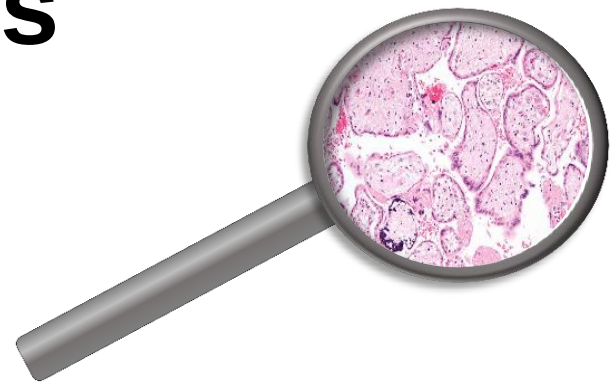
CMV Action

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Congenital CMV

A practical introduction for midwives



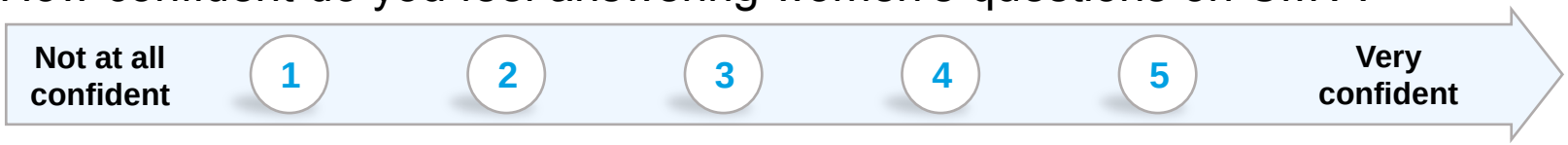


Before you start...

Please write down your answers to these 3 questions. At the end of this module we will give a link to a short evaluation form and this will help us to keep improving this module.

On a scale of 1 – 5, with 1 being not at all confident and 5 being very confident

- How confident do you feel answering women's questions on CMV?



- How confident do you feel advising women how to reduce risks of acquiring CMV infection?



- Do you know what steps to take if CMV infection is suspected in pregnancy?



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By the end of this module you will:

1. Understand how CMV can affect babies



- **1.1** What CMV is and the symptoms it can cause
- **1.2** How CMV is spread
- **1.3** How risks of CMV infection in pregnancy can be reduced

2. Know what you can do to limit the impact



- **2.1** Give advice on reducing risks
- **2.2** Know how to reduce your own risk if you are planning a pregnancy
- **2.3** Know what to do if infection in pregnancy is suspected
- **2.4** Understand what would happen if a newborn baby was diagnosed with CMV

This module will take about an hour. Portfolio activities may take longer

Learning objectives

1. Understand how CMV can affect babies:

- 1.1 What CMV is and the problems it can cause
- 1.2 How CMV is spread
- 1.3 How risks of CMV infection in pregnancy can be reduced

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Congenital CMV is a common virus that can damage unborn babies

CMV or **cytomegalovirus**
(si-to-MEG-alo- vi-rus)

is a common virus that that can infect anyone



Most people won't even know they have CMV but if a pregnant women contracts the virus she can pass it on to her unborn child with catastrophic results



2 to **3** babies everyday



will be damaged by CMV

That's almost **1000 babies every year** in the UK

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CMV is the leading preventable cause of hearing loss

- Some babies are obviously ill at birth (~15% of those affected by CMV)
- Most will not show obvious symptoms yet account for two thirds of disease burden e.g. through hearing loss that develops in the months and years after birth



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Lyra's story



Lyra was born to parents who had never heard of CMV. Her delivery was straightforward but it was evident at birth that she was a very sick baby; her parents were told she might not survive.

The doctors treating Lyra diagnosed CMV infection quickly but admitted they knew little about the infection and were liaising with specialists in London. The doctors started treatment with anti viral drugs the day after she was born. Scans and tests showed chronic liver damage, low platelets and extensive brain damage.

Lyra's parents were told that it was unlikely she would ever walk or talk and would probably never even know they were her mum and dad. They had to come to terms with the knowledge that their daughter was severely disabled and medically fragile.

Blood tests showed that Lyra's mother had contracted the virus early on during the pregnancy but, as CMV is not routinely screened for, the infection had not been picked up.

Lyra is now nearly 3 years old. CMV has affected her whole body. She has severe cerebral palsy. She can't roll, sit or hold her head up. She has chronic liver disease, epilepsy that is complex and difficult to control, damage to her lungs, kidneys and spleen, scoliosis of the spine, dislocated hips, feeding difficulties and more. She can't fight infection. She is blind. But she can hear and she smiles for her mum and dad. Those smiles are priceless.

