



ARTHRITIS CARE

*Empowering
people with arthritis.*

BREAK OUT!

**THE COMPLETE
LIFESTYLE GUIDE
FOR YOUNG PEOPLE
WITH ARTHRITIS**



GETTING ON WITH LIFE

In this *Breakout* guide you will meet 12 young people with arthritis who tell it like it really is. No-one says having arthritis is an easy ride. But the people in the *Breakout* guide all have fun, friends and plenty of tips on leading a full life – even if that means giving yourself more of that much needed time to chill.

Whether you're waiting for a diagnosis or wanting to meet someone young with arthritis who knows what it's like, read their stories and try new things for yourself. You might know what works for you and what you need – perhaps you need to find out, or want to know what lies ahead. Right now, look no further, and enjoy.

Here are a couple of things to think about. One – living a normal life and doing normal things is a lot easier if you can talk about

All I can think is how much this guide would have helped me as a 10-year-old with arthritis, especially the way people talk about their arthritis

Carly, 20

your arthritis with other people. Everyone here has found things feel a lot better when you talk about your concerns and needs.

Here's a tip to get you started. Practise a few lines to tell someone openly, if briefly, what it's like having arthritis – think of it as your 15 seconds of fame.

Two – being independent doesn't mean going it alone, and with the *Breakout* guide you're in good company. ■

Disclaimer: Opinions and actions mentioned in the *Breakout* guide are not necessarily recommended by Arthritis Care. Please exercise your own judgement about whether or not something is likely to help you, and where appropriate, take professional advice from your health professional.

BREAK-OUT



4

4 YOU'RE NOT ALONE

Info about arthritis

5 HOW TO DEAL WITH FRUSTRATION

Niall McLaughlin gives some tips on dealing with frustration

6 EXPRESSING YOUR FEELINGS

Shelley Hayward and Rionah McNichol talk about hobbies and finding out what you are good at

8 TALKING ABOUT ARTHRITIS

Have a few facts to give out, advise Rosie Buttery and Jane Perks

10 SURVIVING SCHOOL

Dan Fielding and Rionah McNichol show how to get support from school



10



12

12 SUPPORT FROM FRIENDS

Talking to other people with arthritis can make it easier to talk about it with your friends

14 FEELING GOOD

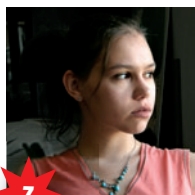
Shelley Hayward and Dan Proctor suggest how you can feel good about yourself

16 HAVING A LIFE

Concentrate on what you are able to do, say Kate Fleetham and Niall McLaughlin

18 TOP TIPS

Twelve ideas for managing arthritis in everyday life



7



9



18

CONTENTS

20 FITNESS FIRST

Give yourself a sporting chance to keep fit, say James Chamberlain and Dan Fielding

22 HOW FRIENDS CAN HELP

Three ways to get support from friends

24 BECOMING INDEPENDENT

Check out all the details if you're moving out, say Jane Perks and Emma Wells

26 PREPARING TO TRAVEL

Travel with arthritis takes extra planning but is well worth it, says Clare Allen

27 EQUIPPED FOR UNIVERSITY

Kate Fleetham finds there is more support for students than she realised

28 SUCCESS AT UNIVERSITY

There is a huge range of support for students, say Clare Allen and Rosie Buttery

30 GOING OUT

Rionah McNichol and Niall McLaughlin show how going out needn't wear you out

32 FRIENDS AND MORE

Finding supportive friends shifts attention from your arthritis say Kate Fleetham and Shelley Hayward

34 FINDING TRUE LOVE

Suzie Forster shows how to nurture true love

36 A SOBERING THOUGHT

If you drink, be careful, says Clare Allen

37 SOURCES OF SUPPORT

Where to look for support and advice



YOU'RE NOT ALONE

Being able to talk to other young people with arthritis can make all the difference

Speaking to other people with arthritis can provide such an insight into all aspects of how arthritis affects our lives. I have met many kind and compassionate people through online forums at www.arthritiscare.org.uk and even on Facebook – **Kate Fleetham**



SOME ARTHRITIS FACTS

- There are about 27,000 people in the UK with arthritis under the age of 25.
- Women are more likely to develop arthritis than men.
- There are more than 200 types of arthritis. The most common in children and young people is inflammatory arthritis.
- It is not known what causes arthritis.
- At the moment, there is no cure for arthritis. However, there are many ways of protecting your joints, such as keeping mobile with exercise and by taking medication.
- If you have sex when you are on methotrexate and several other disease-modifying treatments you should make sure you use protection as the drug can harm the development of a baby. This is the responsibility of both partners.
- Only a third of children will have juvenile idiopathic arthritis (JIA) into adulthood.

