



A Message for New Families

Welcome to the Cri du Chat Support Group of Australia. While an unexpected diagnosis may feel frightening, we would like you to know that there is an active group of families across Australia, and the world, keen to welcome you and to offer information, friendship and support.

Children with Cri du Chat Syndrome can lead happy, fulfilling lives as valued members of their families and communities. Many aspects of the condition described may worry new parents a great deal, but please remember that not every child has every symptom, and that there are many minor problems that can be dealt with once you overcome your initial shock and fear of the future, and as you find ways to help your child develop and learn.

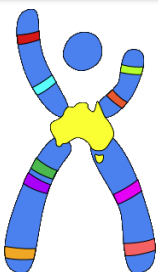
Your child is a unique individual with his or her own wonderful personality, gifts and shortcomings just like everyone else. He or she is not a syndrome! Regardless of how mild or severe your child's condition is, it will cause you a lot of grief, worry and sadness but at the same time, he or she will bring you enormous joy and love. Whilst it can be very difficult to accept in the first days or months, yours and your family's lives can be enriched by the experience of raising a child with Cri du Chat Syndrome. We know this from our own experience.

This support group is run by parents of children and adults who are living with Cri du Chat Syndrome. As such, our major concern is for other parents. We want them to know what we wish we had been told when our babies were born. In the past, limited understanding of this syndrome caused many parents to experience more pain and confusion than necessary. Many of us have felt anger and frustration as we have tried to find out how to help our children. This support group allows families to share their experiences, and all they have learned from living with Cri Du Chat Syndrome, and helps to give our children a voice through collective knowledge.

We understand that the knowledge of what might go wrong in the future can be very frightening and may make you want to hide from the reality, but it can also help to make you feel prepared. We know that knowing what you might expect helps you to anticipate and plan so that the future is not so scary. Best of all, knowing what is possible gives you goals to work towards and hope for the future. Knowledge can be frightening, but it can also be empowering.

As you journey in the early stages of this unexpected journey, please know that so many who have travelled this road before you are willing and able to extend a hand of friendship when you feel ready to connect.

The Cri du Chat Support Group of Australia, Founding Members and Current Families



Cri du Chat Support Group of Australia Inc.

Information. Friendship. Support.

3 Georgia Crt, Ferntree Gully Vic 3156, Australia

Email: info@criduchat.org.au

<https://criduchat.org.au>

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So, where to from here?

Connecting with other families

Many new parents have found value in connecting with others who have been through a similar experience. When you feel ready, there are a number of ways to actively connect with the support group and our families.

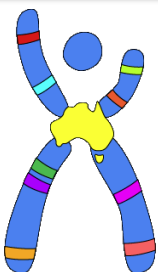
- **Send an email to info@criduchat.org.au:** In most cases, you will receive a reply within 24 hours if you have indicated that you are a new family seeking to connect. The committee is run by parents, and while it is not always possible for an immediate response to be given, priority is given to new families connecting for the first time (or friends and family contacting the group on their behalf).
- **Request to join the closed Facebook Group:** Cri du Chat – Australian and New Zealand Families (<https://www.facebook.com/groups/193249824069090/>)
Requests to join this group must be approved by another member, so we ask that where possible, you include a brief message with your request, or make contact via email in the first instance so we can look out for your request. This group provides a space for families to ask questions, share challenges and to celebrate achievements. We have over 50 Australia families represented in the group, with a range of ages and levels of ability.
- **Complete the group membership form:** An official registration will ensure you are added to current mailing lists, and are made aware of upcoming events and group happenings. Extended family, friends, and community members are welcome to register as *associate members*, and *full membership is reserved for immediate family members living with a child with Cri du Chat Syndrome*.
- **Read the Family Stories pages on the group website:** Sometimes, a great place to start to learn more about family experiences of living with Cri du Chat Syndrome is to read the family stories that have kindly been shared by group members.

Other Initial Points of Contact for New Families

- **Centrelink:** Register for Carers Payment and/or Carers Allowance (Some families have received a Carers Adjustment Payment also)
- **Better Start or NDIS** (depending on your locality): Financial support for early intervention
- **State-based Disability Services** (list of contacts available on website)
- **My Time (playgroups):** Opportunities to connect with other parents of children with a disability

Ongoing support

Ongoing support is always available for 'not so new' parents who may want to talk to someone about a particular issue they may be facing with their child (starting school, specific health issues, adult support issues such as employment, accommodation and life planning). You can make such requests through the Facebook Group, or by emailing info@criduchat.org.au, in which case we will try to link you with a family willing and able to share their experiences with you directly.



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