Many more families have stories to share

Watch CMV Action's video featuring babies and children affected by CMV

https://www.youtube.com/watch?v=iRN3oh5z4CU

You can read other family stories on the **CMV Action** website

Meet Rubie



Meet Alicia



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Learning objectives

1. Understand how CMV can affect babies:

1.1 What CMV is and the problems it can cause

1.2 How CMV is spread

1.3 How risks of CMV infection in pregnancy can be reduced

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Quiz: Put in order of the risk these things could pose to unborn babies

A



Cat litter

B



Sheep

C



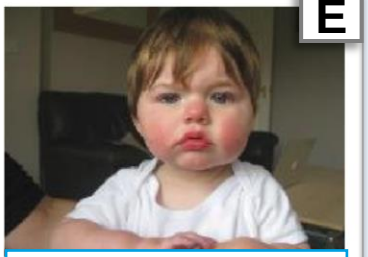
Small Red Spots

D



Unpasteurised Cheese

E



Rash on Cheeks

F



Dribbly Toddler

G

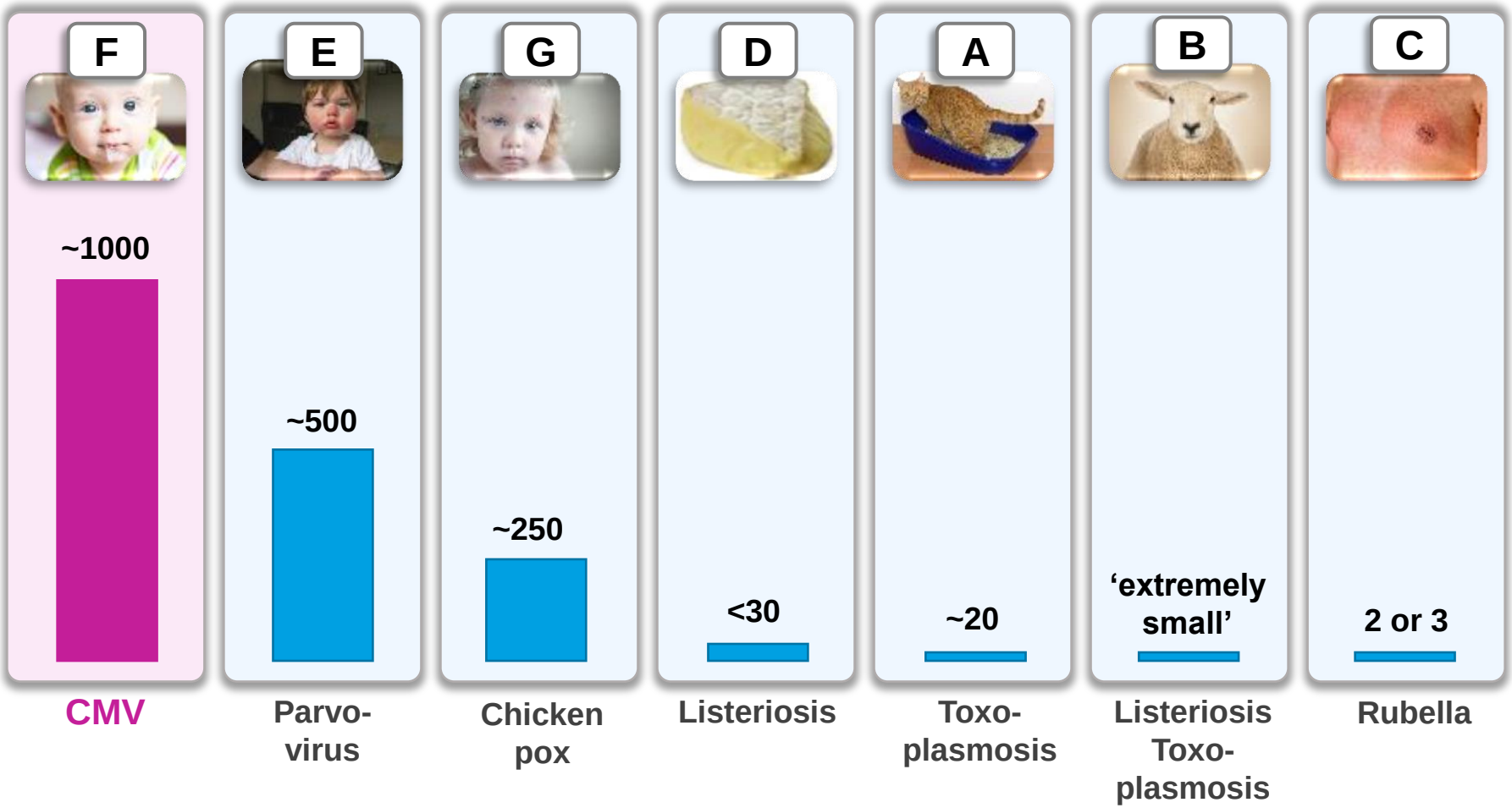


Scabbing or Blistering Spots

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Answer: CMV affects more babies every year in the UK than other infections

Approx number of babies affected per year by pregnancy infections



Sources: Dollard 2007, Griffiths 1991, NHS Choices, Public Health Laboratory Service Working Party 1990, Chapman 1993, Gay 1994, Public Health England 2014

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CMV is mainly spread through small children's bodily fluids

- CMV is transmitted through close contact with bodily fluids
- The main way women catch CMV is from the urine or saliva of young children: pregnant woman who already have young children or work with young children are at greater risk
- A child who catches CMV can be healthy but can have the virus in their bodily fluids for months
- Younger children pose a greater transmission risk than older children: there are higher levels of virus found in their bodily fluids and they are more likely to spread these around (e.g. drooling, mouthing toys)
- Infection rates are high for small children who attend nurseries. This may cause a mild illness only

Sources: Cannon, 2005. Cannon, 2014

Beware the drool! Saliva is a key risk

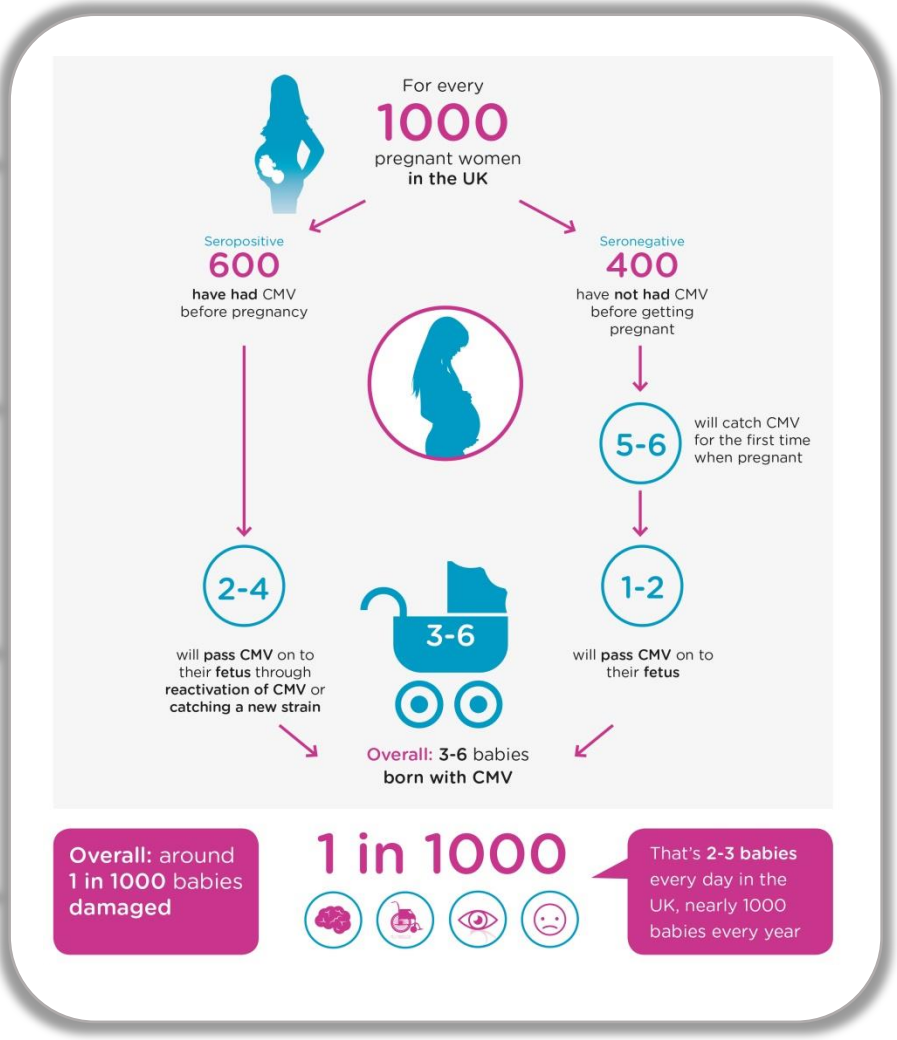
- There are higher levels of CMV virus in children's saliva than urine
- Behaviours that increase exposure to saliva e.g. sharing food & utensils, kissing on mouth, wiping face are common practice between mums and kids
  - These activities also allow for direct transfer of CMV to mucous membranes
- Exposure to urine mainly comes through nappy changing. Most women say they already clean hands after this
  - And since transfer takes place via hands (or another intermediary surface) it's less likely the virus survives