HOW TO DEAL WITH FRUSTRATION

Niall McLaughlin says how you deal with feelings of frustration is as important as how you deal with your body

When you are diagnosed with arthritis it comes as a shock at first. After some time it sinks in that it is here to stay, and it is something you have to get used to and deal with. It is a life-changing thing and it brings its own share of frustrations. To help with the stiffness from lying down all night, I give myself extra time to get ready in the morning so I do not rush or panic.

Having young nephews who cannot understand why their uncle cannot play with them as much as they would like is a difficult thing. When they get older you can start to explain why you can't get down on the floor or run. I get around this by playing with Lego or board games on a table, instead of getting down on the floor. I have also taught my older nephew the basics of basketball as I don't have to strain my knee or hip joints in this game.

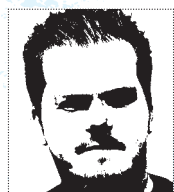
I find it frustrating that when you are on medication that brings on weight gain, you may not eat as much as some people but it



Eating a balanced diet can help control weight gain, and tastes good too

looks like you are overweight. This is something which is difficult to control, but I know it is important to watch my diet, take as much exercise as I can by going to the gym and taking walks, and cutting down on alcohol.

I always try to have an answer for any frustration brought on by arthritis, have a positive outlook on everything and find other ways of getting a task accomplished.' ■



Niall McLaughlin (26) has had juvenile arthritis since he was 12. He is starting a degree in music

Did you know that...

The Source, Arthritis Care's free and confidential helpline for young people, can offer you information and support on any issue that might be bothering you? Freephone 0808 808 2000 (10am-4pm weekdays) or email: TheSource@arthritiscare.org.uk

EXPRESSING YOUR FEELINGS

Having an outlet keeps you in touch with yourself, says **Shelley Hayward**

When I first found out about my arthritis, I was in a state of shock as I thought it was a condition that only old people got. I didn't know who to talk to as I felt there were so many people that had far worse conditions than me and that nobody would understand how I felt.

Over the years I have learnt that talking about my feelings to my friends and family really helps. They are the people who know me the best and also know how to put a smile on my face.

I think my personality helped a lot with me accepting my arthritis. I am a very bubbly and happy person, so always try to have a smile on my face. When I realised that nothing would make my arthritis go away, the best thing I could do was to smile and learn how to deal with the pain and everything that comes with it.

You can express your feelings in



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Developing a hobby, such as playing the piano, is a great way to let your feelings out

Talking about my feelings to my friends and family really helps

many different ways. If you feel uncomfortable talking face-to-face

about it, then writing a letter or email is a good way to communicate. I have found that a really good idea is to develop

a hobby that relaxes you, for example playing an instrument or a sport, and pursue it as much as possible.

Relaxation has a key part in helping you to accept your arthritis.' ■



Shelley Hayward (19) has had arthritis since she was 14. She is training to be a primary school teacher



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You can change a dark mood into a brighter one, says **Rionah McNichol**

There is a lot more to you than just what you see

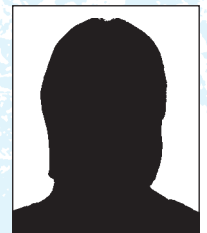
I talk about being determined, but there are times when it is not easy. Frustration can be a big issue. I have low days when I am really sore and start asking all the questions – after all, why me?

I went to a park one day with my friends. They were all jumping around doing handstands and cartwheels. It made me remember that before I developed arthritis I was very active and athletic and could have done this with the others. But I realised I couldn't do it any more and it really, really upset me. But I woke up the next day and said to myself that I might not be able to do cartwheels and handstands but I can do a lot more than that, and

there's a lot more to me than the physical side.

Something I had to deal with was feeling very self-conscious about the way I looked because my bottom jaw didn't grow enough, due to the arthritis. This meant I had a large overbite, and to make it more obvious I also have large teeth. I was very self-conscious as a teenager about how I looked but have since had surgery to correct this.

Thinking positively about what I have got is something I do now when I am feeling down – there's my course at university and my career ahead of me. So I think about what I do have, not what I don't. ■



Rionah McNichol (25) has had juvenile arthritis since she was 10. She is doing a social work degree and wants to work with young disabled people

Rosie Buttery has found that having a few simple facts on hand makes life a lot easier

Here you are, trying to get on with your life – perhaps struggling to open a coffee jar. You are angry at yourself. Why can't you do it? Chances are, you are also angry at the world: why are there no seats in changing rooms? Then someone says the words we all hate: "What's wrong with you?"

