R.I.S.A. INC

CONTACT TRAINING PROGRAMME: PART B

REFLUX INFANTS SUPPORT ASSOCIATION INC.

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GENERAL INFORMATION ABOUT REFLUX AND ITS MANAGEMENT

Most calls will be from mothers with babies with symptoms of 'normal' reflux i.e. they will exhibit 'normal' reflux behaviours.

Having simple bits of information about such behaviours can make the world of difference in management e.g. knowing that some children seem to be more irritable about an hour after a feed can help a mother understand the comfort feeding pattern, plan the day better and so on.

As we become more experienced Contacts, it is important not to withhold simple information. We must not forget that we are talking to someone who may be experiencing reflux for the first time.

It is also encouraging for a mum to hear that her baby is 'normal' after all, albeit 'normal for a refluxer'. This can help to improve her self-confidence by letting her know that the baby's behaviour is the normal result of reflux, and not the result of her mothering techniques.

Give suggestions on that basis that:

- ✓ All babies are different; this may or may not work for your baby but it may be worth a try (if you feel comfortable with the idea).
- ✓ Try those things that fit your situation and what you want for your baby, routine, etc.

WHAT IS REFLUX?

Gastro-oesophageal reflux (often just called reflux) is a condition in which the acidic contents of your stomach, (partially digested food and acid), frequently reflux (wash back) into the oesophagus. It may or may not cause vomiting.

TIME FRAME

Always be positive when answering the inevitable question about how long the reflux will last, especially when talking to a mum with a baby of a few weeks of age. Be prepared for this question.

One possible response could be that giving a time frame is difficult because every child is different, and they all improve at their own rate. Milestones can be helpful to know because most babies will improve at those times, but be aware this is not always the case (so try not to get your hopes up too far- it's difficult to deal with if it doesn't happen at that time). Milestones generally given are at 6 months (i.e. when baby is sitting up and eating solids), and by the time they are walking. You could mention there is a chance of regression for a while, during the time they are crawling, or learning to crawl (as they spend more time horizontal).

There is always hope the child will improve earlier rather than later. In the meantime, it may be best for parents to focus on managing the reflux and taking each day as it comes.

REFLUX MANAGEMENT OPTIONS

All children with reflux are individual. In some situations medical advice and reassurance may be all that is needed, while in others it may take some time to find the treatment that works best.

1. Lifestyle changes (also known as conservative treatments).
2. Medications (if a child's symptoms are severe or persistent). Doctors may also occasionally use medication for a limited time to help determine if a child's symptoms are due to reflux.
3. Referral to a paediatrician or paediatric gastroenterologist for further evaluation.
4. Surgery in a very small number of cases.

HEALTH PROFESSIONALS WHO MAY PLAY A ROLE

- Doctors (GPs, paediatricians, paediatric gastroenterologists, paediatric allergists, paediatric surgeons, paediatric respiratory specialists)
- Child Health Nurses; midwives
- Allied health professionals (e.g. speech pathologists, dietitians, psychologists)
    - Speech pathologists – who specialise in feeding and swallowing issues (local children's hospital feeding team)
        - Suck-swallow-breathing co-ordination
        - Bottle fed infants- the most appropriate teat and bottle to suit
        - Transitional feeding problems- delayed starting of solids, difficulty managing lumpy food etc
        - Behavioural feeding problems related to illness
        - Oral stimulation for infants receiving tube feeds
    - Dietitians – who specialise in children with feeding problems or food sensitivities
        - Volume of feed required to meet calorie and nutrient requirements
        - Bottle fed infants- most appropriate formula
        - Diet changes necessary in response to food allergies or intolerances
        - Ideas on the texture of food and all other factors that affect reflux
    - Lactation consultants
- Complementary medicine (alternative) therapists (e.g. Bowen therapists, chiropractors, massage therapists, osteopaths)

COMMON REFLUX BEHAVIOURS AND STRATEGIES

Suggestions from other reflux parents. Families should always check with their doctor or child health nurse if they are unsure of any strategy, or if they have concerns.

