

Infant and Child GORD Diagnosis and Experiences Survey NZ 2021/2022 vs 2006 SUMMARY

Introduction

The survey was carried out via mailchimp, and advertised via our Newsletter and Social Media.

The introduction to the Survey was:

This is an informal survey for current New Zealand residents who have a child who has/had a diagnosis of gastric reflux disease.

Please complete this survey even if your baby was diagnosed early, treated early and outgrew reflux early. (The survey is to be completed once for each child that has a diagnosis of gastric reflux disease.)

The purpose of the Survey is to attempt to identify diagnosis delays, access to healthcare and support, the duration of gastric reflux disease in children and the impact of all these factors on families. A very similar survey was carried out in 2006. This will enable us to compare results. We hope to be able to share this information with health professionals with our Awareness Week postage distribution.

Gastric reflux disease is defined as:

GORD occurs when stomach acids are "refluxed" into the oesophagus/throat and cause inflammation and discomfort/pain, or other complications such as feeding or breathing problems. There may or may not be spilling or vomiting. (Managing GORD <https://www.cryingoverspiltmilk.co.nz/treatment/gord/>)

There were 148 responses collected between 29/11/2021 and 05/03/2022 compared to 120 responses in 2006.

The highest number of responses were from the Waikato where our National Coordinator is based, followed by Auckland, Southland, Canterbury and Wellington.

In 2006, the highest number of responses were from Auckland, followed by Canterbury (where our National Coordinator was based), Waikato and Wellington with Southland having no responses.

Symptoms

The main symptoms that led to participants first seeking help from a health professional in 2021/2022 are:

1. Irritability/crying - 92.6%
2. Poor sleep and/or appeared tired - 71.6%
3. Refusal to feed/difficulty feeding - 60.1% down from 70%
4. Gagging/choking - 56.8% up from 27.5%

Further investigation revealed that 85% of those with irritability also reported feeding difficulties, gagging/choking or apnoea type episodes.

Age

Almost 80% of parents sought help before their child was three months old.

59% of the children still had gastric reflux at the time of the survey's completion.

Of the remaining children:

- 41% had outgrown it by 1 year
- 66% by the age of 18 months
- 76% by the age of 2 years

These are the "magic milestones" that parents are often given by health professionals.

Of the children who still had gastric reflux:

- 44% were under the age of 1 year
- 55% under the age of 18 months
- 66% (63 children) under the age of two years

23% of these children were over the age of 5 years. We know that our statistics of ongoing GORD are likely to be high as those who outgrow GORD early are less likely to seek support.

We hear you! - Feelings

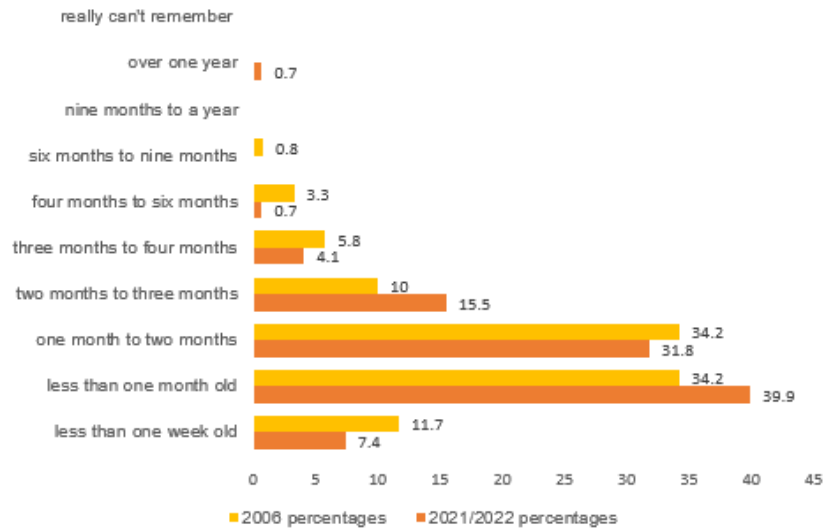
After seeking help, we asked how participants felt.

