



Helping your teenager become more independent in their healthcare: a guide for parents



Helping your teenager become more independent in their healthcare

Adolescence can be challenging for any teenager, and living with a chronic condition such as Juvenile Arthritis (JIA) is an additional challenge. As well as medical considerations, JIA can influence relationships with family and friends and may have an impact on self-image. Pain or stiffness may also restrict or interfere with school, recreation, and work activities.

What is perhaps most important though, is that your child will need to learn how to take responsibility for managing their JIA. As your child moves through their teen years and becomes an adult, they will gradually take on increasing responsibility for all aspects of managing their condition. The earlier children are taught to manage their own treatment, the better they accomplish this as adults. The major part of this transition will take place during the adolescent years. This information sheet discusses the way you can help your teenager to become more independent in their health care.

The role of parents

The process of helping your child learn to manage JIA starts when they are young. Children as young as 7 years old can be encouraged to develop helpful ways of thinking about and coping with JIA. Give your child information about their condition, involve them in decision-making, and teach them problem-solving and coping skills as early as possible. Always encourage your child to express their feelings and concerns so that you can find ways to deal with them together. Working through problems with your child shows them how you make decisions and manage their health care.

When the time is right, your teenager can begin to take more responsibility for their own health care. It is usually helpful to begin thinking about this from the start of high school. A good way to start is with simple things like getting your child to remember medications and appointments (although you need to keep an eye on these things too). Eventually, teenagers need to begin to meet with their health care providers on their own, for some part of the appointment time. Independent visits can be phased in over time as you and your teen feel comfortable. Having 'alone time' with their doctor and treatment team helps teenagers begin the transition to taking full control of their care, and also gives them the opportunity to discuss private issues with their doctor. Going to appointments alone will get your teenager used to the idea that, soon, this responsibility will be entirely their own.

Tips to help your teenager remember medications

It is not always easy to remember to take medications. Teenagers have busy lives and it may easily slip their minds. They may also see taking drugs negatively; as a burden, a lack of control, or a reminder of a condition they would rather forget. It is also easy to forget medication if they are not experiencing active symptoms to remind them. However, following medication routines is a critical part of taking responsibility for managing JIA, and crucial for optimal pain relief and function.

You can encourage your teenager to:

- Connect pill-taking with another daily activity, like taking a shower in the morning or brushing their teeth at night.
- Write down when to take their medication on a chart or calendar which can be kept on the fridge, or by the bathroom mirror if tooth brushing is the cue they use. It is helpful to mark off the reminder when they've taken it. Use colored pens to help you keep track of more than one type of medication.
- Set an alarm on their computer, mobile phone or digital watch to remind them to take their pills.

ROYAL
CHILDREN'S
HOSPITAL



Southern Health

- Use a pill container so it is clear what needs to be taken and when. This does not have to be a boring plastic box – encourage your child to pick a funky pencil case, cosmetic purse or tin to keep their medication in – just make sure the sections are clearly labeled.
- Remember to take medication if their normal routine is broken by, for example, by going away for the weekend. You can help by asking them if they would like you to ring or send a text message to check in with them about their pills.

Letting go

At some point, all parents struggle with their teenager's growing independence. For parents of a child with JIA, this can be even harder than usual. After having spent so much time overseeing your child's care, it is sometimes difficult to encourage independence and watch them assume responsibility for their own care. Some parents may even resist their child's efforts to become more independent because they worry that their child will not be able to care for themselves properly. But all teenagers will eventually have to manage their own health as adults, and parents need to prepare them for this task. Teenagers can look after themselves competently if they are well prepared. Proper preparation means making sure that they know all they need to know about their condition, its management, and the repercussions of not taking care of themselves.

How will your child cope with greater independence?

Some teenagers eagerly embrace their growing independence and responsibility for their own care. Others feel anxious and prefer to continue to rely on their parents. It is important to find a middle ground. Parents should continue to provide support while they encourage their children to take steps on their own. The ultimate goal should be to gradually transfer complete responsibility of care from you to your child.

