



PATIENT INFORMATION

Milk Oral Immunotherapy (MOIT)



You have been given this information on milk immunotherapy as we have discussed this with you in your child's recent allergy clinic appointment. Please take the time to read this information and ask us if you have any questions. Contact details are provided at the end of the document.

Introduction

Cow's milk is the most common cause of food intolerance, affecting 2-3% young children. Symptoms can include skin rash, itching, wheezing and cough, vomiting and diarrhoea. Most children will start to outgrow their milk allergy at school age. Some will resolve completely, others will only have slight improvement, which may mean that they can take a small amount of milk, but larger amounts may still cause unpleasant symptoms or allergic reactions.

MOIT is short for 'Milk Oral Immunotherapy.' The term 'desensitisation' is also sometimes used. This is a treatment programme where children are given an increasing amount of fresh milk to help them develop tolerance to cow's milk. The purpose of MOIT is to increase the tolerance to milk so that larger amounts of milk can be taken without any allergic symptoms.

It is important that when a child is on this treatment programme that they follow a strict milk-free diet, until they have complete resolution. The only milk they may have is the daily dose on their treatment plan. Every day, your child will drink a 'dose' as outlined in the protocol below. At the end of the treatment protocol, your child will drink 250mls of fresh cow's milk, or as much as they can tolerate without symptoms.

Any skipping of stages to speed up the reintroduction plan could result in a reaction and we strongly advise you not to do this.

We will ask you to sign a consent form before starting treatment. This is to ensure that you are familiar with the purpose of this treatment and an agreement to adhere to the 'golden rules' of the protocol.

What side effects will my child experience?

During the treatment protocol, your child may experience mild allergic side effects such as rashes, lip/facial swelling, wheeze and abdominal discomfort. Severe or

‘anaphylactic symptoms’ occur rarely, however, as the child is taking a food to which he or she is allergic, we prescribe an Adrenaline Auto Injector (AAI) as a precaution. We will train you in how to recognise an anaphylaxis and how to use your emergency treatment.

When do I give the milk dose?

This treatment involves giving a measured dose of milk, every day for a minimum of 67 days.

The first dose is given under supervision, in hospital. We recommend that each subsequent dose is given in the morning, at home.

We also recommend that exercise and hot showers are avoided 1 hour before and 2 hours after the milk dose is given. This is because these activities can act as ‘co-factors’ and can bring about a reaction or make one worse. So there may need to be some adjustments to your normal home routines, in order to fit the milk dosing into your family life.

What happens if symptoms develop?

Follow your allergy action plan. If the symptoms are mild, give your child antihistamines to relieve the symptoms. Once your child is well and symptoms have resolved, you must notify the allergy team.

We will usually advise you to go back 4 levels (days) on the treatment plan and continue at this level for 7 more days. If symptoms settle after 7 days, continue taking this dose for another 7 days and then progress with the treatment plan. If symptoms do not settle within 7 days then contact the allergy team and take regular antihistamines until symptoms settle (we may advise going back again).

You will have been advised on which antihistamine to use and at what dose. In the rare event that your child has anaphylactic symptoms, treatment with your AAI will be necessary.

Will my child’s milk allergy completely resolve at the end of the programme?

Sometimes, children do not achieve the maximum dose of 250ml (1 glass of skimmed or semi skimmed milk). We will advise you to continue daily milk exposure at the

lower dose that your child has been able to tolerate. After 3 months we may try to achieve the maximum dose again.

It seems that once a child has reached a maximum dose and can tolerate drinking a good amount of milk each day, that they must continue to consume milk and/or other dairy products daily (or almost every day) to help maintain their tolerance.

