



How others can help...

>>> Helping a family with a child newly diagnosed with JIA

Grandparents, relatives and family friends can play a very important role in supporting families with a child with Juvenile Idiopathic Arthritis (JIA). Research shows that the more social support a family has the more likely they are to be able to manage treatment demands, resulting in improved health for children. Recent research conducted in England revealed that grandparents provided the most significant ongoing support for families, including advice, and emotional, practical and financial support. Parents valued this support more than that provided by health professionals and peer support groups. Below are some suggestions about how family and friends can help.

Ideas for grandparents

In an English study, grandparents of disabled or chronically ill children said 'Grandparents often feel afraid and do not quite know how to help or how to get involved'. You may feel that you live too far away or are too frail to help, however your moral support can still make a big difference even if you are unable to physically help. Here are some ideas about how you can help:

- When offering help, be honest about things you feel able to do.
- Keep offering help – things change and the family may suddenly need help where they didn't before.
- Be led by parents – they will tell you what they need.
- Listen to parents when they need to let off steam. This is normal, and you are a safe and supportive person they can talk to.
- Just be there.
- Regular phone calls or letters show that you care, even if you live far away.
- Give both the child with JIA and their siblings lots of love, care and attention.
- If you are able, offer to help buy needed equipment or 'treats' for the family like a meal out every now and again.
- Get involved in a support group for information and support (e.g. Arthritis Victoria).
- Help with fundraising for services for children with JIA and their families.

Other ideas for relatives and friends

- Share information you find about local support groups and services. However, make sure that the information is correct and comes from a reliable expert source.
- Prepare a meal for the family that can be frozen and used when needed.
- Write a card or send flowers to show you are thinking of them.
- Offer to help with the garden, shopping, or fetching prescriptions or medicines.
- Offer to accompany the child and parent to different appointments. Help with transport and moral support is valued by parents.
- Offer to babysit, or if you live too far away, you could have each of the children in turn to stay. Each child will value having special time with you. Both the child with JIA and their healthy siblings need to feel special every now and again.
- If it is appropriate, you could offer to stay at the family home and mind the children while the parents have a night away. This is less disruptive to the children's normal routine and allows easier access to any special equipment.

Acknowledgements:

Choices for Families of Children with Arthritis (2003)

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