
Paediatric Rheumatology Department

Helping your teenager to independence in healthcare

A guide for parents/carers

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

Your child will also need to learn how to take responsibility for managing JIA. As they move through their teen years and become an adult, they will gradually take on an increased responsibility for all aspects of managing their condition. The earlier children are taught to manage their own treatment, the better they accomplish this as an adult. Transition into adult care will occur during the adolescent years. This information sheet discusses the way you can help your teenager to become more independent in their own health care.

The role of parents

Helping your child learn to manage JIA can start when they are quite young. Children as young as seven 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 of dealing 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 upper school. A good way to start this is with simple things like getting your child to remember medications and appointments, although you need to keep an eye on this too! Eventually, teenagers need to begin to meet 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 begin to feel comfortable. Having 'alone' time with their doctor and treatment team helps teenagers begin the transition and allows them the opportunity to discuss private issues with their doctor. Going to appointments alone will get your teenager used to the idea that, soon, the responsibility will be entirely their own.

Tips to help your teenager remember medications

It is not always easy to remember to take your medications. Teenagers have busy lives and it may easily slip their minds. They may also see taking drugs negatively, as a burden, 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 teen 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 brushing teeth is the cue they use. It is helpful to mark off the reminder when they've taken it. Use different coloured pens if they have to take more than one kind of medication
- set an alarm on their computer, mobile phone or digital watch to remind them to take their pills
- 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 personalise it according to their tastes
- remember to take medication if their normal routine is broken by, for example, going away for the weekend. You can help by asking them if they would like you to phone or text them to remind them

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 practical and manageable 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 medication. Both alcohol and drugs have the potential to react 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 teenager 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 a way of deflecting attention. 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.

Peer influence can also include the pressure to share. If your teen is taking strong medication 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 your medications is illegal and very dangerous. Talking openly and non-judgementally with your teenager about their choices is the key to helping them make sound decisions.

What happens if there are any problems?

As your teenager takes more responsibility for their own care, some of the decisions may cause problems. Teenagers need to be feeling confident that they can discuss what happened with their parents without fearing reprimand or criticism. 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 those involved. Moving on to a new health care setting is like graduating from school. Some teenagers find the new experience exciting while others prefer the security of their old situation. Young people are expected to be more able to manage their own condition in an adult setting and to take complete responsibility for themselves over time.

There are several ways to increase the chances that your teenager will 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's treatment team and family actively plan for it. Hospital policy usually dictates a transition between the ages of 15 and 18 years old.

Key steps to a healthy transition

- Encourage teenagers 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.
- Allow teenagers to make choices about medication, physical activities and lifestyle.
- Teenagers need to gradually attend appointments alone to promote their sense of independence and responsibility.
- Give teenagers responsibility over time for taking medication, making appointments, doing exercises and filling prescriptions.



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