

A “From Me and MY Friends to You and Yuurs” Resource:

What is JIA (Juvenile Idiopathic Arthritis)?

JU- VUN- AY- UHL ID- EE-O-PATHIC RTH-RYE- TUS

JIA is a condition which means that peoples joints get swollen, stiff and painful. Juvenile just means that it affects young people, idiopathic means that there is no known cause and aortitis literally means inflammation of the joints. JIA is not contagious- you can't 'catch it' as such. It is caused by problems with the immune system where the immune system essentially gets confused and attacks itself.

In addition to painful joints, people with JIA can experience symptoms such as tiredness, temperatures and rashes. There are lots of different types of JIA and LOTS of different joints in the body, so each person is affected differently. Some people may get something called 'uveitits' which is inflammation in the eye causing painful, red eyes and difficulty with vision.

People with JIA may struggle with walking long distances, playing sports or tasks such as writing and opening bottles. JIA can affect most of the joints in the body so even tasks such as eating can become challenging. JIA often comes in 'fares' where peoples symptoms may be worse for a period then they can improve, this can make it hard to plan

To treat JIA most people, take regular medication. This can be in the form of tablets, injections or infusions (where the medicine is given into a vein in hospital, usually every 4-8 weeks.) Unfortunately, sometimes this medication can make people feel sick or tired or give them headaches which can significantly affect mood and ability to conduct day to day life. Sometimes people may use a wheelchair or crutches for a bit to help them be able to do more whilst in a flare.

How does JIA affect...

....me physically?

I struggle to walk long distances and with tasks such as running or standing so sometimes I may use crutches to allow me to keep going for longer. I also find writing or typing for prolonged

periods challenging. Opening bottles or jars can also be difficult. I find that I have to go for However I've found that over time JIA has affected me differently, when I was young it was things such as not being able to keep up with playing in the park or the playground that bothered me the most whereas now my struggles are far more linked to things such as independence, socialising, studying and working. However, there are lots of ways of adapting tasks or activities so that you can do much more even if it does just mean doing things differently. For instance, I still managed to go interrailing even on my crutches, largely because of the support of my friends and the attitude of 'doing things differently.'

.. me mentally?

JIA often affects my mood. If I am struggling to keep up with something, I can often get frustrated or annoyed at myself and if it's a situation I'm not comfortable in, I can get quite anxious about it. When there are times where I've had to put my health first and not been able to do something or had to leave something early, I can get sad about this and can snap at people or get angry at things. This is not excusable, but it can help if people understand why I am feeling the way I am. Living with pain constantly is exhausting, and it can often impact on sleep, which makes the exhaustion worse. Some days are better than other days and there are weeks where I don't feel any of the emotions above but sometimes I just need people to be patient with me.

.... my life

- **I have to pace my activities a lot more** ☑ I am the kind of person who likes to be busy all of the time however I can't always do this. This has been a really hard skill to learn and one I have not enjoyed learning and one I am still learning.
- **Life can be unpredictable** ☑ surprise hospital admissions, side effects which one week you barely notice and other weeks knock you down like a truck, significant fare ups can all make it harder to plan your life. This also means that sometimes it is more important to plan to try and give you the greatest amount of control over your life as possible.
- **I can't always do or join in everything** ☑ whilst lots of things can be adapted this isn't always possible and there are times, for instance on nights out where the adaptations

often take away the enjoyment of the activity itself. However, this can be very flare dependent and is VERY dependent on my mood.

3 things your friends can do to help

- **Be mindful of the pace you are walking** ☑ this is a really easy thing for friends to do. When people are walking fast it can be hard to keep up and can make people feel pressurised when they feel themselves falling behind. Its makes a huge difference having someone to be able to talk to and walk alongside without this pressure
- **Listen** ☑ listen to your friend. They are the expert on their own condition and what they are experiencing. They know where their limits are, and whilst sometimes people may need a wee reminder, it is always better to communicate with, have discussions and listen to your pal.
- **Ask** ☑ If you see someone struggling with something, asking that person if they would like any help can be a helpful thing to do. It is always better to ask in a non-condescending manner than immediately begin helping as this can be very annoying however this should not put you off offering help in the first place.

A friend's perspective...

I had known Beth for around two years before she told me about her JIA. Before she told me, I didn't really know a lot about the illness. I had always thought that it was an illness that affected older people, I had never thought about it being something that one of my best friends would ever have to deal with. However the more I learnt about JIA and how it effects Beth and her daily life, I learnt that this was not at all true. Throughout the 5 years Beth and I have been friends, her health has fluctuated a lot, and from this I learnt that the very best thing you can do for your friend with a chronic illness is just to be there to support them. There are several ways you can do this:

- When your friend is going through a period of good health, celebrate them, and when their health isn't as good, try to support them in any way you can.

- Another way you can help your friend with JIA is as simple as watching how quickly you walk. Slowing your pace so your friend doesn't feel like they have to keep up is really easy way to help.
- Ask your friend if they need any help, help can be as simple as offering your arm for a bit of physical support or carrying a heavy bag so they don't have to. Always ask your friend first if they want help, as they are more than fully capable of doing anything, but sometimes things might be done slightly differently and sometimes because they can do something shouldn't mean they have to.
- Go at your friends pace and always try to be understanding of their situation and actions, including how they tell other people and how they chose to deal with things.
- The final thing is to remind your friend that they can do anything despite their chronic illness, just that sometimes things may need to be done slightly differently. As a friend you can help by planning to go to a coffee shop with a ramp etc instead of steps, something you might not have noticed but would make a huge difference to a wheelchair user and would mean a lot to them that you considered it.

The main way to support your friend with JIA is really just to be there for them and remind them whenever they're having a wobble that they can do anything they want to and that you're always there for them.

If you want to learn more

<https://arthursplace.co.uk/> ⓘ information and articles for young adults (14+)

<http://www.snac.uk.com/> ⓘ Scottish Network Arthritis in Children

<https://www.jia.org.uk/> ⓘ Lots of information from NRAS, resources for both children, young people and adults

<https://www.versusarthritis.org/about-arthritis/young-people/> ⓘ Versus Arthritis has lots of resources on all things rheumatology. Worth while exploring this site

<https://patient.info/news-and-features/what-its-like-to-be-a-young-person-with-arthritis>  a
article written by a young person

It's also worth having a look at some of our blogs or listening to our podcasts.

About the Authors...

Beth (she/her) ...is 20 and is from Leeds but spends most of the time living in Glasgow. She is currently a medical student at Glasgow university.

Izzy (she/her) ... is also 20, and from Leeds but is living in Newcastle studying History.

They have been friends since high school and have been on lots of adventures together from Berlin to Durham.

Get Involved...

We would love to get as many people involved in creating these resources as possible! If you are a young person living with a chronic illness, disability, or long term health condition, and would be interested in making a similar resource based on YOUR experiences, we would love to hear from you! You can email us at thelunaprojectuk@gmail.com ! You can also find us on social media @thelunaprojectuk !