

R.I.S.A. INC

CONTACT TRAINING PROGRAMME: PART A



REFLUX INFANTS SUPPORT ASSOCIATION INC.

ARBN 124 656 097

P.O. BOX 1598, FORTITUDE VALLEY, 4006.

PHONE: (07) 3229 1090

www.reflux.org.au

EMAIL: info@reflux.org.au

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CONTENTS

BECOMING A RISA INC CONTACT	3
BACKGROUND	4
OBJECTS OF THE ASSOCIATION.....	4
CONTACT CALLS AND EMAILS.....	5
RISA INC CONTACT CALL SYSTEM	5
RISA INC CONTACT EMAIL SYSTEM.....	6
COUNSELLING ETHICS.....	6
GIVING OUT NAMES OF DOCTORS	6
CONTACT CALL CHECK LIST	7
BASIC ROLE OF A RISA CONTACT	9
THE TYPES OF CALLS	10
PREPARING TO MAKE A CONTACT CALL.....	11
MAKING THE CALL	13
CONTACT CALL INSIGHTS.....	14
BLOCKING YOUR TELEPHONE NUMBER (information provided by Telstra)	15
CALL BACKS	16
CALLERS REQUESTING BULK BROCHURES, POSTERS ETC	16
CALLERS WITH OLDER CHILDREN.....	17
DEBRIEFING	17
SUGGESTIONS FOR CRISIS CALLS	17
SOME SUGGESTED ANSWERS FOR TRICKY QUESTIONS	18
PRACTICE QUESTIONS.....	19
PARENTS OF REFLUXERS.....	20
RESOURCES.....	21
RISA MEMORY JOGGER	22
EXPENSES SHEET.....	23

BECOMING A RISA INC CONTACT

The basic role of a RISA Contact is to communicate with other parents who want to talk about their reflux baby or child. Often this involves talking to parents over the phone, but it can also be via email, through various online forums or at Coffee Mornings, depending on your preferences.

Your Contact Trainer will lead you through a programme to help you prepare for this role, especially in relation to your first calls. You will have support from an experienced Contact for as long as you need.

Before beginning this programme there are a number of things which must be considered to help you decide whether or not you will be able to fulfil this role within the guidelines set by RISA Inc. While considering the following points, please keep in mind the basic role as stated above.

TO BE A CONTACT

1. Financial membership of RISA Inc must remain current while you continue as a RISA Inc Contact for insurance purposes.
2. You need to be a parent or main caretaker of a reflux child or be closely associated with a reflux child, and be at a stage where you can put your own experience into the background. It is essential that you focus on the problems faced by the caller/coffee morning attendee. Your reflux experience and your growing knowledge of others' reflux experiences will enable you to maximize help with their unique situation.
3. **It is the policy of RISA Inc that Contacts do not in any way intervene in the medical treatment of a reflux baby** e.g. by suggesting that the caller try a particular drug, or that the caller try natural therapies.
4. RISA Inc requires that you be familiar with the objects of the Association and that you adhere to its ethics.

If you feel uncertain about any of the above, then you may need to reconsider whether to become a Contact at this time. Please continue to phone/attend coffee mornings for support and remember that RISA Inc is always in need of help in other roles. Your honesty in this decision is valued.

IF YOU BECOME A RISA INC CONTACT

You cannot always leave your own reflux situation in the background if/when you become a RISA Inc Contact. It is important to seek support from fellow Contacts for your ongoing reflux situation. This is an ideal opportunity for discussing, in a professional way, any problems encountered in your role as Contact, in addition to your own situation.

BACKGROUND

The Reflux Infants Support Association (RISA) Inc began in 1982 (under the name of the Vomiting Infants Support Association of Queensland). Five mothers, each with a reflux infant, had a meeting because they had a common need for emotional support and encouragement. They felt that other parents would benefit from the formation of the group.

The word 'reflux' was not commonly used at that time, therefore the phrase "Vomiting Infants" was thought to be appropriate, but it has always covered all types of gastro-oesophageal reflux. Because some reflux parents were hesitant to make contact if their child did not vomit, in 2001 our name was changed to Reflux Infants Support Association Inc. (Reflux is the more commonly used term for gastro-oesophageal reflux).

RISA Inc advises parents to seek a medical opinion and then helps the family to cope with the day-to-day pressures of living with an infant or child who suffers from gastro-oesophageal reflux.

OBJECTS OF THE ASSOCIATION

- a) To encourage and to give confidence and moral support to families of children with problems associated with gastro-oesophageal reflux.
- b) To enable members to assist in providing this support and information so that families can make the necessary informed decisions.
- c) To provide a means of communication for sharing information on the care and raising of children with problems associated with gastro-oesophageal reflux.
- d) To give support to whichever form of feeding the parent chooses as best for the child, the parent and the family.
- e) To provide parent to parent contact particularly through an individual Contact role as well as group activities.
- f) To acquaint the public with the problems and the needs of the family and the child with a view to receiving understanding, support and financial aid.
- g) To encourage, assist and co-operate with the medical and allied health professions, public health and education authorities, government and welfare agencies, and other interested groups to support families of children with problems associated with gastro-oesophageal reflux.
- h) Public relations and community education including antenatal, parental and school education.
- i) To provide seminars, lectures, film screenings, speakers and any other services which the Association may consider desirable for the promotion of its objects.
- j) Undertaking sponsoring and encouraging research of the condition and liaison with interested individuals, organisations and researchers in Australia and overseas.
- k) Making available the experience of families with a child with problems associated with gastro-oesophageal reflux, and the results of research to members of the Association and to other interested persons and organisations.

- I) Collection, publication and dissemination of information for the guidance of families and others and provision of resource facilities.