People eventually twig that there is something different about me. If I'm with people I don't see that often I will usually wait for them to



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TALKING ABOUT ARTHRITIS

bring it up in their own time and then answer with my standard speech: "I have juvenile idiopathic arthritis. It's a chronic autoimmune disease that affects all of my joints and muscles. I've had it since I was born and it just means that sometimes I can't do some things." If I'm feeling particularly rough I will usually add that it's a bit like having several sprained joints and flu at the same time.

If it is a new friend or colleague then I will usually pick a quiet moment and make a joke or have a gentle moan about "me old bones",

then explain that I have a chronic disease that affects my joints. I then find others are more confident about asking me questions and I am more relaxed when answering them. The better others understand you and your condition, the easier it is for them to know when to offer help (and when to pretend that they can't open the coffee jar either). ■



Rosie Buttery (22) has had juvenile arthritis since she was a baby. She has just finished a psychology degree

Did you know that...

you can chat to other young people with arthritis on Arthritis Care's discussion forums about anything you like? Log on at www.arthritiscare.org.uk/forum

It's up to you when and how to tell other people about your arthritis



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Other people sometimes need to know about how your arthritis affects you, says **Jane Perks**, but you can decide how to tell them about it

For the first year after I was diagnosed I will confess that I tried to hide my arthritis. It was only when I was able to say to myself: “Yes I have arthritis”, that I was able to tell other people. I had a standard answer for people like teachers/bosses/university lecturers: “I’ve had rheumatoid arthritis for eight years. It affects all my joints but mainly my hands, back and knees.”

Telling friends was harder for me; so many things go through your head. When? How? Should I be brutally honest and say “I’m in a lot of pain most of the time”? I still haven’t found an exact formula, but the best piece of advice I can give is that there is no right or wrong way of

telling someone you have arthritis. It is entirely up to you how much you want to tell them, when you tell them, how you tell them.

The thing I found most difficult was past experiences where boyfriends “dumped me” as soon as they found out I had arthritis. Sadly, some people are unaccepting, but sometimes it can almost be a blessing – if they can’t accept your arthritis then they aren’t worth the bother anyway. It’s almost like a sure-fire way of finding out whether or not this person is right for you as a friend, boyfriend/girlfriend, boss etc. So long as you are honest and upfront and yet at the same time comfortable in what you are saying you can’t fail.’ ■



Jane Perks (21) has had rheumatoid arthritis since she was 13. She is studying psychology

SURVIVING SCHOOL

When people start to understand arthritis, a lot can change, as Dan Fielding discovered

'School was quite hard for a while because people didn't understand why I couldn't do things. PE teachers were the hardest because they want you to try to do their lessons and would make me do as much as they could. But after my dad spoke to the teachers, things were all right.

When I first went to school, I was bullied a bit. People would say things to me. Then after a couple of years they started to get to know me and they were fine then. I dealt with it because I never really minded what people said to me, and I had friends who were close to me. Once I could explain to the people that were bullying me, what I had to do to get on with things because of my arthritis, they respected me. I once gave a talk to my class for my English GCSE about arthritis and it made a big difference because people appreciated what I had to live with. In the last year I didn't



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really get much stick. People who might have done this were fine, and I just got on with them. If people asked, I would tell them a bit about my arthritis but it wasn't something I talked about in detail.' ■

Did you know that...

if you need help with your arthritis at school you might be able to get this with a statement of educational needs from your local authority?



Dan Fielding (18) has had juvenile arthritis since he was two. He is studying information technology



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Rionah McNichol shows what a good school experience can be like

‘My goal was to get to university. I knew it was going to be difficult with my arthritis so I was determined to go. At one point I missed a lot of school and it was very hard, but I worked harder to catch up.

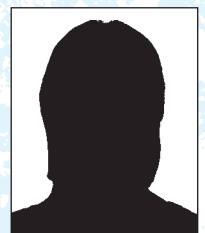
My advice is to take every bit of support you can get. I was lucky, because I was able to go to a secondary school that was very supportive. At one stage they even changed my timetable so I didn't have to change classrooms all day and could have my friends in the same form class. That was very important to me.

It's also very important to know that you are entitled to extra help if you have a statement of educational needs (SEN). I was also given a taxi

to and from school because I couldn't use the bus. I also got a laptop computer and printer so I didn't have to struggle with writing.

