



# <u>Information for GP Practices</u>: FREQUENTLY ASKED QUESTIONS – Cow's milk protein allergy (CMPA)

These questions/issues support the understanding of CMPA (also known as cow's milk allergy) and adherence with <a href="https://example.com/html/>
HWE CMPA Guidance">HWE CMPA Guidance</a> and <a href="https://example.com/html/>
supporting resources">https://example.com/html/>
supporting resources</a> .

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#### **SAFEGUARDING**

Child maltreatment can co-exist with other medical conditions. Contact with a child or caregivers, review of the record for prescription or audit or receipt of a health care professional letter may initially give you cause for concern:

- It is not just about stopping a formula because it is no longer being requested on prescription is the formula necessary but not being given? Why?
- Have you seen any outstanding instructions that have not been actioned?
- Do you have concerns about something you have read in the care record?
- Are key healthcare professionals supporting this child aware of current safeguarding review meetings and the support plan in place?

If, at any time healthcare professionals have concerns about the safety or wellbeing of a child in their care, they should discuss their concerns initially with their line manager or practice safeguarding lead(s) and follow their organisation's safeguarding policy.

Further information about safeguarding on HWE ICB website can be found here.

#### **ICON**

#### www.iconcope.org/

This is an initiative supporting caregivers and healthcare professionals to prevent abusive head trauma. It helps people who care for babies to cope with crying.

- Resources are available for HCPs <u>here</u>
- There are various resources for caregivers on the website: Click <a href="here">here</a> for "Infant crying and how to cope –
   Information for parents and carers" leaflet and <a href="here">here</a> for an easy read version of this.



Infant crying is normal



Comforting methods can help



It's OK to walk away



Never, ever shake a baby

Speak to someone if you need support such as your family, friends, midwife, GP or health visitor.

### **Local health visiting contacts:**

Hertfordshire residents: Contact health visiting on 0300 123 7572.

GP can also refer to Herts Infant Feeding Service.

West Essex residents: Contact health visiting on 0300 247 0122.

(Switchboard, Essex Child & Family Wellbeing Service).

### 1. Parents/caregivers don't want to do the HOME MILK CHALLENGE – is it necessary?

The HOME MILK CHALLENGE is **intended for** and is the *only way* to diagnose the most common form of CMPA – *mild/moderate non IgE mediated (delayed onset) CMPA*. After around 4 weeks on a cow's milk free diet, it involves reintroduction of a very small amount of cow's milk protein to see if the same symptoms result, thereby confirming the diagnosis.

- This process is explained in the <a href="MAP resource"><u>iMAP resource</u></a> if formula fed, it would mean starting with adding a scoop of the original OTC infant formula with the remaining scoops of CMPA formula in the first feed of the day and gradually building up unless and until symptoms return. If exclusively breastfeeding led to the original symptoms, mum would gradually reintroduce cow's milk back into her own diet. As soon as symptoms return, the trial is stopped. If symptoms don't return, this would indicate the original symptoms were not due to CMPA and there is no need for the CMPA formula/cow's milk free diet.
- ❖ Diagnosis is key to prevent unnecessary dietary restrictions and inappropriate prescribing, which could risk child feeding/growth issues, and impact on availability of CMPA formulas and prescribing spend.
- ❖ This is not solely the responsibility of the dietitian/paediatrician/allergy nurse the GP can initiate and follow up.
  NOTE please do NOT promote the HOME MILK CHALLENGE for suspected IgE mediated (immediate/acute onset) CMPA diagnosis for that is by blood test/skin prick test in the specialist allergy setting.

#### 2. If mum is breastfeeding, should they exclude cow's milk from their own diet?

Some milk proteins from mum's diet can pass through breast milk and cause symptoms of cow's milk allergy in their child. However, much less milk proteins pass through breast milk, and consequently it is when infant formula or solids are started (also known as weaning) that a child with CMPA is more likely to experience symptoms.

GP should undertake an allergy focussed clinical history to determine how symptoms presented:

- Mum would need to exclude cow's milk from her own diet if symptoms presented when solely breastfeeding.
- If the child had not experienced any symptoms when being solely breastfed and mum was still including cow's milk in her own diet, mum would NOT need to exclude cow's milk from their own diet. However, the child's diet (if having solids) must be cow's milk free, and any top up formula must be a prescribed CMPA formula.
- ❖ It is recommended that mum purchases a daily vitamin D supplement providing 10 micrograms/400 IU vitamin D and if mum's own diet is cow's milk free, also a daily calcium supplement providing 1000mg calcium (as it can be difficult to meet calcium requirements when breastfeeding on a cow's milk free diet).
- Refer to HWE Cow's milk free diet for breastfeeding mum and Cow's milk free diet for child.

