

Experience Caring for Babies with Reflux Disease

Introduction

Thank you for taking the time to complete this survey and share your experiences caring for a baby with gastro-oesophageal reflux disease (GORD). If you have more than one child with reflux, please complete this survey for the first child with reflux. You may skip any question you do not wish to answer. The survey will take about 20 minutes to complete.

The survey aims to explore the symptoms shown by the baby and your experience getting a diagnosis, treatment and management of this condition from health services in Australia, with a focus on the first 12 months of the child's life.

Responses to this survey will be used by the Reflux Infants Support Association (RISA Inc) to develop education and information materials for health care professionals in Australia to help them better understand the impact of GORD on babies and families.

Survey data will be aggregated and de-identified in any materials developed for this purpose. You will be given the option to provide your name and contact details at the end of the survey if you wish to be kept informed about the project or share further information about your experience. This information will be kept confidential and you will not be identified in any published material.

If you have any questions, or would like further information, please contact the Reflux Infants Support Association at info@reflux.org.au.

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Personal Details

This page gives demographic information about yourself and your family.

1. What is your age?

2. What age is the child with reflux disease?

3. What is your gender?

4. What State do you live in?

5. What is your postcode?

6. What is your marital status?

7. What is your current employment status?

8. What is your relationship to the child with reflux?

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History

This page gives basic family history for the child with reflux disease

9. What formal diagnoses does the child have? (Please select all that apply)

- Gastro-oesophageal reflux disease (GORD)
- Cows milk protein intolerance/ allergy (CMPA/I)
- Multiple food intolerances/ allergies
- Asthma
- Otitis Media
- Sleep Apnoea
- Sensory Processing Disorder
- Autism Spectrum Disorder
- Irritable Bowel Syndrome
- Eosinophilic Oesophagitis (EoE)
- FPIES
- Other (please specify)

10. Do you have a family history of GORD?

11. How many of your children have GORD?

12. If you have more than one child with reflux, please briefly provide any additional information about your experience caring for this child and how this experience might have differed from your experience caring for the first child with reflux.

13. Was the birth:

14. Did the child or the mother receive antibiotics within 1 week after birth?

15. Did the mother have antibiotics during pregnancy?

Diagnosis

This page provides information about your experience seeking a diagnosis for the child's health condition

16. At what age did you first start to notice that something wasn't quite right with the child?

17. What signs/ symptoms did the child show? Please select all that apply.

- Overt reflux/ regurgitation (vomiting)
- Silent reflux
- Frequent wet burps
- Frequent hiccups
- Diarrhoea
- Mucus/ blood in the stool
- Constipation
- Bloating stomach
- Eczema
- Severe nappy rash
- Other skin rashes
- Frequent colds
- Congested nose
- Persistent cough
- Recurrent ear, nose, throat infections
- Severe unsettledness ("colic")
- Failure to gain weight/ thrive
- Other (please specify)

18. At what age did the child receive a diagnosis?

19. Who initially assessed the child and suggested they might be experiencing reflux?

20. Please provide any further information or comments you would like to share about your experience (positive or negative) obtaining a diagnosis for the child.

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Treatment

This page provides information about the treatment the child has received for reflux disease.

21. Over the course of the child's life, what treatment has been prescribed by health professionals to treat their reflux and associated conditions? Please select all that apply.

- Proton pump inhibitors e.g. Losec
- H2 antagonists e.g. Zantac
- Pro kinetics e.g. erythromycin, domperidone
- Stool softeners/ laxatives e.g. lactulose, osmolax
- Other medication
- Breastfeeding exclusion diet
- Non-cows milk infant formula
- Thickened formula
- Endoscopy
- Fundoplication
- Other (please specify)

22. Over the course of the child's life, have you sought alternative or supplementary therapies for the child's reflux disease?

23. If yes, what treatment have you sought? Please tick all that apply.

- Homeopathic remedies
- Elimination Diets
- Supplements e.g. probiotics, vitamins, broths
- Chiropractor
- Bowen Therapy
- Chinese Medicine
- Prefer not to say
- Not applicable

Please provide any further information or comments

24. Please provide any further information or comments about your experience treating the child's reflux disease during their first year of life.

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Management

This page provides information about how you, your family and health professionals manage the child's reflux disease.

25. Thinking about the child's first year of life, what techniques did you try to manage their reflux disease? Please select all that apply.

- Keeping the baby upright during and after feeds
- Smaller, more frequent feeds
- Elevate the cot/ bassinet
- Abdominal massage
- Dummy
- Slept baby upright (e.g. in carrier, bouncer or on parent/carer)
- None
- Prefer not to say
- Other (please specify)

26. Do you consider that the child's reflux is currently well managed?

- Yes
- No
- Don't know
- Not applicable

27. When the child was first diagnosed with reflux, were you informed and involved to the extent that you wanted to be in decision about the care, treatment and management of the child's reflux and related conditions?