CONTACT CALLS AND EMAILS

Depending on personal preferences, RISA Inc Contacts may wish to

- respond to telephone and or email messages;
- have their first name, telephone number and town/area listed in the Contacts Directory in the RISA NEWS newsletter
- hold Coffee Mornings

All expenses are reimbursed. Please keep all your receipts, complete a claim form and send to RISA's Treasurer. Claim forms can be found at the back of this manual.

TREASURER: _____

EMAIL ADDRESS: _____

ADDRESS: _____

RISA INC CONTACT CALL SYSTEM

The main telephone system is operated via the internet, so if you have internet access, you will be invited to join the online forums on RISA Inc's website. If you do NOT have internet access, you can be notified of any telephone calls that need doing (or any coffee mornings that have been requested in your local area, if you would like to host any).

The system may change from time to time; however, the system currently works with the Contact Call Co-ordinator allocating a Contact (based on suitability and availability) to do the call. All requests for Contact calls are also posted on the RISA Contact forums (Contact Calls to be done thread). If you are able to do the call, you are asked to post when it has been completed (or ask the Co-ordinator to do this for you), so other contacts are aware of this. If you are not able to complete the call for any reason, please let everyone know by posting on the forums and/or notifying the Co-ordinator so someone else can try to do the call. Please liaise with the Contact Call Co-ordinator regarding the system, and to work out a method that suits.

- Your help in updating the forums as the call is completed would be appreciated
- If you do take on any calls, please avoid calling mobile phone numbers as much as possible. If necessary, limit the time of calls – ask the caller for a landline number you can use instead.
- There are times that we get a caller's answering machine when we try to do a contact call. Please leave a message on the answering machine and ask the caller to please ring or email RISA to let us know a time that may be convenient to call.

RISA INC CONTACT EMAIL SYSTEM

Most requests for contact emails are received through RISA Inc's webmail. The system may change from time to time; however, the system currently works with the Email Secretary also having the role of Contact Email Co-ordinator. When an email is received at RISA Inc's webmail address, the Email Secretary/Co-ordinator forwards the email (without personal email address) onto an Email Contact. If you are able to do the email, you are asked to send the reply back to RISA Inc's webmail address (info@reflux.org.au). The personal email address is again removed and the reply is forwarded back to the person who submitted the email. The completed original and the reply, as well as any subsequent correspondence are saved onto RISA Inc's account at www.box.net. The responses are also posted in the RISA Contact forums (New Contact Emails to be done thread).

If you are not able to complete the email for any reason, please let the Email Secretary know so someone else can respond. Your help in updating the forums as the call is completed would be appreciated.

COUNSELLING ETHICS

<u>DON'TS</u>	<u>DO's</u>
Do not give advice or make decisions for the caller	Do suggest
Do not diagnose	Do encourage the caller to seek a medical opinion
Do not give medical advice	Do quote on information from RISA's Medical Advisory Panel or the Information Booklet
Do not pass on negative bias or prejudice about specific doctors, Child Health Nurses or hospitals	Do pass on names of at least three doctors who will be of help (but only when requested)
Do not recommend one doctor/service over another	Do give all alternatives available. Do explain they must make their own decisions.
Do not change the caller into the counsellor.	Do let them know you understand. Do give personal experiences if asked to do so

GIVING OUT NAMES OF DOCTORS

It is RISA's policy to NOT RECOMMEND particular doctors. It is important to provide the names of three doctors, but only if specifically requested. It is also important the caller decides on what type of doctor they wish to see i.e. GP, paediatrician, paediatric gastroenterologist. It may be necessary to give information on the differences between these types of doctors and encourage callers to discuss with their partners. If a person is in an outlying area, simply give the name of the doctor closest to them and then the names of two others. **In this way the caller cannot state that you have told them to see a specific doctor. It must always be their decision.** These same rules apply to other health professionals.

Traditional (Orthodox) vs Alternative (Complementary) Medicine: Do not recommend any type of alternative treatment over traditional medicine; NOR one type of alternative treatment over another.

Do not give your personal opinion on this issue. You may be able to suggest they do some research and find well respected, qualified therapists who are registered with their professional body. They may want to ask about their experience and success rate with reflux children; what to expect from treatments, how many may be required, and the estimated total cost of treatment.

Some Alternatives: Naturopathy, Osteopathy, Homeopathy, Chiropractics, Massage Therapy, Cranio-Sacral therapy, Reflexology, Bowen Therapy

Family and Home Help: Only recommend this if caller mentions not coping at home, or that there are family problems (otherwise you may be assuming there are problems when there are not.) Again, it is a good idea to give several alternatives for them to choose from.

CONTACT CALL CHECK LIST

DETERMINE IF THE CHILD HAS A DIAGNOSIS OF GASTRO-OESOPHAGEAL REFLUX

If the child **DOES** have a diagnosis of Gastro-Oesophageal Reflux, then the Contact call can proceed, and a Special Edition Newsletter can be sent to the caller.

- If you would like an email copy of the Special Edition Newsletter (SEN), please ask. You can email this to families if they would like one
- Hard copies are kept by our Poster/Information Brochure distribution officer. You can ask her to send a printed copy to the caller if they would like one or you can ask for copies of your own to distribute

If the child **DOES NOT** have a diagnosis of Gastro-Oesophageal Reflux:

- recommend the parent talk to their doctor about their concerns,
- explain to the parent that you are unable to provide advice on reflux until the diagnosis has been made (it is important a parent seeks medical advice, especially as lots of other conditions can present similarly to reflux)
- send the parent a RISA Information Brochure if they would like one (do **not** send a Special Edition Newsletter)
- encourage the parent to contact RISA again if their doctor does diagnose the condition as gastro-oesophageal reflux

CHECKLIST DETAILS TO FIND OUT

It is important to find out:

CHILD'S AGE

TREATMENTS TRIED/BEING USED

MEDICATIONS

HOW MEDICATIONS ARE ADMINISTERED

SLEEP PATTERNS/ISSUES

FEEDING PATTERNS/ISSUES

IRRITABILITY/OTHER REFLUX SIGNS

MOTHER'S SITUATION - tiredness; general health; isolation; receiving support from family/friends?