- ✓ **Reflux may be worse about an hour after a feed**. This may be because the stomach is actively digesting the feed. Baby may be more irritable or may display other reflux signs an hour after a feed; they may want to feed again an hour after a feed as this can be soothing to some babies; and some babies catnap (sleep for very short periods e.g. 5 or 10 minutes after a feed)

- Feed baby as upright as possible, and try to keep them upright for half an hour after a feed.
- Avoid lying baby flat or putting them in an upright seated position immediately after a feed.
- Avoid overfeeding baby – if baby vomits after a feed, do not feed them again. Wait until they are due for their next feed (Talk to a child health nurse if parents are unsure or worried baby isn't getting enough)
- Offer smaller meals more often
- Try to settle baby within an hour after a feed
- Notice signs of irritability before it escalates and try to settle baby earlier rather than later
- Parents may like to consider offering baby a dummy/pacifier or a clean finger as sucking can help some babies to settle
- Change baby's nappy before a feed rather than after, if possible
- Avoid tight nappies and elastic waistbands
- If baby is demanding a feed before they are due, try to postpone the feed. Try distracting them e.g. taking them for a walk
- Complete the feed within the hour (including solids). Try giving solids and milk feed at the same feed. When solids are started it is easy to fall into a 2 hourly feeding pattern with milk feed at 6am, cereal at 8am, milk feed at 10am etc
- Consider using thickeners as this can help some babies (it won't help all babies)
    - Bottle fed babies can use AR (thickened) formula or use formulas thickened with commercial food thickeners
    - Breast fed babies can have a spoonful of milk or water thickened with commercial food thickener before or after a feed
- If baby continues to be distressed an hour after a feed, discuss concerns with the doctor

✓ **Babies may wake or can be harder to settle between the hours of midnight and 2am.** Many parents report this

- Understanding there could be a reason for baby's constant waking may help parents cope, and stop them becoming angry with baby.
- Try to avoid feeding them unless they are due for a feed as this can set up the 'feeding every hour' routine
- If possible, take turns with partner with shifts or night about
- If you need to talk, call a 24 hour helpline
- Plan ahead to deal with night-time wakefulness. It may help to remember parents need/want baby to sleep at that time so keep activity quiet and restful. Dim lights.
- As a last resort if baby won't settle, it may help to turn on the lights and television, make a warm drink and accept you will be up for a while. This may help prevent you from becoming angry.
- Talk to the doctor if the situation continues

✓ **Baby capsule may place baby in a U-shaped position.** This can cause pressure on their abdomen, which may result in more reflux episodes during car travel.

- Try to limit car travel to short trips

- Time your travel to the time of day when baby is least likely to be refluxing e.g. before a feed rather than after.
- Invite friends to visit you. If a friend invites you to dinner or lunch, ask if they would mind bringing the meal to your home instead, and explain the reason why.
- If prescribed, try using an antacid just before the car trip
- Try relaxing music on the car trip
- Place baby in upright car seat as soon as it is safely practicable, or experiment with alternate baby seats, if able

✓ **Increase in abdominal pressure may cause more reflux episodes.** This may be the result of such things as overfilling the stomach, greater activity and movement on the part of the baby.

- Avoid overfeeding. If baby vomits, wait to feed them when they are next due for a feed. Parents should talk to their child health nurse if they are concerned about their weight or unsure if baby is taking enough food
- Try offering smaller feeds more often
- Try using some milk from the feed to mix with cereal, vegies etc when solids are commenced rather than giving all the milk feed and then following with extra solids
- Avoid tight nappies and elastic waistbands
- Avoid car seat positioning immediately following a feed
- Avoid baby slumping as this can cause more reflux episodes
- If baby is distressed, try to comfort them earlier rather than later. Crying and coughing can increase abdominal pressure

✓ **Parents often report that their child's reflux worsens at times of stress** e.g. teething, overtiredness, illness or infection, pain, change in routine, change in weather, vaccinations etc; when they are crawling or learning to crawl or they are constipated

- Try to develop as much of a routine as possible, especially with feeding and sleeping
- Being aware of the reason behind a baby/child's distress can sometimes help families cope
- Try to address any underlying issues and if the child does not settle, talk to the doctor
- Do not presume reflux is the reason for a baby or child's irritability. If parents are concerned or the bad episode persists, they should talk to their doctor.

✓ **Reflux is often worst around the age of 4 months.** It has been shown that reflux peaks at around 3 – 4 months of age, when babies are much more active and aware, and when fluid intake is very high. The degree of reflux drops off gradually until around 6 months, when the child sits up, but tends to increase again at around 7 – 8 months when crawling begins. (Dr Mark Patrick, The symptoms and medical management of gastro-oesophageal reflux. VISA Seminar, Brisbane 1992)

✓ **Reflux can be cyclic –** baby can have good and bad days or good and bad times of the day

- Persist with new things for a few days, not just once
- Retry things which did not work in the past. They may work when the child is older.

SUMMARY OF LIFESTYLE CHANGES

Lifestyle changes may help to control your child's reflux or make them feel more comfortable. It may involve trial and error to find the strategies that work best. Keep in mind that even if medications are used, these strategies can still be helpful.

1. Avoid exposure to tobacco smoke.
2. Feed babies in an upright position if possible, and keep them upright for at least thirty minutes after each feed. Older children should avoid lying down for several hours after a meal.
3. Try feeding smaller amounts more often, unless this upsets them. Frequent large feeds can trigger reflux. Older children should eat smaller meals more frequently and avoid large meals, especially before exercise, or bedtime.
4. Avoid overfeeding. It is not recommended to feed babies again if they vomit. Talk to your doctor or child health nurse to ensure your infant is taking appropriate amounts of food.
5. Burp baby more often (as tolerated).
6. Thickened feeds may be effective for <u>some</u> babies, especially those who vomit.
7. Avoid tight clothes e.g. nappies and elastic waistbands; and ensure clothing around abdominal area is loose fitting.
8. If comfortable considering this, offer baby a dummy/pacifier (or clean finger), as non-nutritive sucking may help baby to settle
9. Minimise foods and drinks that cause irritation, or increase the risk of reflux. Examples of these are spicy foods, citrus fruits, tomatoes and other acidic food, fatty foods and caffeine.
10. Consider food sensitivities
    a. "*Difficulty with any foods may be* indicators that investigation for *suspected food intolerance* should be considered." Joan Breakey, dietitian
    b. In babies- if a food allergy or intolerance is suspected, a two week trial of hypoallergenic formula can be helpful if your infant is formula-fed. If breastfeeding, mothers may choose to eliminate specific foods e.g. cow's milk and soy from their diet (with medical supervision)
    c. In older children- Consider the possibility of food allergy or intolerance; in particular to cow's milk protein, and seek medical advice
11. Older children should also
    a. lose weight if they are overweight
    b. avoid or minimise caffeine as caffeine has been found to relax the lower oesophageal sphincter, increase the amount of gastric acid secreted, and increase the risk of GORD. It can also impact on sleep and can cause irritability and anxiety. Caffeine can be found in tea, coffee, energy drinks, some soft drinks (e.g. colas), cocoa and some over the counter medications
    c. avoid alcohol and cigarette smoke (and all types of tobacco) as these can decrease the tone of the lower oesophageal sphincter. Cigarette smoke also irritates the oesophagus and lungs
    d. consider using chewing gum after meals as it may reduce acid reflux and help clear acid from the oesophagus
    e. consider drinking a glass of lukewarm water after eating as it can dilute and wash out any acid in the oesophagus

12. Bed position
    a. **In babies under 12 months of age - elevating the head of the bed to treat gastro-oesophageal reflux is not supported by evidence from research studies**
    b. Over 12 months of age- elevating the head of the bed may reduce reflux in some children

13. Sleep position
    a. Under 12 months- as directed by doctor- follow SIDS and Kids recommendations re safe sleeping (on their back). The side sleeping position is **not** stable, increases the risk of sudden unexpected death in infancy and is **not recommended.** (see more information under Sleep positions for babies)
    b. Older children should be encouraged to find a comfortable sleeping position. Sleeping in the prone position (on the tummy) may be helpful as it has been shown to reduce episodes of reflux. Sleeping on the left side may also be helpful for some children over the age of twelve months. Discuss this option with the child's doctor.

SLEEPING POSITION FOR BABIES www.sidsandkids.org

> *DO NOT UNDER ANY CIRCUMSTANCES SUGGEST TO A PARENT THAT THEY PLACE THEIR BABY ON THEIR TUMMY OR SIDE TO SLEEP. IT IS IMPORTANT THEY DISCUSS ANY CONCERNS WITH THEIR DOCTOR*

(*Information below provided by Dr Jeanine Young, Nursing Director- Research, Royal Children's Hospital & Health Service District, Brisbane)*

Parents should ALWAYS follow the SIDS and Kids Safe Sleeping recommendations for positioning infants for sleep. **To reduce the risk of sudden infant death** and sleep baby safely, parents can (SIDS and Kids, 2007):

- **Sleep baby on their back** from birth – never on their tummy or side
- Sleep baby with their **head and face uncovered**
- Sleep baby in their own cot or bassinette in the **same room as them** for the first 6 - 12 months
- Provide a **safe sleeping environment, night and day**: safe cot, safe mattress, safe bedding and safe sleeping place
    - Put baby's feet at the bottom of the cot
    - The cot must meet the Australian standard for cots
    - No additional mattresses or extra padding should be placed in a travel cot
    - Tuck in bedclothes securely so bedding is not loose
    - Keep quilts, doonas, duvets, pillows, cot bumpers, sheepskins and soft toys out of the cot or sleeping place
    - Use a firm, clean mattress that fits snugly in the cot
    - **Bouncinettes, prams and strollers have not been designed as sleeping products and therefore baby should not be left unsupervised if they fall asleep in them**

Sleeping baby on their back does not increase their risk of breathing in or choking on their milk or vomit. Babies with **gastro-oesophageal reflux should be placed on their back to sleep on a firm, flat mattress that is not elevated** (Craig, Hanlon-Dearman, Sinclair, Taback, & Moffatt, 2004). Healthy babies protect

their airway when placed on their back, as long as their swallowing and arousal abilities are not impaired.

Side positioning is unstable and not recommended as an alternative to sleeping baby on their back. Aids and devices intended to keep baby in certain sleep positions are not recommended; they do not prevent baby from rolling onto their tummy (prone), and they limit baby's movements as they get older (SIDS and Kids, 2007) (Queensland Health, 2008).

As infants grow older, beyond the age of five to six months, they will move around the cot and roll over; however a safe cot and safe sleep environment is still necessary. Settle your baby to sleep on their back, but let them find the sleep position they feel most comfortable in (SIDS and Kids, 2007) (Queensland Health, 2008).

Parents of some infants with a rare medical condition may be advised by their doctor to sleep baby on their side or tummy, but parents should only do so if their baby's doctor advises them to in writing (Queensland Health, 2008)**.**

SHOULD I CHANGE TO BOTTLE FEEDING?

Many callers ask if they should change to bottle feeding. RISA Inc supports breastfeeding as the preferred option, however it is important to remember that as a RISA Contact **our role is to support and encourage mums through the decisions they have made in caring for their reflux babies. Regardless of our own views on breast vs bottle feeding, our role is to support the parent in their choices. RISA Inc's role as a breast feeding supporter must be seen as secondary to the role o helping the mum through the stresses of caring for a child with gastro-oesophageal reflux.**

In addition, many mums who contact RISA Inc or attend coffee mornings have already made the decision to change to bottle feeding.

INFORMATION THAT MAY HELP

The parents need information which will help them make their decision. To say that breastfeeding is best for her baby will only cause guilt should her efforts to continue breastfeeding fail. So what can we say?

1. **Changing to bottle feeding will not cure reflux.**

   It is important for parents to know this in advance so that they will not be devastated if they wean, lose their milk and find that they still have feeding problems e.g. the baby may continue to refuse the bottle instead of the breast.

   It is common for a baby to show an amazing improvement for the first three days to a week on changing to bottle feeding, so the mother may initially think she has done the right thing, only to find out later that she could have perhaps persevered. This can result in more guilt and more insecurity for future decisions.

2. **As changing to bottle feeding will not cure reflux, it is important that the mum has other reasons for changing** e.g. the pain (both emotional and physical) caused by the baby pulling on and off can no longer be endured; sleep deprivation for the mother has reached the stage that she needs to be able to leave the baby with someone perhaps for an overnight break; the baby's weight gain is slow and the mother is constantly worrying about the amount of milk when the baby is receiving; etc…

3. **When changing to bottle feeding, it may help to maintain the best breast feed of the day**, often the early morning or middle of the night feed. Often mums do not realise that it is possible to produce breast milk in this way. **By maintaining one breast feed, it can be easier to reintroduce total breast feeding if bottle feeding is not successful.**

   (*Continual changing of formula is not recommended as baby has to cope with different varieties of milk. Dr Mark Patrick*)

4. **Eliminating dairy or other products totally from the breastfeeding mother's diet can sometimes cause an improvement in a baby or child with reflux**

   Several trials of a few weeks at a time are needed to be sure that such a drastic change to the mother's diet is warranted. It may be necessary for the breastfeeding mother to remove all traces of dairy from her diet – this means learning the hidden ingredients (e.g. whey, casein, lactalbumin) and reading all food labels. Soy may also need to be removed as half the babies allergic to dairy are allergic to soy. Any major changes to diet should be done in consultation with a dietitian or doctor as nutritional deficiency may result e.g. when eliminating dairy products, concerns might include the amount of calcium in the diet and whether or not to use soy milk as a substitute.

5. **It may be helpful to talk to a Lactation Consultant, Child Health Nurse or Australian Breastfeeding Association Counsellor** if problems with expressing, supply decrease and breast refusal are the reasons for considering the change to bottle feeding.

   Remember, THE DECISION LIES WITH THE BREAST FEEDING MOTHER AND NOT WITH THE RISA Inc CONTACT. Support the mother in her decision.

   If the mother's decision is to bottle feed you could say something like:
   "You must feel relieved that you have made the decision."
   "Perhaps your partner could help you with the feeds."

Listen to the problems which she is experiencing and empathise. Refer her to other support personnel as already mentioned if they have any specific breast feeding problems.

FOOD SENSITIVITY (ALLERGY OR INTOLERANCE)

Food sensitivity seems to be common in babies and children with gastro-oesophageal reflux. Medical studies link cow's milk protein allergy to reflux in over 40% of babies.

Breastfeeding – information as above. If the mother needs to avoid cow's milk for more than 2 weeks or avoid more foods, she needs advice/supervision from a dietitian who specialises in food sensitivities

Bottlefeeding – prescription formulas are available (they are expensive without a prescription).

Prescription formulas

Elemental (amino acid based) formulas – Neocate; EleCare – protein completely broken down

- Taste bitter, can be gradually changed over from previous formula over 7 – 14 days or the taste can be disguised with sugar or golden syrup if necessary. Vanilla is sometimes suggested but this is not recommended as some babies are sensitive to it.

Extensively Hydrolysed formulas – e.g. Pepti Junior; Alfaré – protein less completely broken down

Non-prescription formulas

Partially Hydrolysed (HA) formulas – e.g. Nan HA; S26HA – protein partially broken down

- If allergy to cow's milk is suspected, must only be used on the advice of the doctor

Soy formula

- should only be used when baby is over 6 months of age – talk to the doctor
- Approx half the babies sensitive to cow's milk protein will be sensitive to soy products

Goat's milk formula

- Goat's milk is as allergenic as cow's milk
- Goat's milk protein is similar to cow's milk protein and the adverse symptoms that were noticed with cow's milk often reappear approx. 6 weeks after starting goat's milk formula

Lactose free formula (lactose intolerance is a reaction to milk sugar, not milk protein)