- Yes
- No
- Don't know
- Not applicable

Please provide any further information about how involved you were in decision-making

28. In the first year of the child's life, did you have a key health professional coordinating the child's care and treatment for reflux disease?

- Yes
- No
- Don't know
- Not applicable

29. If yes, was the health professional a:

30. If there was a key health professional looking after the child, were you able to easily contact the health professional with questions or enquiries about the child's symptoms, care and treatment?

- Yes
- No
- Don't know
- Not applicable

Please provide any further comments

31. Would you recommend the key health professional caring for the child to family or friends with a child with reflux?

- Yes
- No
- Don't know
- Not applicable

32. Were solids introduced to the child with reflux earlier than 6 months on advice from a health professional?

- Yes
- No
- Don't know
- Not applicable

33. If yes, did the introduction of solids reduce the child's reflux disease symptoms?

34. Is the child still experiencing reflux?

- Yes
- No
- Don't know

Please add any other comments

35. If the child isn't experiencing reflux, at what age did you realise this?

36. Please provide any further information or comments about how well the child's reflux disease and complications were managed at home and by health professionals in the first year of the child's life.

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Impact

This page provides information about the impact of the child's reflux disease on themselves, you and the rest of the family. You may skip any question you do not wish to answer.

37. On a scale of 1 to 10 (0 being no impact, 10 being greatest possible impact), please rate how having a child with reflux disease impacted on your quality of life in the first year of the child's life.

1	2	3	4	5	6	7	8	9	10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

38. Thinking about the first year of the child's life, how did caring for a child with reflux disease impact on your quality of life or that of your partner/family/loved one? Please select all that apply

- Diagnosis of post-natal depression/ anxiety
- Diagnosis of post-traumatic stress disorder
- Undiagnosed mental health disorder such as depression or anxiety
- Increased strain on the primary relationship (marital, de facto or otherwise)
- Financial strain
- Poor physical health including injury, chronic disease
- Decreased participation in the workforce or absenteeism
- Prefer not to say
- Other (please specify)

39. In the first year of the child with reflux disease's life, please indicate approximately how much your out of pocket costs have been to manage and treat the condition (e.g. medications, formula, doctors and specialist appointments):

40. Does the child have any other identified health or psychological conditions that you think could be linked to their reflux disease?

- Yes
- No
- Don't know
- Prefer not to say

If yes, please provide further information

41. Has having a child with reflux affected your decision to have more children?

42. Please provide any further information or comments about how caring for a child with reflux disease has affected you and your family, particularly in the first year of life.

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Health Service Use

This page provides information about the health services you have sought or used since the child with reflux was born to help treat and manage their conditions.

43. What health professionals was the child referred to immediately after being diagnosed with reflux disease (e.g. by a GP or Paediatrician)?

- Paediatrician
- Paediatric Gastroenterologist
- Paediatric Allergist
- Speech Pathologist
- Dietitian
- Other (please specify)

44. In the first year of the child's life, did you self-refer to any health professionals to help you care for the child with reflux? I.e. seek to identify the appropriate person to treat your child's conditions and then obtain a referral from a GP or other source.

If you self-referred, please provide a bit more information about why you chose to do this

45. Did you experience a delay in time between obtaining a diagnosis for the child's reflux disease and receiving appropriate treatment to manage their condition?

- Yes
- No
- Don't know
- Prefer not to say

If yes, please provide further information about what caused this delay

46. What health professionals are currently involved in caring for the child's reflux disease and associated complications/diagnoses?

- GP
- Nurse
- Paediatrician
- Paediatric Gastroenterologist
- Paediatric Allergist
- Speech Pathologist
- Dietitian
- Psychologist
- Occupational Therapist
- Other (please specify)

47. Thinking about the child's first year of life, did you feel that the health professionals caring for the child had a good understanding of reflux disease and its complications in babies?

- Yes
- No
- Don't know
- Prefer not to say

Please provide any further comments

48. Thinking about the child's first year of life, did you feel that the treating health professionals adequately and appropriately supported you in caring for the child with reflux disease?

- Yes
- No
- Prefer not to say
- Not applicable

Please provide any further information

49. In the first year of the child's life, did you visit hospital or an Emergency Department to seek care and treatment for the child's reflux disease?

If yes, please provide any further information about your experience attending hospital

50. If yes, please indicate how many times you have visited hospital to seek care and treatment for the child's reflux disease (or its complications) since the child was born.

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Other

51. Please provide any further comments or information that you would like to share about your journey and experience caring for a child with reflux disease.

52. Would you be interested in sharing further information about your story or experience by interview? If yes, someone from the Reflux Infants Support Association will be in touch with you to provide more information.

- Yes
- No
- Other (please specify)

53. Have you heard of the Reflux Infants Support Association?

54. Are you a member of the Reflux Infants Support Association?

55. Have you connected with any other organisation or support group to help you care for a child with reflux disease?

Other (please specify)

56. Would you like to receive further information about this survey and the work the Reflux Infants Support Association is undertaking?

57. If you would like to receive further information, please provide your name and contact details below: