occasionally, mumps causes infertility or permanent deafness.	About 1 in 100 may develop swelling of the salivary glands. Adverse events are very rare.
Pertussis - bacteria spread by respiratory droplets, causes whooping cough, with prolonged cough lasting up to 3 months.	About 1 in 125 babies under the age of 6 months with whooping cough die from pneumonia or brain damage.	About 1 in 10,000 local swelling, redness or pain at the injection site. About 1 in 100,000 may experience a fever, which is usually completely within a few days. Serious adverse events are very rare.
Pneumococcal infection - bacteria spread by respiratory droplets, causes septicaemia (infection of the blood stream) meningitis (infection of the tissues surrounding the brain).	About 2 in 10 patients die. One third of pneumonia cases, and up to half of pneumonia hospitalizations in adults, is caused by pneumococcal infection.	About 1 in 5 will have local swelling, redness or pain at the injection site. About 1 in 100,000 may experience a fever, which is usually completely within a few days. Serious adverse events are very rare.

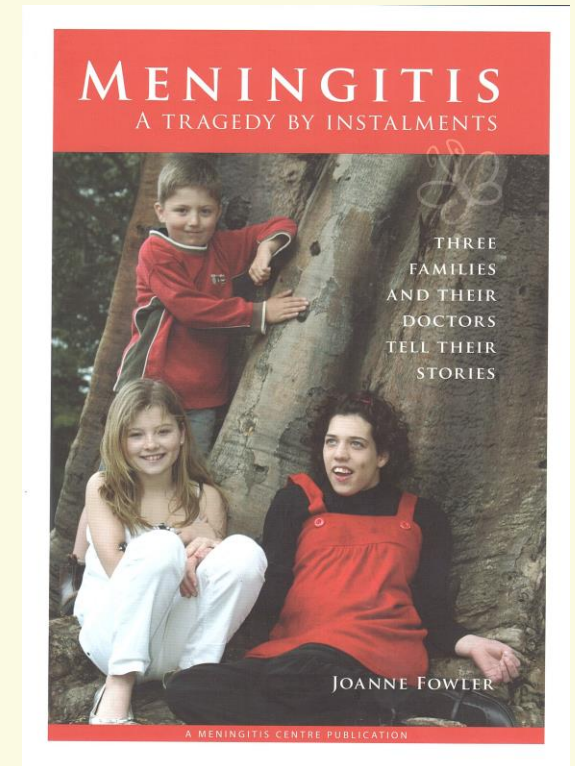
# Resources on Meningococcal

## 📄 '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





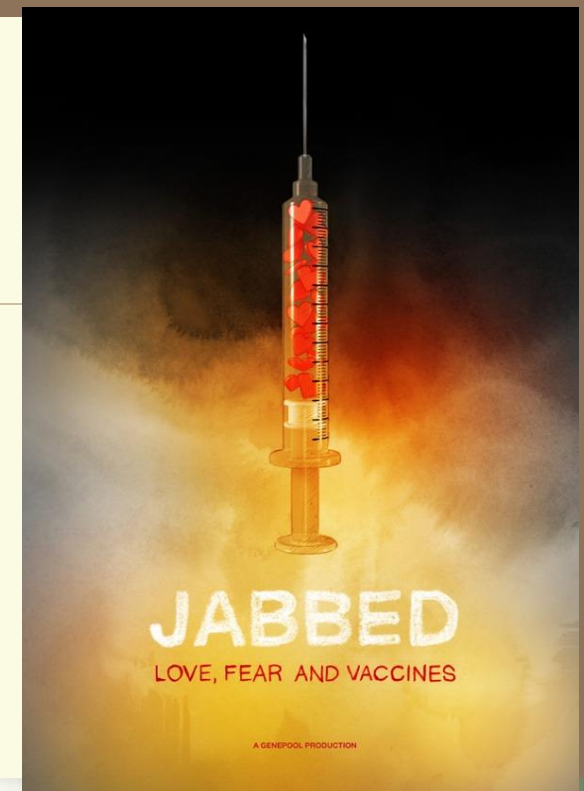
# 'JABBED

## - 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



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