



Dear family member or friend,

Your friend or family member has a child who's been diagnosed with Gastro-Oesophageal Reflux Disease (GORD). You probably know it as "reflux". It can be a very serious condition and difficult for the parents to manage. There are plenty of myths about reflux and lots of them put unnecessary pressure on the family. This letter aims to give you a bit of information about what the family is going through.

The most important information you need to know is that **you can help** and that the family really needs that help. They may be too overwhelmed or exhausted to ask for it so there are some practical suggestions below.

**Babies with reflux disease are in pain.** As a result they can be very unsettled and cry a lot. Their reflux may interfere with their breathing which can become dangerous. They may also refuse to feed which can also be serious or over-feed to comfort. They may or may not vomit. But they are being burned by their stomach contents. Almost without fail, the parents will be having a very difficult time. Sleep will be rare and stress levels will be high. Lots of babies posset or vomit – most of these do not have reflux.

The best support networks come from other people who've been through this before or from friends and family who are willing to learn about it and help the family through.

Reflux does seem to be more common (and possibly more severe) now than in the past. This may be because we recognize it more readily these days or it may be because there are more complex chemicals in the food supply than there were a few decades ago and babies tummies aren't mature enough to tolerate them. Some react extremely severely to different types of food and working out how best to keep the baby comfortable and growing can be a complex challenge.

The parents facing that challenge are sleep deprived and stressed. You can help the family and the baby by:

- **do simple, practical things** like holding the baby while mum takes a shower, turning up with some dinners that can be frozen or taking care of the washing or the dishes. You'd be surprised how difficult it is to get very simple jobs done with a baby who has to be consoled during almost all waking hours. A baby in pain becomes the first priority and everything else comes second;
- **try your very best not to judge the situation.** Believe what is happening. The parents need to know you are in their corner. Because the condition is chronic and sometimes goes on for so long, you may find yourself with what is known as "compassion fatigue" – feeling like it can't possibly be as bad as they're saying. Resist the temptation to fall into that trap. It may be hard to believe, but it is happening. The greatest gift you can give a reflux parent is to simply and on-goingly believe them – without judgement. There is nothing they will appreciate more.
- **research the condition** – have a look at the information on the RISA website ([www.reflux.org.au](http://www.reflux.org.au)) – some of the personal stories might best help understand. Suggest the



RISA facebook page to mum or dad (for some support) or even buy them a RISA membership so they can talk to other parents about what's happening. RISA membership is for families and means you too can ask questions on our forums or borrow books that might help you solve your particular riddle.;

- **Keep an eye on the mental health of both parents.** Chronic sleep deprivation does terrible things to a person and there's a reason they use it as torture. If the parents are telling you they are averaging very limited sleep, encourage them to seek help for themselves as well as their child.
- **Investigate family history** - some of these symptoms run in families. Passing on any information about other family members allergy or intolerances, structural issues to do with the gut like hiatus hernias, irritable bowel syndrome (IBS) or adult GORD may help inform treatment for the child.
- **Look out for the whole family** - other siblings in the family may also be having a very difficult time. A reflux baby can disturb the sleep of all family members, mum and dad are more stressed and cranky than usual and they simply can't provide the normal amount of time to the other children than would usually be the case. Maybe you could make a regular special time with that child or provide mum and dad with some respite (by taking baby for a few hours) and giving the other family members some time together.

While quite a few children grow out of these symptoms by 12 months old, many don't. It may not be helpful to offer the adage "don't worry they'll grow out of it". Sometimes symptoms just change rather than going away. Those with a family history are more likely to be managing an ongoing condition in their children. It may well help them recognize that behavioural issues in pre-verbal toddlers are pain related when the time comes. Lets hope though that your bub is one of the ones who does grow out of it!

You may be getting the idea that infant reflux is a big challenge and comes with a huge learning curve. This family needs a network of support and won't be able to muster the energy to draw it together themselves. Please pass this letter on to other people who love this family. Consider drawing up roster. Understand that the situation is serious and relentless for the parents. By far the best support you can provide is regular and practical. Many people feel they don't know how to help and many reflux families feel so under siege that they don't think to ask.

Don't wait to be asked. Just show up and get amongst it. If it all seems too hard, do it anyway. And don't forget that RISA is here to help. Details are below.

With the greatest thanks on behalf of the baby and family,

**Reflux Infants Support Association**

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