Sources: Cannon, 2014

CMV causes problems in <10% of maternal infections

1.2 How is CMV spread?

- Primary infection (catching it for the first time) happens in ~1 % of all pregnancies
- When mothers catch CMV for the first time in pregnancy they pass it on to the baby ~ one third of the time
- If you have had CMV before pregnancy you can still be affected, though less is known about the risks
- Around one in 5 babies born with CMV will have problems



Sources: De Vries 2013, Kenneson 2007, Nigro 2011 Dollard 2007, Preece, 1983, Stagno, 1986

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Learning objectives

1. Understand how CMV can affect babies:

1.1 What CMV is and the problems it can cause

1.2 How CMV is spread

1.3 How risks of CMV infection in pregnancy can be reduced

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Experts recommend simple hygiene precautions to reduce risks

What do you think would be some common sense hygiene precautions to reduce exposure to CMV?

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Experts recommend simple hygiene precautions to reduce risks

There are simple ways a pregnant woman can reduce the risk of infection to her unborn child



- Watch Professor Paul Griffiths talking about how to reduce risks on ITV news (*thanks to ITV for permission to share*): https://youtu.be/Uftc7E_9fkw

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International evidence supports educating about risk reduction

Small studies across 3 countries suggest education reduces infection. These countries now recommend professionals discuss risks with women.

- **US**: Intervention for pregnant women may have reduced the risk of acquiring CMV by 85% suggesting counselling pregnant women will be effective (Adler 2004). In the USA, the Centers for Disease Control and Prevention (CDC) recommend that pregnant women are counselled on CMV infection prevention.
- **France**: Results suggest that if clear information is given on CMV infection during pregnancy, the rate of seroconversion is lower following counselling than before counselling (Valoup-Fellous 2009).
- **Italy**: Presently, providing hygiene information to pregnant women at high risk of primary HCMV infection appears the most effective approach to prevention of congenital infection (Revello 2014).

There are currently no national guidelines on CMV education in the UK

Learning objectives

2. Know what you can do to limit the impact:

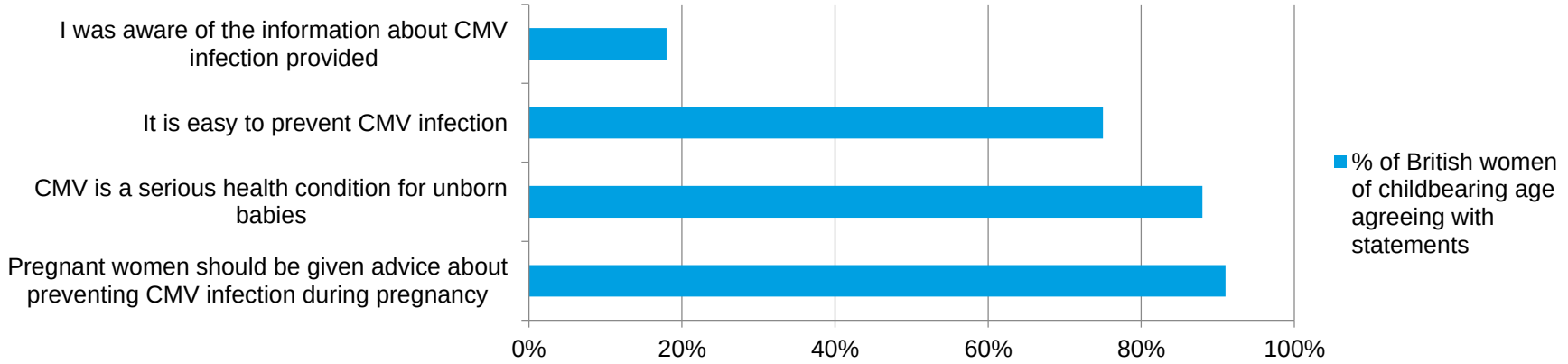
- 2.1 Give advice on reducing risks
- 2.2 Know how to reduce your own risk if you are planning a pregnancy
- 2.3 Know what to do if infection in pregnancy is suspected
- 2.4 Understand what would happen if a newborn baby was diagnosed with CMV and the role that you might play

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Women want to get information about CMV from their midwife

Whilst there are no UK guidelines on CMV education, British women are positive about getting more information (ComRes 2014[1])

- 9 out of 10 women (91%) think that pregnant women should be given advice about CMV infection during pregnancy
- Three quarters of British women of child-bearing age (75%) say that they would value the advice from a midwife



(1) ComRes interviewed 1,008 British women aged 18-44 online between 28th- 30th March 2014. Data were weighted to be representative of all women aged 18-44 in GB by age and region. ComRes is a member of the British Polling Council and abides by its rules. Full data tables are available on the ComRes website – www.comres.co.uk

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There's no way busy Mums have time for this...