1. Treated as neurotic/over anxious - 62.2% up from 41.7%
2. Dissatisfied with care and support offered - 54.7% up from 41.7%
3. Brushed off as due to behavioural or parenting - 49.3% up from 20%

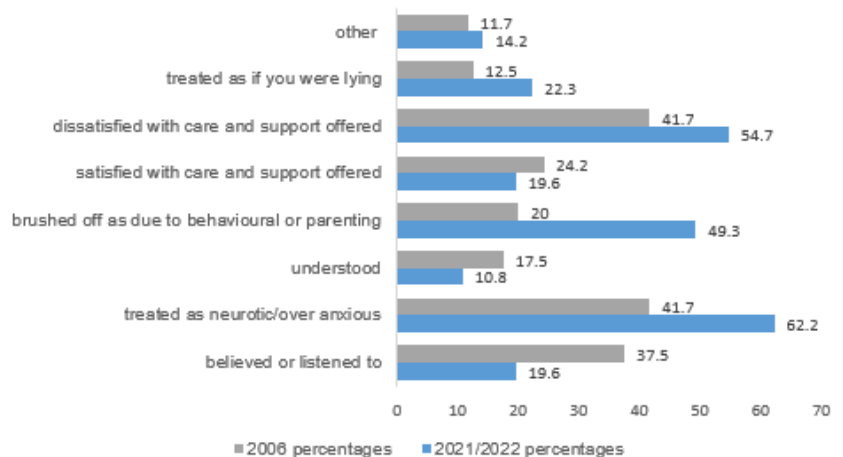
The results of not feeling listened to or heard left participants feeling frustrated, helpless, doubtful of parenting ability and intuition, guilty for not knowing how to help their baby and distrustful of health professionals.

19% felt heard compared to 32% in 2006.

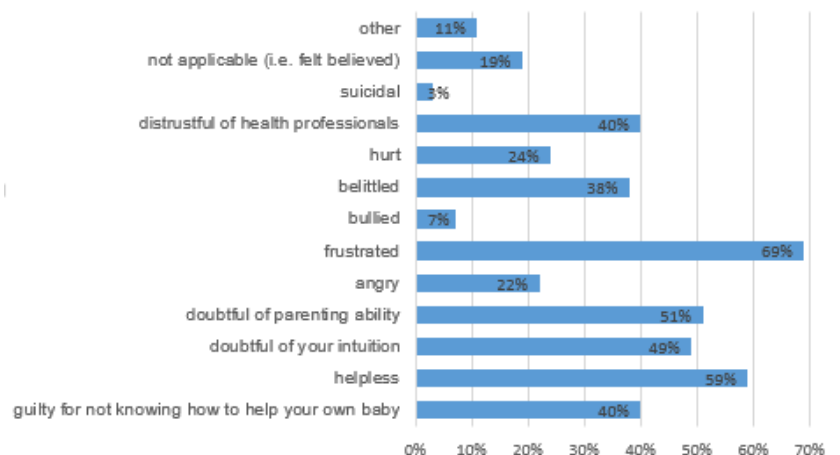
What age was your child when you first sought help?



Did you feel...? (You may choose multiple options)



If you didn't feel listened to, how did this make you feel? (You may choose multiple options)



Diagnosis

The time to diagnosis has increased since the survey in 2006. 52.5% had received a diagnosis by one month after seeking help with 19% having had three visits.

In keeping with this 29% of participants saw three health professionals before a diagnosis was made.

Top three reasons that participants thought that there was a delay in diagnosis (four weeks or more):

1. "all babies cry/spill" - 56.1%
2. Baby always appeared happy when distracted - 35.1%
3. Health Professional didn't believe me as I was a young or a first-time mother - 33.8%

23.6% said there was no delay in diagnosis down from 32% in 2006.