ANY CONCERNS

It is necessary to run through this check list with every caller, regardless of how “in control” they may appear to be.

A RISA Contact call should not be a “quick call”.

Develop the person’s confidence by showing that you understand the problems being described, and by gathering information which will help you to suggest possible solutions. This may take up to 20 minutes.

It is often at this late stage in the call that a thus far very composed person will let down their guard and open up. Do not be surprised if they begin to cry. Quick answers to initial questions will not allow you to give effective emotional support.

Following are some strategies to help to gain the parent’s confidence in you:

1. Try to develop your ability to **empathise**, i.e. to put yourself in the position of the parent. Their problems may seem minor to what you have gone through, however, for the parent, the problems are BIG and they have been sufficiently stressed by them to make contact with RISA Inc. They may be in crisis. They may be grieving for the “ideal” picture which they imagined their baby would fit.

To enable to caller to express feelings you will need to make statements or ask questions such as:

“You must be very tired”.

“Are you getting any help from others?”

“Do you have relatives or friends living nearby who can help?”

2. It is essential to be able to **praise** them for doing a great job under difficult circumstances, to **reassure** them that their instincts and decisions are valuable

“Oh, that was a good idea.”

“It is good that you are trying to help your baby.”

“It is okay to listen to advice from your friends and relatives etc, but only try those suggestions that you are comfortable with AND which you think might help your baby.”

3. It is important to recognise that you have personal values that will affect your response to a caller e.g. you may believe bottle feeding is the sensible solution to feeding problems in babies; or partners should help with the housework

As your values will often differ from those of the caller, it is vital that you do not impose your values when talking to them

Some effects of imposing information or values on callers:

- a. Contradicting the caller’s right to make their own choice
- b. Creating uncomfortable feelings e.g. pushing a caller to ask others for help if they have grown up with the belief that mothers are supposed to cope without help
- c. Creating resentment and opposition on the part of the caller towards the imposition of values upon them. (David Mooney: VISA Training Day Workbook, Brisbane, 1995)

4. **Having established a rapport, the caller will be more likely to open up when you ask questions related to how they are coping**

e.g. "Is someone able to look after baby for you so that you can get some sleep?"

"Do you have someone who could cook a meal for you sometimes?"

REMEMBER:

Offer suggestions if appropriate. Do not tell the caller what they should do

Show no bias or preference for a particular treatment

Do not discuss doctors, child health nurses or hospitals

BASIC ROLE OF A RISA CONTACT

BASIC ROLE: to be there to talk to another parent/guardian who wants to talk about their reflux baby.

The three most common reasons for calling are

1. **Information** e.g. what is reflux? When is it outgrown? What can I expect?
2. **Help** e.g. ideas for management; practical support services; further medical treatment
3. **Emotional support and understanding** e.g. affirmation of negative feelings (guilt, not bonding); encouragement of decision making; coping strategies

As a Contact, you are NOT there to:

- ⊗ **Diagnose reflux**
Solution: Refer the person to their health professional. Explain the importance of getting a diagnosis of GOR/GORD. Also explain that other conditions can present similarly and it is important that a doctor makes that diagnosis.
- ⊗ **Give medical advice**
Solution: Refer the person to their health professional whenever they have concerns
- ⊗ **Fix problems**
Solution: Offer suggestions and listen to the caller. Refer them to their health professional whenever they have any concerns.
- ⊗ **Make decisions for the caller**
Solution: Offer suggestions and listen to the caller. Allow them to make their own decisions
- ⊗ **Become personally involved e.g. by giving the person your home phone number, or by visiting to give In-Home Help**
Solution: Refer the person to emergency help services and home help services
- ⊗ **Give help with problems not concerning reflux, even though these problems may have resulted from caring for a refluxer e.g. marital problems, post-natal depression**

Solution: Refer the person to their health professional, support groups or Government Services relating to the specific problem

⊗ **Take complaint calls about RISA Inc or RISA Inc members**

Solution: Briefly apologise for the caller's problem and offer to take their name and number so that the President (or their deputy) can call them. **Do not enter into any discussion about the complaint.**

THE TYPES OF CALLS

You can get calls that are any of these, or several, combined.

1. **Information Call** - the caller wants basic information on reflux and home management

Is the child diagnosed? (If not, see information on the Counselling Checklist)

Find out how much they know about reflux (do not assume they know anything about it) and fill them in on basics if necessary.

Use simple language.

Gather the basic information e.g. age, sex and name of the child(ren), feeding patterns, irritability, mother's situation etc (a Memory Jogger is excellent for this purpose).

Ask for postal address or email address if sending out information e.g. Special Edition Newsletter or Information Brochure

Provide some management ideas if requested, and explain the services RISA offers

2. **Decision Call** - the person wants help to make a decision re their child's reflux, e.g. whether to take baby back to the doctor

As well as the above, remember your ethics.

SUGGEST ONLY

DO NOT DISCUSS HOSPITALS, DOCTORS OR CHILD HEALTH NURSES

SHOW NO BIAS OR PREFERENCE FOR A PARTICULAR TREATMENT

DO NOT MAKE DECISIONS FOR THE PERSON

3. **Emotional Call** - the person is distressed and crying

This type of call will require patience and understanding. Long silences may be involved as well as long periods of talking on the person's part. Do not interrupt these monologues as it is important for them to get things off their chest. Do take lots of notes and refer to them later in the call.