How realistic do you think it is for women to follow the hygiene advice in section 1.3?

- Rate the prevention measures according to what % of British women of childbearing age think it is realistic to follow them

Avoiding putting things in your mouth that have just been in a child's mouth	**%**
Avoiding kissing young children on the mouth or cheek	**%**
Clean your hands after coming into contact with bodily fluids	**%**

...or do they?

How realistic do you think it is for women to follow the hygiene advice in section 1.3?

- Rate the prevention measures according to what % of British women of childbearing age think it is realistic to follow them

Clean your hands after coming into contact with bodily fluids	**90%**
Avoiding putting things in your mouth that have just been in a child's mouth	**87%**
Avoiding kissing young children on the mouth or cheek	**64%**

Isn’t this just going to add extra stress?

How do you think CMV advice could be given in an approachable and realistic way?

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That depends on how you discuss it

Evidence from focus groups gives some practical tips

- There is a risk that CMV is seen as 'one more thing to worry about' or that women feel overwhelmed by all the different prevention advice they receive.
- In focus groups (Levis 2014), women preferred realistic prevention messages that are not overly prescriptive and that encourage risk reduction (e.g., "whenever possible", "try to avoid") rather than risk elimination.

CMV Action recommends the following wording

- Congenital CMV is one of the most common causes of birth defects, but there are ways you can reduce the risk to your unborn baby. Although it may be hard to avoid all possible exposures to CMV, by making a few recommended changes while you are pregnant, you can help protect your unborn baby from infection. These include:
  - Avoid putting things in your mouth that have just been in a child's mouth.
  - Avoid getting saliva in your mouth when kissing a child.
  - Clean your hands after touching a child's urine or saliva.

Think of all the advice you offer women, do you think this is the best way? Could you do it better?

Quiz: Who should be given advice about CMV?

Are the following statements True or False?
What does this make you think about who should get advice?



1. If a woman has had CMV previously she can't catch it again when pregnant
2. CMV only causes damage in the first trimester
3. Babies born with CMV are always second (third etc.) children

Answer: Experts recommend ALL women are given advice about CMV

Are the following statements True or False?
What does this make you think about who should get advice?



1. If a woman has had CMV previously she can't catch it again when pregnant — **FALSE**
2. CMV only causes damage in the first trimester — **FALSE**
3. Babies born with CMV are always second (third etc.) children — **FALSE**

Experts recommend that all women are given advice about CMV.
This is because nobody is immune to it, even though some groups of women are at higher risk than others.

Portfolio activity

- **When and how might you discuss reducing risks of exposure to CMV with women?**
- **What challenges might you face and how could you overcome these?**

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Learning objectives

2. Know what you can do to limit the impact:

- 2.1 Give advice on reducing risks
- 2.2 Know how to reduce your own risk if you are planning a pregnancy
- 2.3 Know what to do if infection in pregnancy is suspected
- 2.4 Understand what would happen if a newborn baby was diagnosed with CMV and the role that you might play

Pregnant midwives should follow standard precautions

If you are pregnant or planning a pregnancy yourself you may have concerns about your risks at work. Studies comparing risks and seroconversion for healthcare professionals compared to the general population have concluded the following:

- The consensus is that there is no reason why pregnant staff should be excluded from contact with known excretors of CMV provided standard precautions are taken to prevent exposure to contaminated secretions (Newcastle up on Tyne NHS Foundation Trust 2012).
- Standard precautions should also be used for handling all bodily fluids.
- Pregnant staff should be informed about hygiene interventions (Wicker 2012) and make use of standard personal protective equipment (e.g. glove and aprons) and hygienic interventions.
- Pregnant staff should follow standard infection control procedures as they would to prevent exposure to any potentially infectious agents (NHS Professionals 2010).

Pregnant staff who are particularly concerned about caring for patients excreting CMV should contact their trust's Occupational Health department or CMV Action.