Golden Rules

- ✓ Follow the dosing protocol as outlined – do not skip steps. You can repeat the same step if you wish.
- ✓ Speak to the allergy team before moving up a **stage**. We might ask you to repeat the last dose for a few days/weeks if we feel this is necessary.
- ✓ Avoid strenuous exercise 2 hours after the milk dose and 1 hour before.
- ✓ If your child is ill or has a fever do not increase the dose of milk, continue on a lower dose and do not move up until they are fully recovered.
- ✓ If you have an allergic reaction to another food then treat as appropriate and remain on the same dose for 3 days after the last symptoms have resolved before restarting dose escalation.
- ✓ Contact the allergy team if your child has an allergic reaction.
- ✓ If you are concerned and you are unable to speak to a member of the allergy team then do not escalate the dose of milk

Contact details for the Allergy Team

In the first instance, please use the contact numbers for the secretaries at the top of your clinic letter

Or

please contact the allergy team on:

Tel: 07564 848463

Email: wah-tr.paediatricallergy@nhs.net

Information on the milk dosing schedule

Please ensure that you follow the dosing instructions exactly as written below. There are three stages – the first and second stages involve carefully diluted milk solutions. We will explain to you how to do this, and provide the equipment.

- a. **STAGE 1** Dilution – 1ml of milk is added to 99ml of water (100ml solution) i.e. 1% solution
- b. **STAGE 2** Dilution – 1ml of milk is added to 9ml of water (10ml solution) i.e. 10% solution
- c. **STAGE 3** – Fresh milk

Each stage requires a larger dose of milk as per the instructions below.

- ✓ Three days before each step you must contact your allergy team.
- ✓ While following this protocol, your child must be on a strict milk free diet.
- ✓ Use Semi skimmed or Skimmed milk for all stages.
- ✓ Please make up a fresh solution each day. Do not freeze and reheat

Equipment Required:

- | | |
|--|--|
| <ul style="list-style-type: none">• 1 x 1 mL Syringe• 1 x 10 mL syringe• 1 x 20 mL Syringe | <ul style="list-style-type: none">• 1 x 50 mL Syringe• 2 x pipettes• A clean container |
|--|--|

STAGE 1: Add 1 ml of Milk + 99 ml of Water. Mix			
Day	Date (for your completion)	volume to give	unit
1		1	Drop
2		2	Drops
3		3	Drops
4		4	Drops
5		5	Drops
6		6	Drops
7		7	Drops
8		8	Drops
9		9	Drops
10		10	Drops
11		14	Drops
12		20	Drops

Please ensure you have contacted your allergy team before proceeding to Stage 2			
STAGE 2: Add <u>1</u> ml of Milk + <u>9</u> ml of Water. Mix			
Day	Date (for your completion)	volume to give	unit
13		3	Drops
14		4	Drops
15		5	Drops
16		6	Drops
17		7	Drops
18		8	Drops
19		10	Drops
20		14	Drops
21		20	Drops

Please ensure you have spoken to your allergy team before proceeding to Stage 3			
STAGE 3: <u>Pure Milk</u>			
Day	Date (for your completion)	Volume to give	unit
22		3	Drops
23		4	Drops
24		5	Drops
25		6	Drops
26		7	Drops
27		8	Drops
28		10	Drops
29		14	Drops
30		20	Drops
31		1.5	ml
32		2.0	ml
33		2.5	ml
34		3	ml
35		3.5	ml
36		4	ml
37		5	ml
38		6	ml
39		8	ml
40		10	ml
41		12	ml
42		14	ml
43		16	ml
44		18	ml
45		20	ml
46		22	ml
47		24	ml
48		26	ml
49		28	ml
50		30	ml
51		33	ml

52		36	ml
53		40	ml
54		50	ml
55		65	ml
56		85	ml
57		100	ml
58		130	ml
59		140	ml
60		150	ml
61		160	ml
62		170	ml
63		180	ml
64		190	ml
65		210	ml
66		225	ml
67		250	ml

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Friday from 8.30am to 4.00pm. Please be aware that you may need to leave a voicemail message, but we aim to return your call within one working day.

If you are unable to understand this leaflet, please communicate with a member of staff.