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Foreword

Congratulations to Glenda Blanch and the Reflux Infants Support Association Inc for producing this fantastic book! As any mum with a newborn suffering from reflux knows, we need all the help and advice we can secure – but most of all support. This new book *Reflux Reality: A Guide for Families* has it all.

When my son Callan arrived into this world with reflux, it took me weeks to realise I was the only one in my Mums' Group who was actually getting NO sleep whatsoever. As a first-time Mum, I thought this was the normal 'sleep deprivation' aspect of babies. It did seem a little 'full on' but then everyone said babies cried a lot. Callan was vomiting after a feed (other babies seemed to do this too), but unlike some reflux babies he did not have projectile symptoms – therefore I had no idea – absolutely no idea – that anything was wrong!

As all mums of reflux babies unfortunately know, our babies don't 'sleep like a baby' and nor do their mums and dads! The impact on first-time parents, their relationship and, of course, our tiny new babies is HUGE!

I remember clearly lying on the doctor's gurney watching those fantastic scans of my son in-utero sleeping peacefully. Yet only weeks after he was born, he was the one positioned on the

hospital gurney crying in pain from reflux with an ultrasound on his tiny, tiny tummy trying to work out what was wrong!

All reflux parents know our babies are very unsettled, unhappy, tired and in pain. This fantastic book containing suggested management tips, complementary medicine suggestions as well as traditional medicine, survival and coping techniques for parents and strategies to get your baby to the other side of this unwelcome health issue is hugely welcomed into the world of 21st Century Parenting.

While you are on this journey, use this wonderful book, but also remember this time does pass. Today Callan is a healthy teenager. Surprisingly I think I may even look younger than 'that' reflection in the mirror, during those long, long days and nights of getting him through reflux! He is so active, so happy, doesn't miss a trick and keeps me both on my toes AND young at heart!

Congratulations to Glenda Blanch and RISA Inc for producing this much-needed resource.

Claudia Keech

Founder and CEO, MotherInc

www.motherinc.com.au

Medal of the Order of Australia 2009

If you have tired eyes, frayed emotions, a screaming child, and thoughts of reflux then you have opened the right book! Having lived (or is that barely existed?) through reflux with both of our boys when they were babies, I know firsthand how challenging those days can be. How much more supported I would have felt if I had had a book like this to flip through! In difficult times one of the greatest gifts can be understanding. Even if you are past the worst of reflux I urge you to read this book so you can feel the acknowledgement you desperately needed. Whether you are a parent, professional or interested bystander, you will find this book easy to read, informative, and personally touching. It's the 'little golden book' for anyone involved with the impact of reflux in children.

Felicity Chapman

Founder and director, Mothers Be Heard

www.mothersbeheard.com

nothing but confusing and often belittling advice from [people]. The constant self-doubt I think was the most crippling and exhausting thing."

"Our little boy . . . was/is a nightmare . . . We have been to several doctors, paediatricians, osteopaths, naturopaths, lactation consultants and have invested in battery-operated swings, pouches . . . prams, sleeping hammocks and who knows what else. Although life is much easier than those nightmarish first few months of almost no sleep and a baby that cried for hours on end, life is still not a bed of roses and there are often days where I still jump in the shower to have a good cry."

Carer Stress

It is recognised that carers can be subjected to extreme stress over long periods of time because of the demands placed on them; however, it may not be recognised that caring for a child with reflux can put parents in that position. Even if you desperately seek emotional and/or practical support, you and your child's suffering may be trivialised because reflux is frequently thought to be a trivial issue.

"We took [our baby] in [to hospital] as he spent pretty much all weekend screaming in pain . . . The [doctor said] . . . there is no such thing as reflux and some babies scream 24/7. I just cried . . . Needless to say I'm feeling very tired and stressed and down . . . I've left [my baby] in overnight as . . . my husband and I are at the end of our emotional/mental strings." Lexi

"I know the mental cartwheels we do just to exist another day in the middle of reflux hell. It was almost a relief when I realised I couldn't take any more."