Portfolio activity

- **Does your Trust have a policy on controlling risk of infection for pregnant staff? If not, you could work with Occupational Health to develop one**

Learning objectives

2. Know what you can do to limit the impact:

2.1 Give advice on reducing risks

2.2 Know how to reduce your own risk if you are planning a pregnancy

2.3 Know what to do if infection in pregnancy is suspected

2.4 Understand what would happen if a newborn baby was diagnosed with CMV and the role that you might play

If it's so common, how come I haven't seen more cases of it?

Which of the following are symptoms that a pregnant women with CMV might experience/present? Why do you think it can be hard to identify?

- Lack of energy
- Rash
- Fever
- Flu-like symptoms
- Difficulty breathing
- Enlargement of lymph nodes
- Enlarged liver and spleen
- Abnormal liver function tests
- Vomiting / Diarrhoea



CMV infection can be hard to identify in pregnancy

Which of the following are symptoms that a pregnant women with CMV might experience/present? Why do you think it can be hard to identify?

✓	Lack of energy		YES
✓	Rash		YES
✓	Fever		YES
✓	Flu-like symptoms		YES
✗	Difficulty breathing	*Not normally*	NO
✓	Enlargement of lymph nodes		YES
✓	Enlarged liver and spleen		YES
✓	Abnormal liver function tests		YES
✗	Vomiting / Diarrhoea	*Not normally*	NO

- Most of the time, a woman who has a CMV infection will have no symptoms at all or mild flu-like symptoms.
- Other symptoms such as enlarged lymph nodes and enlarged liver/spleen may sometimes be present. However these can be symptoms of a wide range of conditions, not just CMV.
- Primary CMV infection should be suspected if a woman has symptoms of glandular fever but has negative test results for Epstein-Barr virus or shows signs of hepatitis, but has negative test results for hepatitis A, B, and C (Centers for Disease Control).

Scan anomalies can indicate CMV

Symptoms in fetus may be visible on scans:



- Intrauterine growth restriction
- Microcephaly (small head)
- Intracranial calcifications, though fetal MRI for detection of cerebral abnormalities remains controversial (Bonalumi 2011)

However, if CMV infection has been confirmed in the mother, a normal scan does not guarantee the baby won't be affected

RCOG guidelines recommend that serological screening for congenital CMV should be offered in severely SGA (small for gestational age) fetuses (RCOG 2013)

Oscar’s story



“After trying for a baby for two years, we luckily became pregnant with out first child just two days before we signed the paperwork to undergo IVF treatment. I'm also a midwife of eleven years so seeing people everyday and them telling me their 'lucky' stories of falling pregnant made my two years very long indeed.

My midwife started measuring me at 26 weeks, when she picked up that I was SFD (*small for dates*.) I also never felt my baby move. I started undergoing serial growth scans. I send my own patients for these all the time and they generally come back fine, so I wasn't worried. My consultant did a TORCH blood screen for infections.

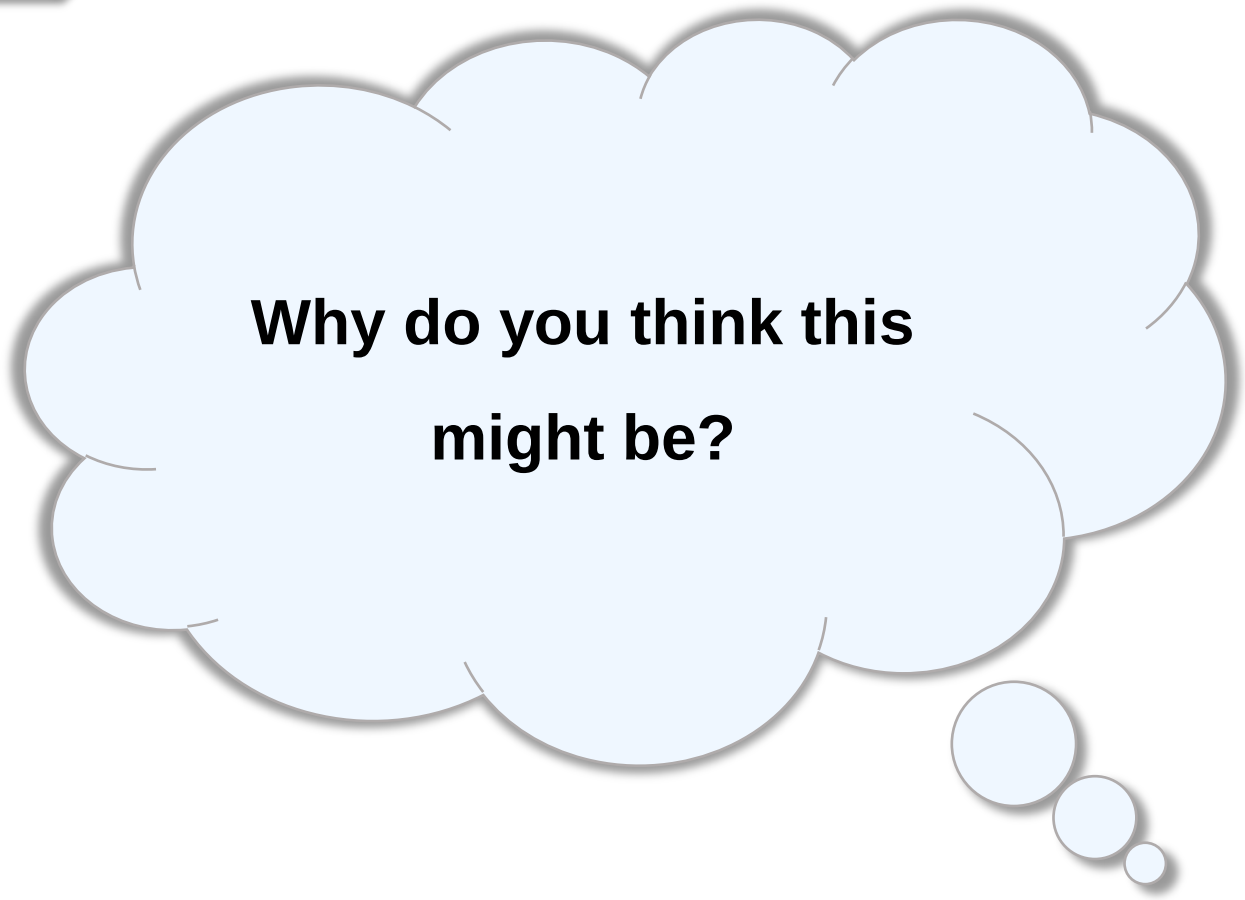
That's when my world crumbled. I had had CMV at some point during the first trimester, meaning my baby could be infected. Whilst I'd heard of it, I had never known anyone who had had cmv.