#### 3. Are lactose free infant formulas/other animal milks suitable for children with CMPA?

Lactose free formulas/products are <u>not</u> suitable for children with CMPA as they still contain milk proteins.

❖ Lactose intolerance tends to be a transient issue following gastrointestinal upset resulting in temporary inability to digest lactose with symptoms such as bloating and diarrhoea. It usually resolves in a matter of weeks. It is not the same as CMPA, which is an immune mediated reaction to the proteins in cow's milk.

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

#### 4. Parents/caregivers report their child is not tolerating the taste of the CMPA formula.

These formulas do taste different, and it will take time for the child to take the formula so readily. It is important to set expectations with the parents/caregivers that it will take time for their child to fully tolerate the taste of the CMPA formula and for symptoms to subside (refer FAQ 5 below). This will help to prevent premature review when parents/caregivers expected a quicker improvement. It may help to add a drop of (alcohol free) vanilla essence to the feed.

Provided the child does NOT have suspected IgE mediated (immediate/acute onset) CMPA, initially the formulas can be mixed to encourage taste acceptance - e.g., mix 25% of the CMPA formula with 75% of the cow's milk based formula, then change to 50% of each and so on until finally full feeds of the CMPA formula are taken. Mixing should last only a few days and will delay symptom improvement, hence the quicker the child is on full feeds of the CMPA formula the better.

#### 5. How long does it take for gastro symptoms or eczema to settle/show significant improvement?

It can take up to 2-4 weeks after starting the CMPA 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 the child is experiencing severe symptoms. It is helpful to advise parents/caregivers that it will take time and to persevere. Audit has found frequent examples of parents that will attend A&E/return to the GP prematurely as they expect an immediate resolution, resulting in inappropriate escalation in treatment to an amino acid formula.

### 6. Some of the CMPA formulas have different stages according to the child's age – is it necessary to change?

There are 2 extensively hydrolysed formulas (EHFs) - Nutramigen LGG range and Aptamil Pepti range - where there is a first stage infant formula and then alternatives from age 6 months.

- ❖ Both Nutramigen 1 with LGG and Aptamil Pepti 1 are suitable from birth across the 12 months age range hence even though there is a Nutramigen 2 with LGG and Aptamil Pepti 2, which are suitable from age 6 months onwards, there is no need to change to them the child can remain on the first stage formula in the range.
- ❖ Whilst routinely the first stage formula will suffice, there are some circumstances where the dietitian may feel that the second stage formula is more appropriate. For example, where the child is > age 6 months, is tube fed and has not started solid foods (also known as weaning) or is not progressing on solid foods as expected, the dietitian may request the second stage formula (such as the Nutramigen 2 with LGG) for that child.
- See also <a href="HWE Managing supplies and when to stop the formula guidance">HWE Managing supplies and when to stop the formula guidance</a>, for circumstances when the second stage formula might be appropriate.
- **DO NOT PRESCRIBE** Nutramigen 2 with LGG or Aptamil Pepti 2 if the child is <u>under the age of 6 months</u> as that is unsafe. It is not appropriate to prescribe an infant formula intended for an age older than the child.
- ❖ Some of the highly specialist CMPA formulas have specific age ranges see below but these should not be initiated in primary care.

#### 7. When is it appropriate to prescribe an amino acid formula (AAF)?

HWE CMPA Guidance details the agreed CMPA formulas and when an amino acid formula (AAF) is routinely appropriate.

Below details <u>additional circumstances</u> where an AAF may be appropriate - and whether the GP can initiate the AAF in such circumstances (refer immediately to the dietitian, if not already done so).

The dietitian/paediatrician/allergy nurse will state the clinical justification in their letter if they are requesting the prescription.

Clinical justification for an AAF (This would be a HWE agreed AAF unless justified otherwise – see FAQ 8 below)	Dietitian/paediatrician/ allergy nurse initiate	**GP can initiate
Anaphylaxis (as stated in HWE CMPA guidance)	YES	YES
If no significant improvement in symptoms following 2 weeks trial of an extensively hydrolysed formula (EHF)	YES	YES
If there is confirmed faltering growth	YES	YES
If there are severe gastro issues (under 2° or 3° care)	YES	NO
If mum is exclusively breastfeeding, looking to start formula, and symptoms were severe (if symptoms mild, an EHF may well be appropriate)	YES	NO

<sup>\*\*</sup>The last column details where it may also be appropriate for the GP to initiate an AAF – however, these circumstances should be understood in the context that 90% of children with CMPA should tolerate an EHF – there is an overprescribing of AAFs in HWE initiated without clinical justification.

## 8. When is it appropriate to prescribe an alternative CMPA formula (i.e., not one in HWE CMPA guidance)?

Below provides explanation of when these highly specialist products may be appropriate. They are <u>not</u> for primary care initiation. In all cases, the child must remain under the dietitian.