The diagnosis of GORD was made equally by GP and Paediatricians (~27%) compared to 2006 where GP's diagnosed 44% of GORD and Paediatricians 23%.

26% of participants have seen a paediatrician compared to 19% in 2006. 31% of those who have seen a paediatrician have sought help solely from a private paediatrician compared to 47% in 2006. Top reasons were length of wait in public system, not getting results elsewhere and personal choice.

The majority of those who have not seen a paediatrician, have not sought this care because their GP is managing reflux well.

COVID-19

We explored the impact COVID-19 has had on access to diagnosis and treatment.

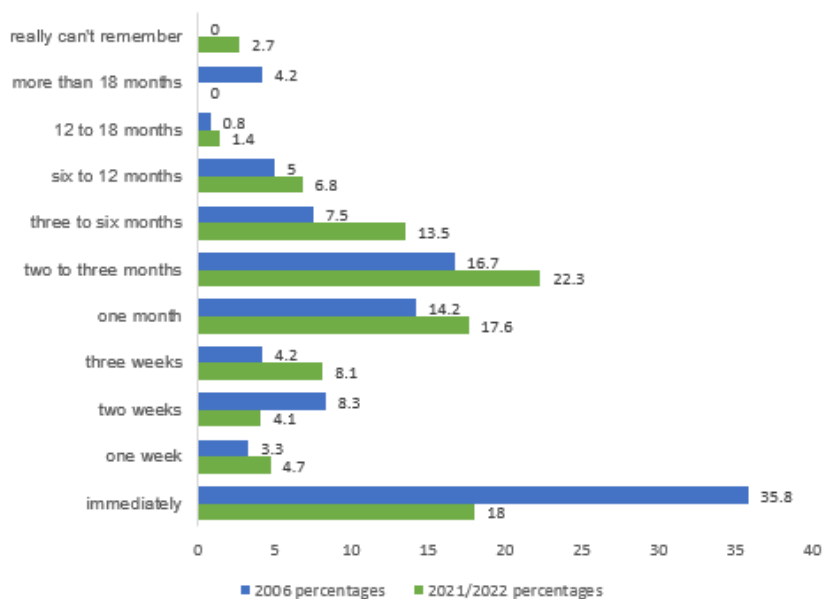
- 89 participants (60%) felt there was no impact
- 59 participants (40%) felt there WAS an impact

The top three impacts were:

1. Lack of access to community support such as Plunket or Dietitian visits - 38 participants
2. Only given virtual impacts which seemed less effective - 25 participants
3. Availability issues with medication and/or formula - 17%

Only 4.7% thought a delay in diagnosis was related to COVID-19.

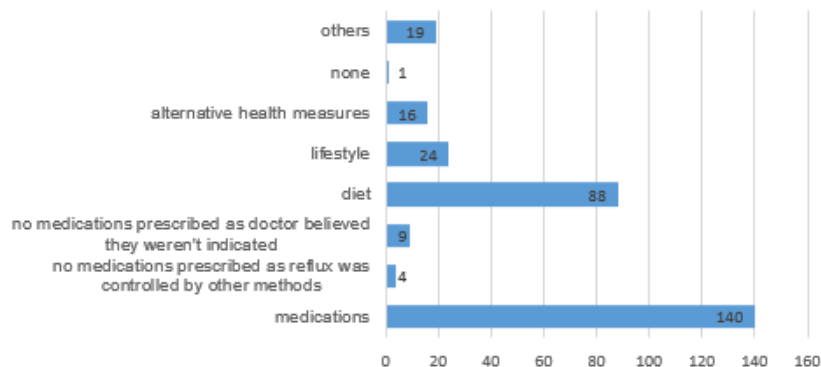
Approximately how long after first seeking help was the diagnosis of gastric reflux made?



Treatment and Intervention

What treatments or interventions were prescribed or suggested for gastric reflux? (Please choose all options that apply)

5% were not treated with medications compared to 2% in 2006



Diet

79% were breastfed at time of diagnosis with 42% continuing to breastfeed despite gastric reflux.