How on earth had I picked this up?

The consultant suggested an amniocentesis, which we had at 33+1 weeks. We also had a brain scan which now showed ventriculomegaly, some brain abnormalities. Our baby was diagnosed with severe CMV, there was poor growth, enlarged liver / abdomen, a small head and no brain activity at all.

Our beautiful baby Oscar William, was stillborn at 33+6 weeks, my shining star.”

UK policy is not to screen for CMV in pregnancy



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UK policy is not to screen for CMV

Routine screening of pregnant women is a controversial topic and there are a number of issues (Hollins-Martin 2013):

- Testing is complicated: detection of CMV IgM antibodies shows a current infection (anybody who has had a past CMV infection will have CMV IgG antibodies). However these IgM antibodies can be present non-specifically during pregnancy and with reactivation or reinfection as well as primary infection.
- If screening shows that a woman has had CMV before, this does not mean she is immune: she could have a reactivation or be infected with a new strain.
- Diagnosis of CMV infection does not mean a baby will definitely have problems, even if foetal infection is confirmed.
- Whilst two potential treatments are available to reduce rate of transmission and improve neonatal outcomes, their effectiveness has not been confirmed.

Therefore **CMV screening does not meet the criteria set by the National Screening Committee in the UK** (National Screening Committee 2012).

However some experts in other countries claim that a general screening programme could reduce disabilities caused by CMV, either by targeting education on seronegative women or enabling treatment of pregnant women & newborns (Hollins-Martin 2013).

But some women may ask about CMV testing

Women may come to your clinic with specific concerns about their risk of contracting CMV

- Occasionally, a woman may have had a close family member diagnosed with active CMV infection and be concerned about how they can avoid exposure. They may also want to know their own CMV status.
- Some women who have been through IVF will have been tested for CMV. If they haven't had it before they will have been advised that there are risks of using a sperm donor who has had a previous CMV infection.
- If a woman has had CMV infection in a previous pregnancy, or knows somebody with a child disabled by CMV, she may be more concerned about risks.

Portfolio activity

- **Roleplay with a colleague how you would manage a case like this where a woman is very anxious and wants CMV tests carried out?**
- **Think back to section 1 of this module. Which facts could help to reassure an anxious woman?**
- **Find out what your Unit and Microbiology Department's policy is on screening on request**

Source: CMV Action helpline queries

You can reassure and potentially refer

Facts about CMV transmission can be reassuring

- CMV is not easy to catch. It is spread through close contact with bodily fluids. You cannot catch it through casual contact such as being in the same room as somebody or touching them.
- Having a CMV infection doesn't mean the baby will certainly be born with problems. There is a 30-40% risk of transmission to the fetus and a 20-25% chance of birth defects if this takes place – less than 10% overall.

