

Tips for Parents and Caregiver

Sometimes when a family member develops a health problem, this can result in changes in how the family interacts and functions. It is important to be aware of changes that might be occurring within your family. Good family functioning has been shown to help children with chronic pain to function better, and lower the likelihood of depression.

It is increasingly common for non-biological parents to have the role of a primary caregiver for a child or adolescent. We have used the term “parents” throughout this handout, however, this may be substituted with grandparents, foster parents, step parents, and guardians.

Pain ownership

Encourage your child to be the expert of their own pain experience. This may involve encouraging your child to be the “spokesperson” for their pain at doctors’ appointments. You can refer to episode 1 for more information on how this may be achieved. Try to avoid speaking on your child’s behalf unless absolutely necessary.

Encourage your child to decide upon which coping strategies they want to use to manage their pain. Ask them how you can help with their pain management; and which activities they are comfortable with you participating in. You can also set reasonable rewards for your child’s positive effort and goal achievement. As a family you can celebrate your child’s successes.

Attention

A parent’s attention means a great deal to most children and adolescents. Certain actions by your child may be performed or repeated in order to gain or keep your attention. It is important that you direct attention to your child’s positive efforts at coping or managing their pain, rather than their pain or illness behaviours. The way you respond to your child in pain can help them develop good coping responses and get back to functioning better sooner.

It is important to avoid reinforcing pain or illness behaviours by following them with special treats or privileges. Typically, when a child is sick or injured, it may be necessary for them to be home from school. During this time, certain boundaries or rules may become relaxed (i.e., child allowed to spend the day lying on the couch; or watching DVDs; or playing computer games). However, when illness or pain is chronic, such privileges may not provide the child with the incentive to get better and back to school. Care should be taken to ensure that time at home from school is not reinforced with special treats or privileges.

Help

Sometimes we do not realise how problems or challenges impact on us. A problem in one area of your life can filter through into other aspects – without you even realising it. Some problems can drain a lot of our energy and coping resources making us so tired that we cannot effectively deal with other stress. It can then take a minor negative event for us to feel overwhelmed.

All families face stress and challenges from time to time. What is essential is how your family responds to them. Encourage your child to express their feelings and worries so that you can help. It is important for you and your child to be honest in acknowledging what stress or worries you have in your life. Consider whether you need any extra help or resources to start addressing the challenges that your family is currently facing.

If you or your family have challenges – aside from your child’s pain and health – don’t put them aside. Make a list; take time to think about them; where possible, work out what can be done to reduce the impact of these challenges on your child and family; seek help if you need it. Try to keep your worries separate to that from your child’s; and make time to discuss them with other adults and health care providers.

Above all, try to maintain a positive or optimistic outlook. It is difficult sometimes, but it is a gift that you can share with your child and family.

A list of online and telephone resources has been provided below.

Key points to keep in mind:

- It is possible for your child and family to function well even if someone in the household has pain
- Encourage and support your child to take ownership of his/her pain. This might involve encouraging your child to be the spokesperson for the pain when talking with his/her health professionals. Help your child to consider and decide what strategies work best for them. Be sure that the whole family knows what pain coping strategies your child has chosen to use so that everyone can support and encourage them. Taking ownership of the problem is the first step towards taking responsibility for getting better.
- Parental attention is highly valued. Try to give your child attention immediately after they engage in helpful coping behaviours. This will make these helpful behaviours more likely to happen again in the future.
- Consider the specific challenges that your family is currently faced with. Don’t brush them aside saying you can’t deal with them now. They may be contributing to other problems within the family. What resources do you need to help you meet these challenges?

Telephone helpline

Sometimes problems can feel over-whelming. Talking with someone about it can help. Sometimes it can be easier talking with trained counsellor who is removed from the situation.

| Resource | Phone number | Availability | Intended age group |
|---------------------------|---------------|----------------|--|
| Emergency ‘000’ | 000 | 24 hours a day | All ages – when you are worried about someone’s immediate safety and don’t know what to do |
| Kids Helpline | 1800 55 1800 | 24 hours a day | People between 5 years and 25 years |
| Headspace | 1800 650 890 | 9am-1am AEST | People between 12 years and 25 years |
| Lifeline | 13 11 14 | 24 hours a day | All ages |
| Domestic Violence Line | 1800 65 64 63 | 24 hours a day | All ages |
| Child Protection Helpline | 132 111 | 24 hours a day | All ages |

Online resources: For children / adolescents

| Resource | Web link | General information provided |
|---------------------|---|---------------------------------|
| Kids Health Website | http://kidshealth.org | Health, emotions and life |
| Headspace | http://www.eheadspace.org.au | Online counselling (email/chat) |
| Youth Beyond Blue | www.youthbeyondblue.com | Youth depression |
| Reachout | www.reachout.com.au | Mental health and well-being |
| Livewire | www.livewire.org.au | Living with a chronic illness |
| Whatworks4u | http://www.whatworks4u.org/ | Mental health of young people |

Online resources: For siblings

| Resource | Web link | General information provided |
|--------------------|---|--|
| Livewire | www.livewire.org.au/siblings/ | Living with a brother or sister that has a chronic illness |
| Your shout | http://www.liquidsalt.com.au/yourshout/ | Living with a brother or sister that has a chronic illness or disability |
| Siblings Australia | www.siblingsaustralia.org.au | Enhancing the well-being of siblings |

Online resources: For parents and caregivers

| Resource | Web link | General information provided |
|--|---|---|
| Alcohol | www.drinkwise.org.au | Responsible drinking |
| Communication Skills that Build Relationships | http://www.familyhealthonline.ca/fho/adolescent/AD_communicating_FHc95.asp | Communication tips for the parents of teenagers |
| Domestic Violence: NSW Family & Community Services website | http://www.community.nsw.gov.au/docs/menu/parents_carers_and_families/domestic_and_family_violence.html | What domestic violence is and what help is available. |