- Not suitable where the baby is sensitive to cow's milk protein
- Lactose intolerance only produces gut symptoms

THICKENED FORMULA

Thickened feeds work well for some babies with reflux (especially those who vomit), but it does not work for all babies. It can make some more unsettled. Discuss with the doctor before trying

Thickened feeds can be used in both breast and bottle fed babies

Commercial food thickeners e.g. Karicare Food Thickener, Guarcol

- Can be mixed in formula or expressed breastmilk to the desired thickness
- A spoonful of formula, breastmilk or water can be thickened and fed to baby before or after a feed
- This allows flexibility to find the thickness that suits baby best

Thickened (AR) formulas

- Cannot alter the thickness of the formula as they must be made to the correct strength
- May need a fast flow teat

MEDICATIONS

Always recommend parents talk to their doctor or pharmacist if they are concerned or have any questions.

1. Antacids e.g. Mylanta, Gastrogel
   - short term relief
   - doctor will tell parents what the maximum dose is per day
   - can interfere with the absorption of some medications

2. Alginates/Thickeners e.g. Infant Gaviscon
   - Do not use with other thickeners unless advised by doctor

3. Histamine-2 Receptor Antagonists (H2RAs or H2 blockers) e.g. Ranitidine (Zantac)
   - Regular use
   - Syrup or effervescent tablet
   - Acid suppressant
   - Weight based- as baby puts on weight, the dose may need to be reviewed

4. Proton Pump Inhibitors (PPIs) e.g. Omeprazole (Losec); Pantoprazole (Zoton); Esomeprazole (Nexium)
   - Tablets/pellets MUST NOT BE CRUSHED OR CHEWED
   - Follow manufacturer's instructions and only use recommended food/water with specific medication.
   - Stops acid production – more effective than H2RAs

5. Prokinetics (Motility medications) e.g. Erythromycin, Domperidone (Motilium); Metoclopramide (Maxalon)
   - Regular use
   - Helps move food etc through gut quicker
   - Can affect absorption of other medications. Do not give at the same time unless advised

LOSEC (advice from AstraZeneca who manufactures Losec)

- The tablet may be dispersed in non-carbonated water (mineral water is not suitable) or non-carbonated fruit juice. Water should not be warmer than room temperature OR
- Disperse in a small amount of water and then add it to a spoonful of pureed apple, pear or yoghurt (if appropriate)
- Do NOT use milk/breast milk or formula in place of water as Losec may be less effective
- Once the tablet is dispersed in liquid, it must be consumed immediately or within 30 min
- Give at the same time each day

- SUSPENSION – must be compounded at a compounding pharmacy
  - Shake bottle well each time before use
  - Check what the suspension agent is- some compounding pharmacists use whey protein which can affect children who are cow's milk protein allergic or intolerant
  - If child has food sensitivities, the flavouring may affect them
  - Some have short shelf life – check with pharmacist
  - May not be as effective as tablets

NEXIUM (advice from AstraZeneca who manufactures Nexium)

- **Disperse ONLY in non-carbonated water**. Other liquids or purees are not suitable
- Gently stir until it dissolves into little pellets
- Administer straight away or within thirty minutes
- Can be administered through a feeding tube

ZOTON (advice from Wyeth who manufactures Zoton)

CAPSULES

- Open a capsule and sprinkle granules on some food or in a drink. Use one tablespoon of apple sauce, strained pears, cottage cheese or yoghurt and swallow immediately OR
- Use a small amount of either apple juice, orange juice or tomato juice. Stir and drink immediately. Rinse the glass two or three times with more juice and swallow it immediately each time
- **Do not use other foods or liquids** because they have not been tested for use with Zoton®. Water cannot be used to dissolve the granules inside the capsules as it affects their pH (Wyeth, 2008), although it can be used to dissolve the granules in the suspension.

FASTABS

- **Take before food on an empty stomach**
- Swallow the tablet whole with a glass of water, or gently suck the tablet, then swallow the granules with saliva
- If the tablet is chewed or crushed, it will not work properly