

Information for Parents/Caregivers:

FREQUENTLY ASKED QUESTIONS - cow's milk allergy/cow's milk protein allergy (CMPA)

1. What is cow's milk allergy?

Cow's milk allergy is when the body's immune system reacts to the *proteins found in cow's milk*. It is also called **cow's milk protein allergy (CMPA)**. Many foods and drinks contain cow's milk protein, including the normal infant formula milks sold in the UK. There are **two types of cow's milk allergy**:

- ❖ Non IgE mediated – also called *delayed onset*: this is *the most common type*, where symptoms come on from 2 hours up to 2 or 3 days after having anything with cow's milk protein in it. Generally, there will be more than one symptom that affects the skin and/or digestive system, for example eczema, diarrhoea, constipation, reflux and blood in stools. *Most children with this type of cow's milk allergy will grow out of it between the age of 1–2 years.*
- ❖ IgE mediated – also called *immediate/acute onset*: this is where symptoms come on quickly, generally within minutes (but could be up to 2 hours) after having anything with cow's milk protein in it. Symptoms can affect the skin such as red and itchy hives and sudden flare ups, and the digestive system such as immediate vomiting or diarrhoea. ***In a small number of cases a particular type of reaction called anaphylaxis may occur - if you notice symptoms of anaphylaxis, such as swelling of the lips or tongue or breathing difficulties, seek immediate medical help as this can be life threatening.*** Most children with this type of cow's milk allergy will grow out of it by the age of 5 - but for the most severe, the allergy may be lifelong.

More information about cow's milk allergy can be found on Allergy UK's website, www.allergyuk.org (help line 01322 619898).

2. Can I still breastfeed if my child has a cow's milk allergy?

If your child has a cow's milk allergy, breastfeeding remains the best way to feed them.

- ❖ The GP/dietitian/paediatrician/allergy nurse will ask questions to help them decide whether you need to exclude cow's milk from your *own* diet.
- ❖ Often it is when infant formula or solids are started (also known as weaning) that the symptoms of cow's milk allergy appear.
- ❖ *If your child did not have any symptoms when you were solely breastfeeding and including cow's milk in your diet, you can continue breastfeeding without having to change your own diet.* You will just need to ensure your child has a cow's milk free diet if you have started them on solid foods, and if any top up formula is required it will need to be a prescribed formula that is appropriate.

If you have been advised to exclude cow's milk from your own diet, you will be provided with the [Cow's milk free diet for breastfeeding mums](#) information leaflet, which contains important information about **supplements you need to take**. There is a separate [dietary advice sheet for your child](#). (Click on these links if you are viewing this from your phone/tablet/computer - *please tell your GP/dietitian/paediatrician/allergy nurse if you don't have access to the internet and need paper versions of these leaflets.*)

3. My child has been prescribed a specialist formula for cow's milk allergy. How do they work?

There are two types of these formulas (also referred to as hypoallergenic formulas) – extensively hydrolysed formulas and amino acid formulas.

- ❖ Extensively hydrolysed formulas are *suitable for most children with a cow's milk allergy*. The proteins in them have been broken down to smaller parts to prevent an immune reaction. They are very well tolerated by 90% of children with a cow's milk allergy.
- ❖ Amino acid formulas are only necessary for around 10% of children with a cow's milk allergy and are for the most severe cases. They are made from the separate amino acids rather than whole proteins (protein is made from amino acids). The separate amino acids are better tolerated in the most severe allergy cases.

4. I want the same formula that my older child was prescribed.

Every child is different - whilst one child has a cow's milk allergy, that does *not* mean that all your children will have it.

In addition, just because one specialist formula was the only one that worked for an older child, it doesn't mean that it will be the same for a younger child, if they too have a cow's milk allergy. They may not have the same severity of allergy nor the same symptoms or health concerns.

5. Can I give my child a lactose free formula?

Lactose free formulas and products are not suitable for children with a cow's milk allergy as they still contain cow's milk protein.

Lactose intolerance tends to be a short term problem following stomach upset - temporarily your child may be unable to digest lactose (a milk sugar), resulting in symptoms such as bloating and diarrhoea. It usually resolves in a matter of weeks. *It is not the same as cow's milk allergy*, which is an immune mediated reaction to the proteins in cow's milk.

6. Can I give my child another animal milk (such as goat, buffalo or sheep)?

Other animal milks and infant formulas based on them such as goat, buffalo and sheep are also not suitable as the proteins in these milks are very similar to cow's milk protein.

7. Can I give my child soya formula milk?

The only soya formula available in the UK is SMA® Soya Infant Formula. It is important to understand that *it may not be suitable for your child*. Please note:

- ❖ SMA® Soya Infant Formula is not recommended as the first line treatment for cow's milk allergy and *is not usually recommended in children under the age of 6 months* due to phytoestrogen content. Phytoestrogens are found naturally in soya and are similar in their make up to the female hormone, oestrogen. Under the age of 6 months, a baby's weight is felt to be too low to safely tolerate the phytoestrogens in soya infant formula.
- ❖ Children may also react to soya - *talk to your dietitian/paediatrician/allergy nurse if you are considering giving SMA® Soya Infant Formula instead of the prescribed formula. They will advise if it is appropriate once your child is over the age of 6 months - but you must buy this from pharmacies/supermarkets/online. It will not be prescribed.*

8. My child is not tolerating the taste of the prescribed formula – what do I do?

It is important to understand that these formulas do taste different. It will take time for your child to readily accept the formula.

It may help to add a drop of (alcohol free) vanilla essence to the feed.

If you are worried that your child is not taking enough of the formula or you have concerns about their weight, keep a note of amounts taken, how many wet nappies/bowel motions you see and contact your health visitor/GP/dietitian/paediatrician/allergy nurse.

*If your child has suspected or diagnosed non IgE mediated (delayed onset) cow's milk allergy, to start with the prescribed formula can be mixed with the cow's milk based formula that led to symptoms originally. Gradually increase the number of scoops of the prescribed formula and reduce the number of scoops of cow's milk based formula in each feed until the feed is purely the prescribed formula. This will delay symptom improvement but may help improve acceptance. **Do NOT do this if your child has suspected IgE mediated (immediate/acute onset) cow's milk allergy – this is where the symptoms appear generally within minutes but up to 2 hours after consuming cow's milk protein. Check with the GP/dietitian/paediatrician/allergy nurse to be sure that it is safe to mix the formulas initially for your child.***

9. Does my child need blood tests or skin prick tests to diagnose a cow's milk allergy?

- ❖ *Blood tests and skin prick tests are only useful in supporting the diagnosis of children with suspected IgE mediated (immediate/acute onset) cow's milk allergy.*
- ❖ *Blood tests and skin prick tests won't diagnose the most common type of cow's milk allergy, which is non IgE mediated (delayed onset) cow's milk allergy. This type can only be diagnosed by following the HOME MILK CHALLENGE.*

10. What is the HOME MILK CHALLENGE and why do I have to do that?

This is the only way to confirm diagnosis of the most common type of cow's milk allergy - *non IgE mediated (delayed onset)*. Although cow's milk allergy may be suspected, the symptoms could be due to something else and not allergy. Diagnosis is essential to prevent unnecessary dietary restrictions that could potentially affect your child's feeding or growth later and could otherwise delay finding out the actual cause of your child's symptoms. It is also essential to prevent unnecessary prescribing of the specialist formulas, which are costly to the NHS.

IMPORTANT NOTE: Do NOT try the HOME MILK CHALLENGE without instructions from the GP/dietitian/paediatrician/allergy nurse. It is NOT for suspected IgE mediated (immediate/acute onset) cow's milk allergy – diagnosis for that is by blood test/skin prick test in the hospital setting.

The GP/dietitian/paediatrician/allergy nurse will provide a leaflet explaining the HOME MILK CHALLENGE to you if you need to do this. After around 4 weeks on a cow's milk free diet, the HOME MILK CHALLENGE involves reintroducing a very small amount of cow's milk protein back into your child's diet to see if they experience the same symptoms. This would then confirm the diagnosis. As soon as symptoms return, the trial is stopped. If symptoms don't return, this would indicate the original symptoms were not due to a cow's milk allergy and there is no need for the prescribed formula or cow's milk free diet. *It doesn't mean that the symptoms were imagined, just that they were not due to an allergy. If symptoms continue, it is important to return to the GP.*

11. My child is still getting symptoms – how long does it take the prescribed formula to work?

It will take time – it is important to understand that you are very unlikely to see an immediate improvement. It can take up to 2-4 weeks after starting the prescribed formula/cow's milk free diet, alongside any necessary treatment (such as creams if eczema is one of the symptoms) for symptoms to settle - and possibly longer if your child is experiencing severe symptoms.

12. My child's stools (poos) have changed since starting the prescribed formula.

It is common for children on these formulas to pass green stools (poos) – don't worry it is not concerning. They may also open their bowels less frequently.

It is difficult to explain what constipation looks like in a child as it differs depending on their age and whether they are being exclusively breastfed. In the first instance you can discuss your concerns with the health visitor. Note, however, the stool pattern of an exclusively breastfed baby (one that is entirely breastfed) changes after age 6 weeks – bowels do open less frequently. After this age, it is not uncommon for an exclusively breastfed baby to go 5-7 days without passing a stool and in the absence of symptoms, this is not something to worry about.

If you are worried that your child is actually constipated (i.e., passing a hard stool), then the GP should assess accordingly but it may well be that the gut is just settling.

13. Why do I need to see the dietitian?

Your GP practice will make a referral to the dietitian as soon as possible once cow's milk allergy is being considered. *We have found that the children who don't see a dietitian are more likely to experience feeding difficulties. They struggle with acceptance of different food tastes and textures when solids are introduced (also known as weaning) as they have remained on the prescribed formula for longer than is necessary.* The prescribed formula will be stopped for many children with non IgE mediated (delayed onset) cow's milk allergy once they reach 1 year of age and it is vital that you know what to do.

The dietitian will explain all about cow's milk allergy, the importance of diagnosis and how it is done, the cow's milk free diet, and how to start cow's milk free solids. They will advise when it may be safe to reintroduce cow's milk back into the diet, and suitable non-dairy alternative milks while that is not possible, so that the prescribed formula can stop if it is safe to do so. Some children will have a lifelong allergy (most won't) and they will require extended support from the dietitian, who will continue to liaise with the paediatrician and the GP for such children.

14. I'm having trouble obtaining enough prescription formula every month.

Healthcare professionals follow agreed guidance on how much formula to prescribe, depending on the age of the child. To start with, you should receive a trial amount that should last a couple of weeks. After that the amounts prescribed every month should follow the amounts shown below.

Note that if you are part breastfeeding, you will need less than these amounts. The GP may issue a smaller monthly amount as a result, or they may issue the amount stated below but the prescription will last longer.

Age of Child	Monthly amount of prescription formula
Up to 3 months (13 weeks)	5x400g tins (from birth) increasing to 12x400g tins by age 3 months
3 to 6 months (13-26 weeks)	12x400g tins (from age 3 months) reducing to 9x400g tins by age 6 months
6 to 12 months (26-52 weeks)	9x400g tins (from age 6 months) reducing to 7x400g tins by age 1 year
1 to 2 years	Dietitian will advise the amount as most children will not need the prescription beyond age 1 year.

Around the age of 6 months, the amount of formula needed will start to reduce as cow's milk free solids are introduced - seeing the dietitian will help you to understand how to do this. If you have any concerns that your child is not feeding as expected, please contact the health visitor, GP or dietitian.

If your child has multiple food allergies or if there are other medical problems affecting their ability to take solids or meaning that they have increased nutritional needs, the amount of formula is likely to be more than stated above and it is likely to be needed for longer. The dietitian/paediatrician/allergy nurse will explain this in their letter to the GP.

15. What is the milk ladder?

If your child has an IgE mediated (immediate/acute onset) cow's milk allergy, it is essential to wait until the dietitian/paediatrician/allergy nurse has advised it is safe to try any foods or drinks containing cow's milk.

The milk ladder is explained in a leaflet given to you by the dietitian/paediatrician/allergy nurse or your GP practice when it is safe for you to reintroduce cow's milk back into your child's diet.

It is a step by step guide that starts with very small amounts of the most tolerated types of cow's milk products and explains how to gradually increase the amounts and types, depending on whether your child reacts to any of the food steps. Some children will move up the steps quite quickly, but for others, it may take longer.

If your child reacts at any stage, you just stop at that point – you can give your child the types of cow's milk product that have been tolerated to that point. You can then retry the failed step in 3 months' time (unless the dietitian/paediatrician/allergy nurse advises otherwise) and continue to go up the steps until cow's milk is fully tolerated.

16. I have been advised that the prescribed formula will stop now that my child is over 1 year of age, but they are not tolerating cow's milk yet.

There are various non-dairy alternative milks available that you can buy from supermarkets, other retailers or online. They are made from different plant based sources such as soya, oat, coconut, almond, pea protein etc.

The best ones to opt for are those fortified with both calcium and iodine. At the time of writing these include:

- ❖ Alpro Soya Growing Up Drink 1-3+[®], Alpro Oat Growing Up Drink 1-3+[®], Oatly[®]Barista (also known as Oatly[®]Foamable) and KoKo[®]Super.
- ❖ **If your child has other allergies, avoid any containing the ingredient(s) that they are allergic to (e.g., avoid soya based milks if your child also has a soya allergy).**
- ❖ Supermarkets also do their own versions of various non-dairy alternative milks.
- ❖ These can be used in foods from age 6 months and are suitable as a main drink from 1 year of age, for children who are not yet able to tolerate cow's milk in their diet but who the dietitian/paediatrician/allergy nurse or GP practice has advised no longer needs the prescribed formula.