The dietitian/paediatrician/allergy nurse will state the clinical justification in their letter:

HIGHLY SPECIALIST CMPA FORMULA/PRODUCT	EXPLANATION
Aptamil Pepti Syneo (£10.98/400g, £21.97/800g)  NOT FOR PRIMARY CARE INITIATION CHILD MUST REMAIN UNDER THE DIETITIAN  Neocate Syneo (£24.82/400g)  NOT FOR PRIMARY CARE INITIATION CHILD MUST REMAIN UNDER THE DIETITIAN  Aptamil Pepti Junior (£18.85/450g)  NOT FOR PRIMARY CARE INITIATION CHILD MUST REMAIN UNDER THE DIETITIAN  CHILD MUST REMAIN UNDER THE DIETITIAN	<ul> <li>Occasionally these may be requested by the dietitian if there is persistent mucus in nappies.</li> <li>Specific contraindications require specialist consideration – expected low use items ongoing.</li> <li>Audit has found that these products are often prescribed in error as "look alike sound alike" errors.</li> <li>Generally used in specialist gastro patients, post-surgery rather than for CMPA.</li> </ul>
Neocate Junior (£37.44/400g)  NOT FOR PRIMARY CARE INITIATION CHILD MUST REMAIN UNDER THE DIETITIAN	<ul> <li>Not suitable for children under the age of 1 year.</li> <li>Generally used as part of an enteral feeding regime (tube feeding) for children aged 1 -10 years with severe gastro issues.</li> <li>Very occasionally, the dietitian may request this product for a child over age 1 year with a combination of multiple food allergies including CMPA, AND where the child is unable to tolerate non-dairy alternative milks, AND there is faltering growth – due to limited options in the age 1-3 year category which support growth for these children.</li> <li>Often wrongly initiated by GPs believing it is a follow on from Neocate LCP - it is not.</li> </ul>
Neocate Spoon (£55.80/15x37g sachets)  NOT FOR PRIMARY CARE INITIATION CHILD MUST REMAIN UNDER THE DIETITIAN	<ul> <li>This is not an infant formula.</li> <li>Highly specialist short term product for children aged 6 months onwards.</li> <li>Expected low use item ongoing.</li> <li>Dietitian may request occasionally for children with multiple food allergies and resultant minimal options for introducing solids (also known as weaning).         Request will include very clear instructions on amounts required - 1 prescription initially to check if accepted by child &amp; then maximum 2 further issues.</li> </ul>

(Date product costs established: 09/04/2024, MIMS)

#### **LOOK ALIKE SOUND ALIKE ERRORS:**

- Many prescribed nutritional products are very similar in name.
- <u>HWE CMPA Guidance</u> includes **Neocate LCP 400g** as the second line amino acid formula do not confuse with other Neocate products detailed above.

#### **DO NOT PRESCRIBE:**

**Alimentum** and **Elecare** remain unavailable in the UK at the time of writing – these products were subject to product recall in March 2022.

## 9. Parents/caregivers do see a private paediatrician and then insist on the formula recommended by the private HCP – it is very difficult to deal with – what do you suggest?

- Please continue to reinforce to the parent/caregiver that <u>HWE CMPA Guidance</u> applies (including the CMPA formula and amounts) whether accessing NHS or private care.
- ❖ When the parent/caregiver requests a referral letter, ensure that the referral is addressed to an "allergy specialist paediatrician".
- ❖ At the same time the referral letter is provided, advise parent/caregiver that if a CMPA formula prescription is required, the patient must see a dietitian. See <a href="https://example.com/html/>
  HWE CMPA Guidance">HWE CMPA Guidance</a> for details of who to refer to.
- ❖ Parents may wish to see a private dietitian if so, they must provide the practice with copies of the dietitian letter(s).
- At all times, if the private HCP requests a CMPA formula that is not a HWE agreed formula or type (i.e., an AAF is requested rather than an EHF), clinical justification must be provided (see FAQs 7&8 above).
- \* Refer also to HWE Guidance on Requests for NHS Prescribing following a Private Consultation.

### 10. What about soya?

Some parents/caregivers may wish to give **SMA Soya Infant Formula** instead of the prescribed CMPA formula.

- **❖** It is <u>not</u> recommended as first line treatment for CMPA.
- ❖ It is <u>not</u> usually recommended for children <u>under the age of 6 months</u> due to phytoestrogen content. However, there are <u>rare circumstances where SMA Soya Infant Formula is the only formula suitable in children under the age of 6 months e.g., in children with <u>galactosaemia</u> this must still be **PURCHASED OTC** (<u>NOT</u> prescribed).</u>
- ❖ Over the age of 6 months, it may be given on the advice of the dietitian/paediatrician/allergy nurse (note children with CMPA can also react to soya). If it is appropriate, it must be PURCHASED OTC (NOT prescribed).

