



Becoming more independent in your health care

A GUIDE FOR TEENAGERS

Being a teenager can be tough for anyone, but having Juvenile Idiopathic Arthritis (JIA) adds extra challenges. There are things you need to do to help keep your arthritis under control, like taking medication, doing exercises, and managing pain. And you have to fit these in around all the other jobs of being a teenager like going to school, having fun with your friends and planning your future!

All these things take time and effort, and most kids are used to relying on their parents to help. Parents are usually really good at remembering doctor's appointments, remembering to buy your medication before it runs out, and reminding you to take it at the right time. However, now you are getting older, you will need to learn to do all these things for yourself so that you feel comfortable about making your own decisions when you are an adult. The sooner you start to learn about how to manage your JIA, the easier this will be in the long run.

How to start being more independent

When you and your parents feel ready to start giving you more independence in managing your arthritis, have a talk with them and pick one thing that you can take responsibility for. Often teenagers start by taking responsibility for their medication. This means remembering to take it at the right time, and keeping an eye on when it is running out so you can arrange to get more.

Tips for remembering to take medication

It is not always easy to remember when to take medicine. Teenagers have busy lives and it may easily slip your mind. Some kids feel that taking drugs is a burden, or a reminder of a condition they would rather forget. If you are not experiencing active symptoms it's even harder to remember, or believe that you really need it. If you feel this way, it's likely to be hard for you to manage your medication effectively, so it's best to speak to your doctor or nurse about your feelings before attempting this. However, following medication routines is a critical part of taking responsibility for managing your JIA, and if you feel ready to try this, here are some tips that might help you remember your medication:

- Fit pill-taking into your daily routine by connecting it with another daily activity, like taking a shower in the morning or brushing your teeth at night.
- For medication that you take once or a few times a week, write down when to take it on a chart or calendar which is kept on the fridge, or by the bathroom mirror if tooth brushing is the cue you use. Mark off the reminder when you've taken it. You can use different coloured pens for different types of medications.
- Set an alarm on your computer, mobile phone or watch to remind you to take your pills.
- Use a pill container so it is clear what needs to be taken and when. This doesn't have to be a boring plastic box – pick a funky pencil case, cosmetic purse or tin to keep your medication in – just make sure it is clean, fastens securely and has sections which can be clearly labeled.
- Make sure you store your medication in a pill container or another safe place like a toiletry bag or wallet when you go away or have a break in routine. It is also useful to get others to help you to remember. Ask a friend to remind you, or get your parents to ring or text you at the right time. The more heads on the case the better!



Being responsible about drugs and alcohol

You may know people who have, or have yourself, tried drinking alcohol or using other drugs. It is pretty common to experiment with substances when you are a teenager – it can be something you want to do because it's fun, or to fit in with your friends. It is always risky for any teenager to use illegal drugs, or to use legal drugs excessively, however when you have JIA there are extra complications you need to be aware of so that you can make informed choices.

Both alcohol and drugs have the potential to interact negatively with medication. Sometimes, the interaction may make the medications less effective, so that you may be 'wiping out' the point of taking the JIA medications in the first place. In other cases, the combination can be very dangerous or even deadly. It's also important to know that JIA drugs may interact with other drugs, such as the contraceptive pill, which may make the pill less effective too. It's important to check all these things and discuss any concerns you have with your doctor, nurse or pharmacist, or to ring an anonymous helpline if you feel more comfortable doing this. The important thing is that you get all the information you need to make these decisions about your health.

There are lots of strategies you could use to deal with people who offer you drugs. Being funny is a very good way of getting people off your back, without seeming uncool. For example, if someone offers you drugs at a party, one quick response might be to say "No thanks, I'm already on more drugs than anyone else here!". Some people feel comfortable just saying "no thanks", or hanging out with a group of friends who don't use drugs. However, if you do decide to drink alcohol or use drugs sometimes, it's important to do this as safely as possible, by having one or two drinks instead of 10 for example, and finding out the impact this is likely to have on your medications and health.

One other thing to consider is that someone may ask you to share your medications, thinking that they'll get them 'high'. You need to be clear about what the drugs you are taking do, so that you can explain it to other people. Most medications for arthritis don't produce a 'high', and aren't any good to anyone but you. In fact, they may even make other people sick. You need to know that sharing your medication is not only pointless, but potentially dangerous and illegal, so that you can make good decisions.

Transition from child-centred to adult care

Eventually, you will need to move away from the treatment team you had as a child and link up with health professionals who care for adults. This is called transition. Transition usually happens about the time you finish school, but you, your parents and treatment team should start getting ready for this much earlier, by helping you become more independent and responsible for your health.

Transition can be quite stressful. Moving on to a new health care setting is like graduating from high school to university. You 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 treatment in an adult care setting, and to take complete responsibility for themselves over time. This doesn't mean that you can't bring your parent or a friend with you though!

There are several ways to help yourself make a successful transition to adult health care. Transition should be a slow process. You should start thinking about and preparing for transition well before you actually do it. In fact, through your teenage years, all the efforts you make to become more independent in your health care will help you when it comes time to move into the adult system. You should learn skills and increase responsibility for your care over several years, and only change to adult care when you feel confident to do this. Hospital or clinic policy usually dictates a transition between the ages of 16 and 20 years.

Steps in learning to manage your own health care

After taking responsibility for your medications, the next step is for you to start spending some time with your treatment team on your own. This can happen gradually. First, spend a part of the appointment alone, and then you can attend whole appointments on your own if you would like. Meeting with your treatment team on your own will help you take control of your care, and also give you a chance to discuss some issues privately. When you feel ready to have some private time in your appointments, discuss this with your parents and doctors.

Below are some questions that you might like to ask your doctor during your private appointment. You can print these out to take with you, or make a list of your own questions. Remember that you can ask questions about anything you'd like: it's your body.

Examples of questions to ask your doctor:

- Will you keep this conversation confidential?
- What's wrong with me?
- Can you draw me a picture or show me what's wrong?
- Can you explain that again because I didn't quite understand.
- What causes this problem?
- Will it get better? When?
- What do I need to do to get better?
- What does this medicine do?
- What will happen if I don't take it?
- What are the side effects?
- How long will I need to take it for?
- What if I forget a dose?
- If I don't notice any improvement, how long should I wait before calling you?
- What side effects or changes should I tell you about?
- What else can I do to help myself feel better?

How will you manage being more independent?

Some teenagers can't wait to be independent and take responsibility for their own care. Others are worried about getting it right or talking to doctors, and prefer their parents to remain involved into their early adult years. A bit of both is usually best – try and learn the skills you need to be independent while relying on your parents for support along the way. The ultimate goal is for you to take over the responsibility for your care completely, and to consider the impact of JIA when making all your major life decisions, such as about education, career and living arrangements. The key is to be “realistically optimistic” about what is and what is not possible for your future.

What if there are problems?

If you are worried about how you are coping at any stage with being more independent, making good decisions, or feeling down, it is important that you speak to someone who can help you. A good place to start is your parents, a doctor or nurse educator, but if you want to speak to someone more privately, your school counsellor or the Kids Helpline (phone: 1800 55 1800) are good options.

Useful websites about transition

www.rch.org.au/transition

<http://depts.washington.edu/healthtr/>