4. **Crisis Call** - the person may be in extreme distress. These types of calls are very unusual

A Crisis Call is one in which the parent (usually the mother) is temporarily unable to adequately care for their reflux child. For example, she may have already abused the baby or siblings or been abused herself, or she thinks that these circumstances will arise in the near future. The caller will feel confused, anxious and helpless. She may be unable to make decisions and the needs of her children and of herself will seem urgent to her.

See further information about the crisis call procedure further on in the manual.

PREPARING TO MAKE A CONTACT CALL

Be prepared

Have a notebook or Memory Jogger and a pen beside the phone, and this RISA Inc Training information nearby. It is sometimes handy to have a couple of 'special' distracting toys for impatient children. A comfortable chair and a place to rest your feet might get you through some of the lengthier calls.

N.B. A Memory Jogger is excellent for getting basic information. Simply fill it out as you listen to the caller and file it alphabetically in a ring binder. Photocopy blank forms as you need them.

Before you make the call

Wait until you are in the mood to listen and help, your child is settled and occupied, and that you have the time.

If the phone is diverted to your home phone so you receive incoming RISA calls, before you answer

Make a decision whether or not to answer the call. Are you in the mood to really listen and help? Is your child screaming? Do you have the time? If the answer is NO and it is a RISA Inc call, listen very carefully to their opening line and the tone of their voice, breathing etc. If they wish for only information and sound fairly stable, tell them you are unable to take the call, take their phone number and ring them back as soon as possible.

If they open with "I am not coping and need some help" you can review your decision to take the call, or give them one or two minutes to get the basic problem off their chest and then explain that unfortunately things are a bit hectic and you could not give them your full attention at this time. Take their number and organise another Contact to ring them immediately. (see Crisis Calls)

Tune in to the person who has contacted RISA Inc:

Body Posture can be a clue for yourself, even though you are not visible to the caller. In telephone counselling the only direct channel of communication is through sounds and hearing. Try to speak in a friendly manner, identifying yourself immediately. Background noises from the caller's end may give you extra information about the caller's situation e.g. there may be demanding or screaming children in the background.

What to listen to:

- Breathing- Is the callers breathing quick and shallow or slow and deep?
- Tone and speed of voice- You will hear various patterns of speech.

Both these can give you clues as to the person and their situation; however it is important not to jump to hasty conclusions.

Assume nothing about the person

Don't assume they are either a good or bad parent, that they have the same views on parenting or medications etc, as you do. Don't assume that they know anything about reflux, or that their feelings in a situation are the same as yours would be.

Keep your language simple

Until you know the person you are speaking with well enough, use uncomplicated language. You may have to explain what 'sphincter', 'oesophagus', 'endoscopy' etc mean as you go along.

Empathise

This means 'to be in their shoes'. This is not difficult with reflex calls. Even if their situation is different to yours, you can imagine what it must be like for them. However, do not say "I understand how you feel", because this is not true. Rather, say "It must be very difficult for you".

Paraphrase

To paraphrase is to feedback to the person the essence or content of what they have just said. It aims to clarify their ideas by restating them, to help the caller move further and talk more deeply about the subject and to express that you understand the content of what the caller is saying. Also, it checks that you are on the right track.

e.g. Caller: My own mother said I am a bad mother, and tells me what to do. My husband is no help around the house and the doctor doesn't listen.

Contact: Your own family and doctor do not understand what you are going through.

Offer a Feeling Response

Similar to the above but in relation to the feeling stated or strongly implied by the person. In response to the above example a feeling response could be: "You feel upset and annoyed at the lack of support you are receiving from the people around you." Sometimes it is easier to begin a feeling response with "It sounds like" or something similar that you are comfortable with.

Ask for Clarification

Check with the person about ALL the facts. "Did you say he has always behaved like this in the evenings?" "Exactly what management did the Doctor recommend?" etc

NEVER preface a question with "why" because it makes them think you are judging them. If they stop talking, but you feel they are not really finished, don't let the silence make you nervous. After a while you can see "You seem to be thinking", or "Is there anything more you would like to tell me?"

Use Open Questions – these begin with "Could", "What", and "How"; never "Why".

Compare an open question "How do you feel about giving your baby medication?" with a closed question "Are you going to give the medicine?" The open question will elicit and answer that will give you a lot more to work on. The closed question will elicit a YES or NO. Closed questions could make the person feel they are being interrogated. They can be useful sometimes e.g. "Have you taken him to the doctor?"

Avoid Letting the Person Know Whether You Believe or Disbelieve What They Have Told You

Don't agree or disagree with any of their statements; don't point out any contradictions or inconsistencies in their statements. Think how they are FEELING and respond to that

Don't Let the Person Force You into Giving Opinions or Answers to their Problems

Try to turn their demands back on them. Say "You seem to think my opinion is important" or "You wish someone could give you an easy answer" or "You seem to be concerned about what I think of you".

Don't Talk at Length about Your Own Experiences

This is their time. Don't unburden yourself to them. If they ask for your experience regarding something, give it briefly.

Dealing with Emotions

If the person is crying and unable to speak, try not to feel uncomfortable. Just take a deep breath and say something encouraging like “You will probably feel a little better when you have had a cry, so I’ll just wait until you feel ready to talk” or “It sounds as though you have been having a bad time”. Again, be prepared for silence.

Terminate the Call

Listen for some natural break- change of voice in the person, other cues that ‘that’s about it’.

You can briefly go back over what you have discussed, both facts and possible suggestions. Point out again the person’s strengths to handle the decisions for actions they have made. Offer appropriate literature, coffee morning dates, newsletter, invitation to ring back. Keep listening to whether the person feels ok about all this.

After the Call

Find some way of releasing tension if need be. Send information away immediately, reading, knitting, cleaning etc may help to clear your mind. If a call has upset you or you have received several calls in a short space of time, please ring an experienced contact. Debriefing is a normal aspect of all areas of counselling work and an invaluable tool in improving your skills as a Contact.