Although children with CMPA can also react to soya, avoid scaring at the point of diagnosis of CMPA. Otherwise, the parent/caregiver will automatically assume their child has a soya allergy as well as CMPA and this will make the dietary changes needed more challenging and can be more anxiety provoking.

Following dietitian/paediatrician/allergy nurse assessment:

- ❖ If removing cow's milk from the diet only results in partial resolution, the dietitian/paediatrician/allergy nurse may recommend trialling exclusion of soya too.
- If exclusive breastfeeding, they may recommend that in excluding cow's milk from their diet, mums do not substitute in additional soya.

In the same way that there is a Milk Ladder (method of reintroducing cow's milk slowly on guidance from an appropriate HCP), there is a Soya Ladder. The dietitians will provide the Soya Ladder to patients, when appropriate, - it is not freely available as it requires specialist dietitian support as a condition precedent to release of this resource.

### 11. Parents/caregivers are worried that their baby's stools (poo) have changed in colour/frequency.

- It is common for children on a CMPA formula to pass green stools this is not a cause for concern. They may also open their bowels less frequently once on the CMPA formula.
- If there are concerns the 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.
- ❖ It is difficult to succinctly give all scenarios of what constitutes constipation in a child depending on their age, whether exclusively breastfed etc. refer therefore to NICE constipation guidance in children & young people CG99 and GP Infant Feeding Network UK (GPIFN) constipation information summary.
- ❖ It is pertinent to note here, however, that the stool pattern of an exclusively breastfed baby changes after age 6 weeks bowels do open less frequently. At that stage, it is not uncommon for an exclusively breastfed baby to go 5-7 days without passing a stool and in the absence of symptoms (refer CG99 & GPIFN links above), this is not a cause for concern.

12. The dietitian has advised that the CMPA formula can stop at age 1 year, but the child is still not tolerating cow's milk to drink. What are the suitable non-dairy alternative milks?

HWE CMPA - Managing supplies and when to stop guidance, explains when it may be safe to stop the CMPA formula in a child over the age of 12 months, and the actions required - see page 2 - the "5 STEP CHECK".

There are various fortified non-dairy alternative milks available in supermarkets that are suitable for a child over the age of 1 year to drink, who is not yet able to tolerate cow's milk but, for whom it is safe to stop the CMPA formula:

- These may be made from soya, oat, coconut, almond, pea protein etc.
- Avoiding any known allergens for the child (e.g., soya milk if has concurrent soya allergy), the best milks to opt for are those fortified with both calcium and iodine. At the time of writing *Alpro Soya Growing Up Drink 1-3+®*, *Alpro Oat Growing Up Drink 1-3+®*, *Oatly®Barista* (also known as *Oatly®Foamable*) and *KoKo®Super* are examples of options in this respect, but supermarkets also do their own versions of various non-dairy alternative milks. These can be used in foods from age 6 months and as a main drink from 1 year of age.
- ❖ Note that any product labelled as organic will <u>not</u> 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).

## 13. How long should a child remain on the CMPA formula? We have mums who insist the child needs it at age 2 or 3, even when the dietitian has guided that the formula can stop.

By the age of 1 year, most children will no longer require a CMPA formula. Parents can be anxious about reintroducing cow's milk products when guided to do so - and request the CMPA formula prescription for longer than is clinically indicated. Audit has found delayed introduction to solids and other feeding issues in such patients.

- ❖ HWE CMPA Formula Flow Chart details the life of a CMPA formula prescription.
- Some children with IgE mediated (immediate/acute onset) CMPA will have lifelong allergy, and there may also be other issues such as faltering growth or multiple food allergies, which require the CMPA formula to continue past 1 year of age such children must remain under the care of a dietitian.
- ❖ HWE CMPA Managing supplies and when to stop guidance explains when it may be safe to stop the CMPA formula in a child over the age of 12 months, and the actions required see page 2 the "5 STEP CHECK".
- Very few (e.g., with severe allergy) will need the CMPA formula beyond 2 years of age.
- Provided the child meets the "5 STEP CHECK", there is no clinical justification for continuing the CMPA formula prescription past 1 year of age and the prescription should be stopped.

## **14.** Are there ScriptSwitch messages and prescribing templates in SystmOne & EMIS to support the guidance?

- Scriptswitch messages for CMPA products have been live for some time these are reviewed periodically and incidentally with any changes in guidance or products.
- CMPA prescribing templates are available in SystmOne and EMIS, but these will require full review once the new guidance is ratified and will take time to update.

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