Some cases may need further action

- If a woman shows symptoms listed in section 2.3 and other infections have been ruled out you **could refer to the maternity day assessment unit or clinic**. **for further assessment**.
- If CMV testing is carried out on request in your Trust you could refer for serological screening.
- If in doubt **speak to your local fetal medicine expert**
- If infection is confirmed, amniocentesis may be recommended and further investigations carried out (e.g. ultrasounds) to identify whether the fetus has been infected.

Portfolio activity

- **Does your Trust have a policy on antenatal and neonatal management of CMV? If not, use CMV Action's guide to develop one**

Learning objectives

2. Know what you can do to limit the impact:

2.1 Give advice on reducing risks

2.2 Know how to reduce your own risk if you are planning a pregnancy

2.3 Know what to do if infection in pregnancy is suspected

2.4 Understand what would happen if a newborn baby was diagnosed with CMV and the role that you might play

Some babies born with CMV will have very obvious signs

Which of the following could be obvious signs of congenital CMV in a newborn baby?

- ❑ Lots of very small (1-2mm) red or purple spots (called petechiae)
- ❑ Larger (2-8mm) red or purple dome shaped spots
- ❑ Low birth weight
- ❑ Pneumonia
- ❑ A head significantly smaller than other babies (microcephaly)
- ❑ Enlarged liver and spleen (hepatosplenomegaly)
- ❑ Yellow skin (jaundice)
- ❑ Signs suggestive of encephalitis or meningitis
- ❑ Anaemia
- ❑ No obvious signs at all

Some babies born with CMV will have very obvious signs

Which of the following could be obvious signs of congenital CMV in a newborn baby?

✓	Lots of very small (1-2mm) red or purple spots (called petechiae)	YES
✓	Larger (2-8mm) red or purple dome shaped spots	YES
✓	Low birth weight	YES
✓	Pneumonia **(rarely)**	YES
✓	A head significantly smaller than other babies (microcephaly)	YES
✓	Enlarged liver and spleen (hepatosplenomegaly)	YES
✓	Yellow skin (jaundice)	YES
✗	Signs suggestive of encephalitis or meningitis	NO
✓	Anaemia	YES
✓	No obvious signs at all **In 85% of cases**	YES





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Early diagnosis is critical to enable treatment

2.4 Action at birth

- Oral and intravenous antivirals (valganciclovir and ganciclovir) are used to treat babies. Evidence suggests key benefit is in limiting the deterioration of hearing loss
- Evidence of benefit of treatment is limited to neonates and so treatment must currently be started before 4 weeks old (though trial is underway to explore giving oral antivirals to older babies/children)
- Early diagnosis is also key to ensure that babies are monitored for future problems



Sources: Kadambari 2011, Martins-Hollins 2013.

Fast and reliable testing pathways must be developed



- CMV testing can be done through urine (not easy with newborns) or saliva swab. Whilst saliva is easy and very accurate not all areas will have pathways in place to analyse and urine sample may be taken instead.
- To confirm a diagnosis of congenital CMV samples must be obtained within the first 21 days of life. Otherwise postnatally acquired infection (from the birth canal and breast milk) cannot be excluded. Postnatally acquired CMV is not currently thought to lead to long term problems in the newborn.
- British Association of Audiovestibular Physicians guidelines state that a fast and reliable pathway should be developed locally to include the audiologists, doctors and the testing laboratory in order to facilitate a timely diagnosis.
- However this does not happen for some babies and they miss the opportunity for treatment

Portfolio activity

- **What role might you be able to play in ensuring that CMV diagnosis is made early enough to commence treatment where appropriate?**

Sources: Kadambari 2011, Martins-Hollins 2013.

Certification and feedback

Thank you for taking the time to learn more about CMV.

Please click on this link to take our short evaluation survey. It will help us to improve the course and develop more free resources.

If you take our CMV quiz and score more than 80% you can print a certificate to put in your portfolio

You can download and print the training summary for your portfolio here

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Further Resources

- Congenital CMV: Antenatal and neonatal care
  - One page summary of the symptoms and next steps set out in this training module – pin it on the wall in the clinic or ward!
- CMV Action leaflet for pregnant women
  - CMV Action's leaflet for pregnant women which has been thoroughly tested with women and professionals
- CMV infographic
  - The full CMV story in pictures

View all resources in the publications section on the CMV Action website. You can download or order copies free of charge: info@cmvaction.org.uk, 0808 802 0030

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- Jenny Spriggs – Community midwife, Lewisham and Greenwich NHS Trust
- Jessica Davey – Research midwife, St George's University of London

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