Your teenager should understand that major life decisions concerning education, career, and living arrangements should be made keeping in mind how their JIA will be managed and how it will influence their overall health and well-being. Being "realistically optimistic" about what is and what is not possible is the key.

Drugs and alcohol

Many adolescents experiment with risky behaviours, and substance use is a concern for all parents with teenage children. Adolescents with JIA, especially those who are taking medication for their condition, need to take special care. Teenagers need to be aware of the potential dangers of combining alcohol or drugs with their medications. Both alcohol and drugs have the potential to interact negatively with medication. Sometimes, the interaction may make the medications less effective. In other cases, the combination can be very dangerous or even deadly. Make sure your child is informed about their medication, and encourage them to check any concerns with their doctor or nurse.

Teenagers may benefit from learning strategies for coping with peer pressure to take drugs. For example at a party, humour can be used as a means of deflecting attention. One quick response might be "No thanks, I'm already on more drugs than anyone else here!" Your teenager may be able to learn to feel comfortable saying no and walking away from an uncomfortable situation. However, it is also important to talk to your teenager about moderation and minimising harm, as it is very likely that your teenager will try alcohol and/or other drugs at some stage, as most teenagers do. Teenagers need to be aware of all the choices they can make, including making new friends who do not use drugs.

Peer influences can also include the pressure to share. If your teen is taking strong medications for pain relief, it is likely that at some point, someone will ask them to share their medications. Teenagers should know, and be ready to tell others who ask, that medications for JIA do not generally produce a 'high'. They should also know that sharing their medication is illegal and potentially very dangerous. Talking openly and non-judgmentally with your teenager about their choices is the key to helping them make sound decisions.

What to do if there are problems

As your teenager takes more responsibility for their own care, some of their decisions may cause problems. Teenagers need to feel confident that they can discuss what happened with their parents without fearing criticism or a reprimand. This is how teenagers learn to problem-solve more effectively. Reinforce that you are confident in their ability to make their own decisions, while still offering advice and support.

If you are very concerned about your child's behaviour, or they seem to be struggling to cope, consult a health professional with expertise in dealing with teenage issues, such as a psychologist, or specialist in adolescent medicine.

Transition from paediatric to adult care

Eventually, your teenager will need to link with health professionals experienced in the care of adults and take full charge of their own health.

This transition can be quite emotional and stressful for all involved. Moving on to a new health care setting is like graduating from high school to university. Young people shift from being the biggest, oldest, and wisest person in the place to being a young, inexperienced "rookie" in a larger and different environment. Some teenagers find the new experience exciting. Others prefer the security of their old situation. Young people are expected to be more able to manage their own condition in an adult care setting, and to take complete responsibility for themselves over time.

There are several ways to increase the chances that your teenager will successfully transfer from a child-centred health care setting to an adult one.

Transition should be a slow process. Your teenager should learn skills and increase responsibility for their care over several years, and only change to adult care when they are confident and responsible enough to move forward. Transitions are most successful when they begin as early as possible and when the child, treatment team and family actively plan to develop the independence, skills and knowledge needed to negotiate the adult system. Hospital or clinic policy usually dictates a transition between the ages of 16 and 20 years.

Key steps to help your teen make a successful transition:

- Teenagers need to be encouraged to take an active part in their own care when they are a child and as they move into adolescence.
- Teenagers should learn about their condition, medical history and treatments.
- Teenagers should learn to solve problems for themselves and to make choices about medication, physical activities, and lifestyle.
- Teenagers need to gradually begin to attend health care appointments alone to promote their sense of independence and responsibility.
- Teenagers should be given responsibility for taking medication, making appointments, doing exercises and filling prescriptions over time.
- Teenagers should apply for their own medicare card, and learn about how to pay for appointments and medications.
- Teenagers should explore various options for adult health care, including finding professionals that they are comfortable with before they make a final transition.

Further information about transition to adult care

www.rch.org.au/transition