MAKING THE CALL

You have the name, phone number, and perhaps some specific details of the person you are calling. Make sure that you have prepared yourself for the call (see previous information).

(Please avoid calling mobile phone numbers as much as possible. If necessary to do so, please limit the time of calls to them- ask the caller for a landline number you can use)

“Hello, my name is I am calling on behalf of the Reflux Infants Support Association. I am calling in response to a message you left on (our messagebank, our email inbox, etc). How can we help?”

*NB If you get an answering machine, please leave a message and try to contact them another time. You can also ask them to contact RISA again to let us know when a convenient time would be to ring. You do not need to continue following up if you are leaving messages asking for a convenient time.

- **Begin to gather information to establish medical diagnosis and to draw a picture of their particular situation**
 - How old is your child?
 - When was he/she diagnosed with reflux? (diagnosis is essential)
 - Who diagnosed the reflux? Was it your GP or paediatrician?
 - What treatment has been recommended? Are medications prescribed?
- **Discuss management**
 - Are you able to hold the baby up after their feed for half an hour?
 - Do you have the bed elevated? (research studies show this is not indicated in babies)
 - How often is baby feeding?
 - What strategies are you using?
 - Is your child on medication? If so
 - o Is it helping?

- How are you giving it?
 - How long has your child been taking it?
- **Discuss emotional needs**
 - How are you coping?
 - Do you have other children?
 - Are you getting help from family or friends?

This initial procedure can be used for almost any call regardless of their first request or question. (It may, however, be necessary to let the caller tell their story first if they seem to want to offload.)

The caller's first statement or questions is not always indicative of the true problem. e.g. *"My baby has been prescribed Losec and it isn't working!"* After questioning, it may become apparent that the baby has shown some improvement but the mother had her hopes set on the medicine curing her baby. Having her detail the specific behaviour shown by the baby before medication was commenced, and the specific behaviours shown now may help her to see that there has been some change.

You can often provide a helpful hint or useful information about managing a child with reflux by carrying the caller beyond the initial question and discussing the sorts of behaviours that a child with reflux may show.

CONTACT CALL INSIGHTS by Glenda Blanch, RISA Inc Contact

Statements that often seem to make a huge difference to the caller:

- ✓ Infants with reflux can be very high needs babies. (A normal, healthy baby can be difficult, but one with reflux can be extremely high needs, made worse by the fact that a lot of family and friends don't seem to understand that)
- ✓ This is NOT your fault and you are NOT doing anything wrong! (If someone could tell you exactly what to do, or what would work, I'm sure you'd be doing it. The fact you aren't just means you haven't found out what works just yet.)
- ✓ There is no right or wrong answer on how best to handle this. They are all individual, and what works for one may not work for another. It really is a matter of trial and error until you find something that works for you and your family.
- ✓ Do what feels right for you and your baby and family. Very often people give advice, and it is often very conflicting (e.g. someone will tell you to pick the baby up every time they cry; and someone else will tell you not to do that because "you will create a rod for your own back") In these circumstances, it can be very confusing, and you need to do what feels right. (It is okay to listen to everyone's advice, but it also ok to ignore it if it doesn't sound like something you would like to try)
- ✓ You are doing a good job, in very difficult circumstances.
- ✓ Do what works, so long as you are comfortable with it, but remember to discuss issues with the dr first.

- ✓ Trust your instincts (and then outline some of the things they have already achieved, like getting the diagnosis, finding some things that help already, going to the dr or child health nurse when they realise something is wrong etc)
- ✓ Look after yourself- not only are YOU as important as your baby, but whose there to look after them if you fall apart?
- ✓ I explain that felt really inadequate and that it felt like everyone else could do a much better job than me, and I just wasn't a good mother. It doesn't help that often family and friends think it is because you are doing something wrong, that you lack any parenting ability, and that all their 'helpful' advice points to you being at fault (e.g. you should be doing this differently, or you should do that; there is something wrong with your milk; you don't have enough milk; you aren't holding them right etc)
- ✓ It is okay to feel grief, sadness, joy, resentment, guilt, pity etc. It is normal, and perfectly understandable. (I generally use examples of my emotions then too, like- I felt grief- for mourning the perfectly healthy baby I didn't have; I felt blessed because they are so special, and I am so very glad they are in my life; I felt sadness for everything they are going through, and also sadness for me, as it isn't at all what I expected; I felt very resentful at times that they wouldn't stop screaming, or leave me in peace for 5 minutes; and then the guilt would come because I knew it wasn't their fault and they were in pain; I felt sorry for myself because it was all so hard, but then felt guilty because I was aware that it could be worse, and there are sooo many other worse problems other babies and families have to deal with. I should be 'grateful' it is only reflux! And on and on the emotional rollercoaster goes) There may be others who are doing it tougher, but you are doing it tough too, and what you have to deal with is often very difficult, and you may have to do it without a lot of support as well. People whose children have other problems often get good support AND understanding.
- ✓ You can drive yourself crazy trying to figure out why today was better or worse than yesterday (what did I do; what did I eat; maybe if I did this; maybe if I tried that). The simple fact is, reflux can be cyclic and some days may just be worse than others, for no reason you will ever know.
- ✓ Reflux can flare when anything stresses them- hot sticky weather is a common trigger that parents notice, along with over-tiredness (vicious cycle), change in routine, colds, infections, teething, vaccinations etc. Sometimes it can help to know that, so that any changes make more sense.
- ✓ It is common for people to not understand how bad reflux in children can be, or how devastating it can be for the entire family. It's not your fault if they don't understand.