Top reasons for giving up breastfeeding were:

1. Found feeding issues too stressful
2. Baby refused to breastfeed

Management of GORD

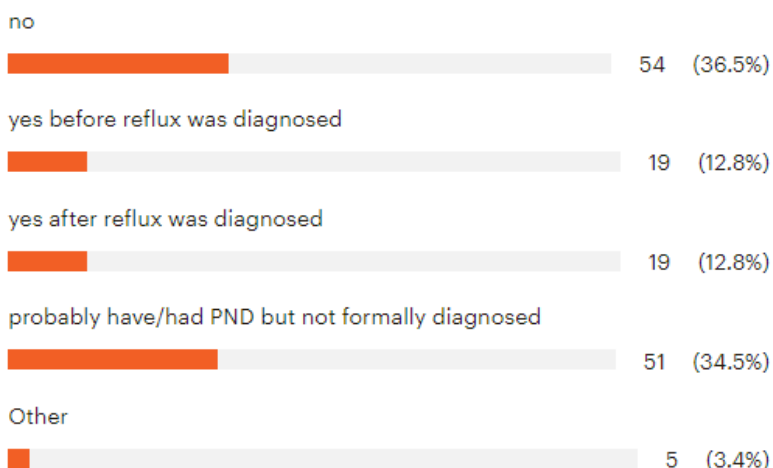
Top contributions to controlling GORD:

1. Prescribed medication - 85%
2. Upright positioning - 54%
3. Dairy free diet - 36%

92% reported that GORD was controlled.

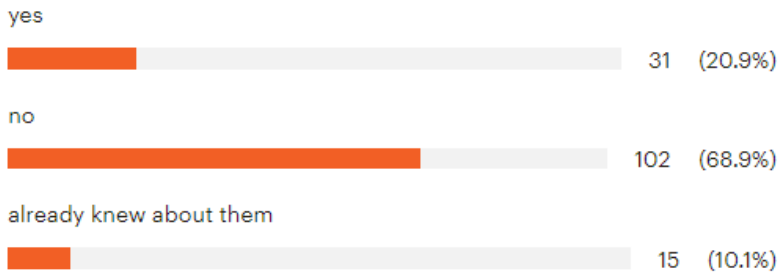
Post Natal Depression

“Have you been diagnosed with post natal depression?”



Support

“Did a health professional tell you about GRSNNZ/Crying Over Spilt Milk/GRASP around the time of diagnosis?”



Conclusion

After looking at the results of this survey, we quickly decided that the main theme was that families needed to be heard. Hence the topic for National Infant and Child Gastric Reflux Awareness Week 2022 is **“We hear you”**.

The “Infant and Child GORD Diagnosis and Experiences Survey NZ” was only completed by those whose children had a diagnosis of GORD.

Although irritability is a non-specific symptom the majority of those who reported this, also reported another concerning symptom of GORD such as feeding difficulties, choking or apnoea type episodes. Our families coping with GORD are vulnerable and need to be heard. The results of them not feeling heard left participants feeling frustrated, helpless, doubtful of parenting ability and intuition, guilty for not knowing how to help their baby and distrustful of health professionals. One quarter have had a diagnosis of post-natal depression with another third probably having had undiagnosed PND. It was pleasing to hear that despite only 19% of participants feeling heard, 92% reported that GORD was controlled.

This National Infant and Child Gastric Reflux Awareness Week, we would ask that you display our poster to help us promote awareness of not only GORD, but gastric reflux.

We have brochures available for distribution all year as gastric reflux doesn't stop during the other 51 weeks. 69% of participants reported that a health professional did not tell them about GRSNNZ around the time of diagnosis. Other parents **“Hear”**.

© Roslyn Ballantyne (RN), Trustee, Crying Over Spilt Milk Gastric Reflux Support Network New Zealand for Parents of Infants and Children Charitable Trust (GRSNNZ) May 2022.
www.cryingoverspiltmilk.co.nz

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