NOTE:

- Any product labelled as organic will not be fortified with extra calcium or iodine etc.
- Rice milk is not suitable as a drink for any child under the age of 5 years due to arsenic content – note also that some coconut based milks may contain a significant amount of rice milk (check the label).

17. When might a child over the age of 1 year still need a prescribed formula?

Whilst many children will not need a prescribed formula after the age of 1 year, there are limited agreed circumstances where the prescription may continue.

The dietitian/paediatrician/allergy nurse will confirm to the GP if any of the following apply to your child, requiring the prescription for a longer period:

- ❖ If your child has IgE mediated (immediate/acute onset) cow's milk allergy and multiple food allergies meaning that they are allergic to all non-dairy alternative milks.
- ❖ If they have been diagnosed with confirmed faltering growth.
- ❖ Or if they have other highly complex health needs requiring the hospital/specialist service.

Ongoing specialist care is essential for these children and parents/caregivers should continue to attend the appointments. The paediatrician/dietitian/allergy nurse will review the prescription to ensure it remains appropriate or advise when it is safe to stop the prescription and what to try as an alternative. They will write to the GP to explain their review and practice staff will look for these letters when they are checking whether the prescription should continue.

18. Will my child have a cow's milk allergy for the rest of their life?

You will be supported to understand the type and severity of cow's milk allergy for your child.

- ❖ *The most common type of cow's milk allergy is non IgE mediated (delayed onset) cow's milk allergy. Most children will grow out of this type between the age of 1 and 2 years.*
- ❖ If your child has IgE mediated (immediate/acute onset) cow's milk allergy, most children will grow out of this type by the age of 5 years - but for the most severe, the allergy may be lifelong.

19. Does my child need an Adrenaline Auto-Injector (adrenaline pen)?

Adrenaline Auto-Injectors (AAIs) are also called adrenaline pens as they contain adrenaline as immediate treatment if your child shows any signs of anaphylaxis. Anaphylaxis is a severe allergic reaction that is life threatening and could be a symptom of an IgE mediated allergy.

Children with a **non IgE mediated (delayed onset) cow's milk allergy**, where the symptoms are delayed and come on from 2 hours up to 2 or 3 days after having cow's milk protein, **do NOT need Adrenaline Auto-Injectors (AAIs).**

Not all children with an IgE mediated (immediate/acute onset) cow's milk allergy will need them either – AAIs are for the most severe form of IgE mediated (immediate/acute onset) food allergy, where symptoms are so severe that anaphylaxis is a risk on exposure to the allergen (the food/substance that is causing the reaction). **If your child's allergy is this severe, the dietitian/paediatrician/allergy nurse will make you aware of this and give you an allergy plan, which explains when it is necessary to use the AAI.** They will also provide access to the training on how to use it. There are two different brands for these in the UK – Jext® and EpiPen® – each differ in how to use them.

- ❖ It is vital that 2 of the same product name are always prescribed and available for use, as both may be needed in the event of an emergency.
- ❖ You should also check the expiry date of the AAIs to ensure that they are still usable. If you have any doubt, check with the dietitian/paediatrician/allergy nurse/GP/pharmacist.

Allergy UK provide an information leaflet on Adrenaline Auto-Injectors and it is available by clicking this [link](#) if you are viewing this from your phone/tablet/computer.

There may be circumstances where schools agree to a spare AAI being stored on school premises – this is in addition to the 2 AAIs that should always be with the child. You can access guidance for schools about this by clicking [here](#) if you are viewing this from your phone/tablet/computer.

(Please tell your GP/dietitian/paediatrician/allergy nurse if you don't have access to the internet and need paper versions of these leaflets.)

20. Useful contacts for further support

“When babies cry, it can be stressful and overwhelming. Help is out there and all you need to do is ask. Talk to someone if you need support, such as your family, friends, midwife, GP or health visitor.”

If you are viewing this leaflet from your phone/tablet/computer, click [here](#) for the **“Infant crying and how to cope – Information for parents and carers”** leaflet. *(Please tell the GP/dietitian/paediatrician/other allergy specialist if you don't have access to the internet and need a paper version of this.)*



www.iconcope.org/advice-for/parents/

Local health visiting contacts:

- **Hertfordshire residents:** contact health visiting on 0300 123 7572 and your GP can also refer you to the Herts Infant Feeding Service.
- **West Essex residents:** contact health visiting on 0300 247 0122 (Switchboard, Essex Child & Family Wellbeing Service).

More information about cow's milk allergy can be found on Allergy UK's website, www.allergyuk.org (help line 01322 619898).

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