

Finding the support you need

>>> Information for parents of a child newly diagnosed with JIA

All parents with a child with Juvenile Idiopathic Arthritis (JIA) need support from friends, family and their community to successfully manage the demands of caring for a child with JIA, not to mention the needs of other children, pets, the house, their job and themselves! Research shows that parents who have enough social support feel happier and more confident in managing these demands. Support also helps families follow treatment plans, resulting in better management of the child's JIA. This information sheet suggests ideas about how to find support.

Ideas about where to find support

- Family members, particularly your parents and siblings. Even if they are not physically able to offer practical help, their emotional support is invaluable.
- Friends can offer both practical and emotional support (see below for ideas).
- Your child's health care team, especially your doctor, rheumatology nurse or psychologist can help with information, advice and support.
- The parents of your child's friends may be able to look after them for an afternoon so you can do other things.
- Support organisations like Arthritis Victoria can help with information, advice, courses, parent support groups, family social days and camps.
- Family Support agencies and Community Health Centres can help with in-home parenting support, parent support groups, or counselling.
- Your church or cultural group may offer both practical and social support.

What to do if you are having problems getting enough support

Some families feel they are not able to ask relatives for help, or have not received support even after asking. This can happen for many reasons, but can result in families feeling lonely and isolated. If this is the case for you, it is especially important to develop a network of friends, neighbours and professional helpers.

However, it is also important to ask yourself if you have really asked for the support you need. Often, relatives and friends do not realise the huge pressures of caring for a child with JIA. Alternately, people may not know how to help. It is OK to ask for help; in fact it is essential to the wellbeing of you and your family!

Ask yourself:

- Have you explained what the difficulties are and what support you need?
- Perhaps you have explained, but you 'spared' them from the worst aspects, meaning that they still don't understand that you need help.
- Even if they do understand, have you given them the impression that you are coping fine and do not need help?

Make a time to talk with key people who could support you, and explain as clearly as you can that you and your family would appreciate any support they could offer. Be prepared with ideas about specific things they could do to help.



Ideas about how friends and family could help

- Have a coffee together every week to relax and talk about how things are going.
- Ask for help with errands, and jobs like shopping or picking kids up from school.
- Ask them to come with you to your child's appointments for help with transport and moral support.
- Ask them to babysit occasionally so that you can go out, or even have quiet time at home to catch up on things.
- Suggest that they might spend some time with your child with JIA, or their siblings, to offer them support and make them feel 'special'.
- Ask if you can ring them if you need to talk something through.

These are only ideas; you may be able to think of other things that would be helpful. The main thing is that you take the initiative to let others know what you need, and accept offers of support if they are helpful. See the information sheet *"How others can help"* for more ideas.

Remember, it is ok to need support!

Acknowledgements:

Choices for Families of Children with Arthritis (2003).

Notes