BLOCKING YOUR TELEPHONE NUMBER (information provided by Telstra)

Unless you block your telephone number, your number (with date and time of the call) will be displayed on the telephone or mobile handset of the person you are calling, where that person has Calling Number Display. You may like to ensure your number is blocked before doing a Contact call- some Contacts have occasionally had callers keep their number and call them back for further support.

You can check if your telephone number is presented to the person you are calling by dialling the following numbers:

- From a fixed home or business phone.....12 7220
- From a mobile phone*#31#

You can block your telephone number when you make a call to another mobile phone or fixed phone (free of charge) by the following options:

- Call by Call Block - If you want to block your telephone number on a call by call basis simply enter 1831 from a fixed phone (#31# from a Mobile) and then dial the number you are calling.
- Permanent Blocking - If you want to block your number on a permanent basis (for all calls) from your fixed phone, call 13 22 00, from a fixed business phone, call 13 2000 or from a Mobile Phone call 125 111.

CALL BACKS

“Call Backs” are not always necessary however if you are concerned about the caller, you may want to call them back 3 or 4 days, or even 1 to 2 weeks after a call. They can be a way of developing self-confidence because you can call at a time which suits you and if the caller asked any questions you can follow up with responses to those questions.

“Hi. This is from RISA Inc calling to see how you are going since we talked the other day. Is this a bad time to call?” “Oh good. And how is Jamie feeding now?”

CALLERS REQUESTING BULK BROCHURES, POSTERS ETC

Whenever you receive a call or email for brochures or posters please contact the Brochure Distribution Person who will mail them out (Alternatively, send an email to the RISAContacts group). Find out:

- How many brochures they would like
- If they would like to be put on the mailing list to receive a complimentary copy of the RISA Newsletter. If yes, be sure to obtain the person’s title and postal address (e.g. Co-ordinator Young Parents Programme of Nurse Unit Manager, Warwick Child Health Services) and notify the Membership Secretary.

(It is important to follow this procedure so that RISA Inc can keep track of those in receipt of our brochures etc, continue to keep them supplied, and check once a year that the material is still required and being used.)

Brochure Distribution Person _____

Membership Secretary _____

CALLERS WITH OLDER CHILDREN

Reflux in the toddler age group can be the underlying cause of behavioural problems.

When talking to a parent with their second or third baby, ask how the older sibling/s are coping. If behaviour is a problem- ask if that child had reflux as a baby or if it had ever been suspected.

Advise the parent to discuss the issue with the doctor if they suspect reflux. Ask about food types eaten by toddler if reflux is still evident.

Refer parent to RISA Contact who has experience with an older refluxer if they would like further information.

DEBRIEFING

It is important at the end of your Contact 'shift' to call your Contact Trainer or partner and discuss your calls. It may also be necessary to do this during your shift if you have a difficult call. If your trainer/partner is not available, call another Contact.

At times you may also wish to call a RISA Inc Contact yourself to offload concerns about your situation with your own refluxer. Please don't forget that you are a RISA Inc member also and that the support network is there for you too. The parents to whom you speak are generally very thankful for the help and encouragement that you give to them. When you feel that you need some help or encouragement yourself (or maybe just plain sympathy), please speak to one of our Contacts. You won't be the first Contact to do this, and it will help you to continue effectively in your role as a Contact.

SUGGESTIONS FOR CRISIS CALLS

Crisis calls are VERY unusual, especially as we return the call after they have left a message. Even if a caller was emotional at the time, they often feel more under control when we call. On the off chance you get a crisis call, it may help to follow this procedure

1. Where is the baby now?

Give assurance that the caller is doing the right thing e.g. "That's good. You have done the right thing to put the baby in the cot. It won't hurt him/her to cry for a few minutes while we talk."

2. Do you have other children? Where are they?

Again give reassurance. e.g. "Watching TV. That's good."

3. Is there anyone you can call on to help right now? e.g. a friend or family member to take you and the baby to a doctor or care for the baby overnight

4. Ask for the name of child's local doctor, paediatrician and/or gastroenterologist

5. Ask where they live- city or country?

6. Assure caller that you WILL do something to help them - give a specific time that you will ring back e.g. one hour

7. **Seek help for the caller** e.g. phone child's GP or Specialist, the hospital they attend, the Social Work Department of that hospital, Child Health Clinic, etc. Do **not** pass on their name.
Find out what help can be offered and then phone the caller back to pass on the information. You may ask the caller if they would like you to make arrangements for them, however, it is better if the caller does this themselves. You will have helped them by providing phone numbers, contact names and what she needs to say when she calls. Lifeline may also be able to help steer you in the right direction.
8. **Phone another Contact if you need help or want to debrief**
If you do not have the time to follow up with getting assistance for the caller, or you feel you are not able to, or you would like to talk to someone about the call, ring another Contact.

SOME SUGGESTED ANSWERS FOR TRICKY QUESTIONS

Q. "Does this sound like reflux to you?"

A. I'm sorry, but I can't help you with that. It is very important that reflux is diagnosed by a doctor, as there may be something else causing the symptoms e.g. an infection can cause vomiting.
Have you considered taking the baby to a paediatrician for a check up?
Would you like me to mail you a brochure which lists symptoms of reflux?
After visiting your doctor, if reflux is diagnosed, please call us again and I'll send out more information.

Q. "Does a .1ml dose of Zantac seem right to you?"

A. I'm sorry, but I can't help you. If you call a pharmacist or your doctor they would be able to double check the dose. Too much Zantac can cause stomach upsets so it is very important not to change dosages without seeing the doctor first.

Q. "My baby is having 10 mls of Zantac every dose, but he's more unsettled and it's so hard to give."

A. "How old is your baby? Are you certain the dose is 10 mls? That seems to be an extremely large dose. It would be best to check the dose with your doctor or a pharmacist before giving any more to the baby. Perhaps there has been a mistake on the label of the bottle.

Q. What would be the right dose?

A. I'm sorry, I don't have that information but 10 mls sounds like it is a lot to give a baby. I really think that you should check with your doctor before you give any more."

Q. "I've just given my baby Zantac and he's thrown up straight after. Should I give him another dose?"

A. I can understand that you are probably worried that if the baby has thrown up the whole dose, his reflux may be worse until the next dose. Unfortunately, it is impossible to know how much he has kept down. It would be best to phone your doctor or pharmacist and have a talk to them about what to do.

PRACTICE QUESTIONS

Exercise: Choose the most suitable responses for RISA Inc Contact Debbie, to make. Some of these responses printed are NOT suitable.

1. "Hi. I have a reflux baby and I wondered if you could give me some advice."

Possible responses:

"Oh yes I love giving advice."

"I'll do my best to help you. How old is your baby?"

"I have two really bad refluxers so I should be able to help you."

2. "My doctor is not helping my baby. He just keeps telling me that the baby is healthy, but he doesn't have to walk the floor all night while my baby won't sleep!"

Possible responses:

"Is your baby on any medication?"

"I think you should see another doctor."

"Can you leave the baby with someone overnight so you can get some sleep?"

3. After collecting information about baby in No. 3, it is apparent that the mother's statement is reasonable.

Possible responses:

"I think you should see another doctor."

"Are you saying that you are unhappy with your doctor and you would like to get a second opinion?"

"I'll give you the names of some good doctors."

4. "My baby is 6 months old and weighs 7.5kilos. What dose of Zantac should I be giving him?"

Possible responses:

"You'll have to ask your doctor."

"I can't tell you that."

"I'm sorry; I don't have information about drug dosages. It is important for you to talk to your doctor about this. Is your baby on Zantac at the moment?"

PARENTS OF REFLUXERS

SYMPTOMS OF PARENTAL STRESS

Physical and mental exhaustion

Emotionally drained

Inability to make decisions

Confusion

Irritability

Depression

Weepiness

Anger towards older children

Neglect of personal appearance

Low self esteem

STRESS MANAGEMENT

Encourage parents to work out their own personal way of relieving stress. Suggestions:

- obtain a babysitter and spend some time together
- talk to a social worker
- get help in the house
- family therapy
- contact RISA
- organise some relaxation time alone

In order for parents to look at Stress Management, they must first realise their own rights as a person and as a parent. You may have to encourage mothers to accept that they have the right to:

- make own decisions
- not cope all the time
- be under stress
- be tired and frustrated
- have help in the house
- have babysitting
- leave child with someone
- time alone and with partner

It is also important to understand the partner's point of view, however if mothers say something contrary to what is below, that is their opinion and should not be contradicted by you, the Contact. Husbands, as well as the above, have the right to:

- some time and attention from his wife
- to establish a relationship with his child
- to make decisions with wife regarding the child's reflux

As a RISA Inc Contact you are not trained to counsel parents regarding personal or marital problems. We do not become involved in these areas, but simply encourage parents to seek further professional help.

RESOURCES

State	Centre	Phone Number	Email
National	Lifeline	13 11 14	
	<i>Healthdirect</i> Australia 24 hour	1800 022 222 (NT, NSW, ACT, SA, WA, TAS)	
QLD	Ellen Barron Family Centre	07 3862 2333 (Brisbane metro) or 1800 177 279 (24 hour)	www.health.qld.gov.au/cc/hs/about.asp
	13 HEALTH	13 HEALTH (13 43 25 84) (24 hour)	
	ParentLine	1300 301 300	
NSW	Tresillian Family Care Centres Parent Help Line 24 hour	METRO AREA: (02) 9787 0855 ALL OTHER AREAS: 1800 637 357	www.tresillian.net
	Parentline	1300 1300 52	www.parentline.org.au
	Karitane 24 hour	1300 CARING (1300 227 464)	www.karitane.com.au
	ParentLine (24 hour)	1300 1300 52	
ACT	Maternal and Child Health QEII	(02) 6207 9977	
	Parentlink	13 34 27	www.parentlink.act.gov.au
	Parentline	02 6287 3833	
	Tresillian	1800 637 357	
VIC	The Queen Elizabeth Centre	(03) 9549 2777	www.qec.org.au
	O'Connell Early Parenting Centre		www.mercy.com.au
	Tweddle Child +Family Health	(03) 9689 1577	www.tweddle.org.au
	Parent Line	13 22 89	www.parentline.vic.gov.au
	Maternal /Child Health line 24hr	13 22 29	
WA	Nurse on Call (Health Line) 24hr	1300 60 60 24	
	Ngala Family Resource Centre	HELP LINE: (08) 9368 9368 FREE CALL: 1800 111 546 - country	www.ngala.com.au
	Parenting Line	Perth 08 6279 1200 Outside Perth 1800 654 432	
SA	Child & Youth Health		www.cyh.com
	Parent Helpline	1300 364 100	
	Parenting SA	08 8303 1660	www.parenting.sa.gov.au
	Torrens House	(08) 8303 1530	
TAS	Parenting Line	1800 808 178	
	The Parenting Centre Hobart	(03) 6233 2700	
	Parenting Centre, Launceston	(03) 6326 6188	
	Parenting Centre, Burnie	(03) 6434 6201	
NT	Parentline	1300 30 1300	
	Northern Territory Families Website	1800 005 485	

*More parenting support information is available at: <http://www.kidscount.com.au/english/contact.asp>

RISA MEMORY JOGGER

DATE FOR SELF/OTHER

NAME

ADDRESS FOLLOW UP ACTIONS/OPTIONS

..... TELEPHONE

EMAIL ADDRESS

CHILD'S NAME CHILD'S AGE

OTHER CHILDREN /AGES REFLUX?

BABY'S REFLUX DIAGNOSED? YES/NO (If no, recommend they talk to their doctor about their concerns; explain the importance of getting the diagnosis, and send only an information brochure)

PAEDIATRICIAN/GASTRO/GP OTHER

FEEDING: Breast Bottle Solids

PRESENTING SYMPTOMS

NOTES/INFO GIVEN

Projectile vomiting Sleep disturbance

Vomiting (Day/Night)

Possetting Prolonged crying/screaming

Regurgitation Blood in vomit or stools

Repeated coughing Poor weight gain

Repeated choking Swallowing problems

Hiccoughs Oesophagitis

Snuffles Apnoea

Fights feeds Recurrent infections

Comfort feeds (Ear/Throat/Chest/Sinus)

Irritability Other:

MEDICATION PROCEDURES

Gaviscon Ba swallow

Antacid e.g. Mylanta Endoscopy

Domperidone (Motilium) pH probe

Cisapride (Prepulsid) Manometry

Ranitidine (Zantac) Allergy testing

Omeprazole (Losec, Other:

(Probitor, Acimax etc) ADMINISTRATION

Zoton

Nexium Surgery

Other:

COMPLICATIONS

Food intolerances/allergies

Asthma Diarrhoea/Constipation Other:

MOTHER/PARENT'S SITUATION ? Support ?Coping, general health, tiredness etc

.....

WOULD YOU LIKE ME TO SEND INFORMATION?

CALL BACKS

POSTAGE or EMAIL SENT

RISA MEMORY JOGGER

DATE FOR SELF/OTHER

NAME

ADDRESS FOLLOW UP ACTIONS/OPTIONS

..... TELEPHONE

EMAIL ADDRESS

CHILD'S NAME CHILD'S AGE

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MOTHER/PARENT'S SITUATION ? Support ?Coping, general health, tiredness etc

.....

WOULD YOU LIKE ME TO SEND INFORMATION?

CALL BACKS

POSTAGE or EMAIL SENT



RISA Inc - Reflux Infants Support Association Inc.

EXPENSES SHEET

ARBN: 124 656 097 / ABN: 64 158 190 024

RISA Inc volunteers can claim all reasonable out-of-pocket expenses e.g. phone calls, stamps, that are incurred during the performance of their role. Please note that RISA Inc Management Committee must approve all purchases before they are made. Volunteers will then be reimbursed for these approved purchases. Receipts must be obtained and an expenses claim filled in and submitted to the Treasurer *.

On the following page, there is a claim form (Expenses Sheet) for your out-of-pocket expenses; simply print it out, fill in the details, attach receipts and any other documentation, and mail it to:

RISA Inc Treasurer

P.O Box 1598
Fortitude Valley
Queensland, 4006

If you would like your reimbursement to be deposited directly into your bank account, please also complete the bank information details on the Expenses Sheet.

* You are not required to send the Expenses Sheet in every time you incur an expense. You are welcome to maintain it until you reach an amount that you are comfortable with i.e. \$5, \$10, \$30, but please do not let it get too high (over \$100) before making a claim for reimbursement. Please also note that according to our Model Rules, amounts over \$100 must be paid by cheque.

Alternatively you can scan the **completed sheet AND your receipts**, and email the claim to RISA Inc at info@reflux.org.au. This will then be forwarded to our Treasurer. If you take this option you will still need to keep your originals in a safe place in case they are ever required by the treasurer.

PLEASE mark your email as '**Expenses Claim For Treasurer**'

A scanned copy of your receipts and documentation must be included with your claim

RISA Inc Management Committee

Expenses sheet checklist:

- Have you written your name on the Expenses sheet?
- Have you completed all your expenses details and totalled the amounts?
- Have you attached your receipts and any other documentation?
- Have you completed the section on bank details (if you would like to be paid by direct bank deposit and your total is below \$100)?



Expenses Sheet

ARBN: 124 656 097 / ABN: 64 158 190 024

* Please attach original documentation/receipts

Claimants Name:				Month:			
TELEPHONE RECORDS:				POSTAGE DETAILS:			
Date	Name	Telephone Number	Cost	Date	Name	Address	Cost
TOTAL TELEPHONE:				TOTAL POSTAGE:			
SUNDRY DETAILS:				SUNDRY DETAILS:			
Date	Name	Purpose	Cost	Date	Name	Purpose	Cost
SUBTOTAL SUNDRIES:				TOTAL (TELEPHONE, POSTAGE, SUNDRIES):			

BANK DETAILS (Complete this section if you would like to be paid by direct bank deposit)	
BANK/BRANCH	
ACCOUNT NAME	
BSB NUMBER	
ACCOUNT NUMBER	

TREASURER'S DETAILS (to be completed by treasurer)		
TREASURER'S SIGNATURE:		
REIMBURSEMENT	TOTAL PAID:	DATE PAID:
PAID BY:	CASH CHEQUE DIRECT BANK DEPOSIT	REFERENCE or RECEIPT NUMBER (if applicable):



RISA Inc - Reflux Infants Support Association Inc.

Expenses Sheet

ARBN: 124 656 097 / ABN: 64 158 190 024

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Claimants Name:				Month:			
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SUBTOTAL SUNDRIES:				TOTAL SUNDRIES:			
SUBTOTAL SUNDRIES:				TOTAL (TELEPHONE, POSTAGE, SUNDRIES):			

BANK DETAILS (Complete this section if you would like to be paid by direct bank deposit)	
BANK/BRANCH	
ACCOUNT NAME	
BSB NUMBER	
ACCOUNT NUMBER	

TREASURER'S DETAILS (to be completed by treasurer)		
TREASURER'S SIGNATURE:		
REIMBURSEMENT	TOTAL PAID:	DATE PAID:
PAID BY:	CASH CHEQUE DIRECT BANK DEPOSIT	REFERENCE or RECEIPT NUMBER (if applicable):