Chances are that you need to be taken seriously, need to be listened to, and need to know you are believed. There is a toll from extreme chronic stress (e.g. health issues, depression, relationship problems), and even the risk of child abuse. These issues need to be recognised, and practical help and emotional support provided. This may help you cope, and it may also reduce the long-term cost to society.

Living with Reflux: Ethan and Tyler

From the perspective of Felicity Chapman, social worker, counsellor, reflux parent and founder of Mothers Be Heard (www.mothersbeheard.com)

Reflux is a four-letter word to me. It means torturous sleep deprivation, constant mess, endless washing, numbing exhaustion, and relentless crying – sometimes not just from the baby!

While my two wonderful boys are now happy and energetic, with no sign of the havoc reflux caused, I can recall those moments of pure desperation as if it were yesterday. Both vomited in large volumes and 'silently' refluxed (sounded like gulping), were excessively irritable, fed and slept poorly. Bibs were simply mandatory and sleep was a precious commodity.

No health professional suggested Ethan's distress might be because of reflux, and Tyler [my second child] was four months old when he was finally diagnosed. It helped that he projectile vomited in front of the doctor! Until then, I hadn't really felt believed by professionals or family and friends. A lot of what happens with reflux happens behind closed doors and in the dead of the night, and that was the most difficult aspect for me.

The doctor started Tyler on Losec and gave me a reflux pamphlet [written by the hospital where both boys were delivered]. Losec helped a little, but the questions were obvious: why wasn't

I given this information when Ethan was a baby? Why was there no reference to GOR on many parenting sites? Why hadn't any child-health nurse or midwife told me about the possibility of GOR and that there is a gastroenterology nurse at the hospital where they were born?

The Impact

As a social worker, I think of how GOR can impact the individual. It can have an effect on a parent's psychological, behavioural, emotional, physical and social wellbeing. Likewise, I believe that public perception, the quality of professional intervention, and the degree to which parents are supported, can have a huge impact on how they experience GOR.

Sleep deprivation, lack of information and practical support, the way people minimised the experience of GOR by suggesting that all babies fuss a bit, the fact that our babies were healthy and didn't seem to get distressed when people visited all contributed to feelings of inadequacy, anxiety, thinking that it must just be me, increased intolerance to stress and social isolation.

I don't think I had Post Natal Depression, but I certainly remember feeling exasperated, crying, and having emotional outbursts. I wouldn't be surprised if studies show a strong correlation between PND and parents dealing with reflux. Of course all of this had an impact on my relationship with my husband and children. I'm blessed with a supportive partner and, while the strain showed in our relationship, mostly we knew we were both just plain spent.

Unfortunately, both of us looked liked we were coping when we weren't. Perhaps I needed to swallow my pride and look more frayed; perhaps this image adds weight to the saying 'you can't

judge a book by its cover'. Everyone, even the baby, can look healthy and normal but GOR can be a private hell because the ferocity of its blow can often be unleashed when no one else is around.

Families dealing with reflux need permission to talk about their reality. They need offers of help instead of waiting for them to ask for help. They need help with the washing, looking after the baby so they can get some much needed respite, getting the dishes out the way, and having meals delivered. Most of all, they need to be believed.

Reflux might still be a four-letter word to those who endure it, but there are other four-letter words that are much more uplifting. Words like help, care, RISA, and hope can make the journey a lot more bearable.

Mothers Be Heard has a website and holds workshops aimed at supporting mothers; especially women who have recently become mothers.

Relationship Difficulties

Relationship difficulties are common amongst reflux families, and although it is a sensitive topic, it is unfortunately another reality of reflux for some families. When you factor in the issues families face, it makes sense there is often conflict within the family unit.

"An unhappy baby eventually leads to unhappy parents. This was supposed to be the happiest time of our lives . . . but it had truly brought out the worst in both of us." Ula

Complete exhaustion and sleep deprivation can hinder communication, especially if you feel overwhelmed, unsupported or helpless. Other factors can also contribute, such as