At school I wore tracksuit bottoms which were more comfortable for my joints, but they made me look different, so it was good to have support from my friends. I wore orthopaedic shoes and people sometimes made comments, but it was like water off a duck's back to me.

You don't want to be different when you're a teenager – you don't like it, but I realised I should use all the help I could get. I remember thinking “I don't like the thought of someone carrying my bag and following me around”, but I had very good friends who helped.’ ■



Rionah McNichol (25) has had juvenile arthritis since she was 10. She is doing a social work degree and wants to work with young disabled people

SUPPORT FROM FRIENDS

Emma Wells found that people of any age with arthritis can offer support in their own way



Emma Wells (23) has had rheumatoid arthritis since she was 17. She is working towards her NVQ in business administration

‘When I developed rheumatoid arthritis I was just happy to be diagnosed and be able to start treatment. However, as I started to feel better I realised that I didn’t know anyone else who was young and had arthritis. I had a lot of support from my family but I decided that I needed to find people in a similar situation as I felt isolated and had a lot of unanswered questions about my future.

When I heard about the Arthritis Care group meetings, at first I wasn’t interested in going. I just imagined everyone sitting around talking about bingo and drinking tea, but to be honest it was so different. Everyone was really friendly and made me feel very welcome.

I think the thing that helped me the most was that it showed me that just because I had rheumatoid

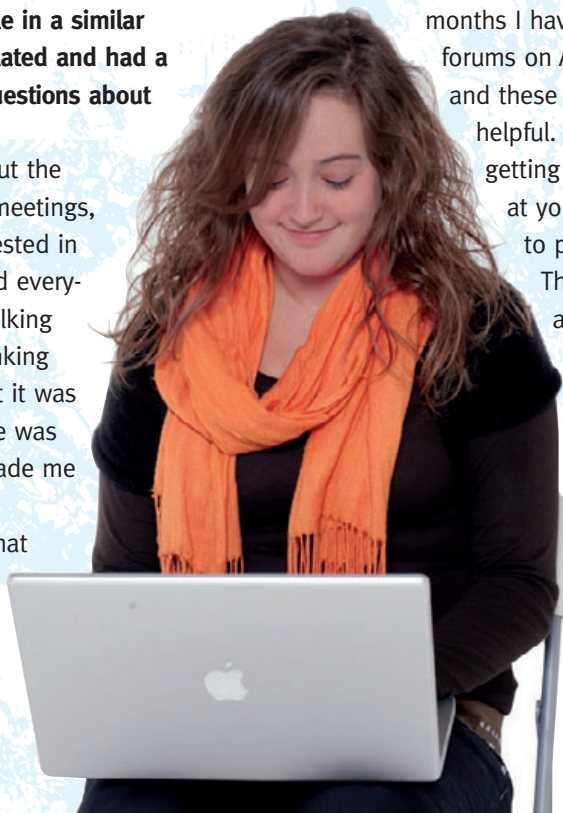
There is always someone around who will reassure and talk to you

arthritis, it didn’t mean the end of my life. There were people in their 90’s at these meetings and they were still active and had such a positive outlook on life. But it would have been nice to have people my age to talk to. Over the past six months I have come across the forums on Arthritis Care’s website and these have been really

helpful. If you have difficulties getting out, you can just sit at your computer and talk to people from all over.

There is always someone around who will reassure you and talk to you. We all have something in common but I do miss the face-to-face contact I had with the group.’ ■

Arthritis Care’s online discussion forums are a good way of communicating with and getting support from other people



Clare Allen, Dan Fielding and Shelley Hayward discuss the impact that Arthritis Care's workshops have made on their lives

'I feel a lot more positive about my arthritis after attending Arthritis Care's young people's workshop. It was invaluable to chat to others and share experiences, as so often having arthritis causes me to feel isolated from my peers. I feel I understand my medications better and the importance of taking it regularly. I also feel more connected with other young people with whom I can share my worries and concerns. It showed me that there is a whole support network out there which I can take advantage of, which makes me feel more empowered and able to push for the care I need.'

Clare Allen

'I met others my age with arthritis for the first time when I went to Arthritis Care's workshop for young people. It was really good to talk to other people like me. It was mainly girls with arthritis rather than boys, but I tend to get along with girls a lot more than guys anyway. They are easier to talk to as well.'

Dan Fielding

'Arthritis Care's young people's workshops have had a huge impact on my life. They helped me to talk to my friends and explain to them what I was feeling. I don't feel alone anymore because there are people who know exactly what I am going through. I feel more comfortable with it and have begun to understand myself more. I now feel a lot more positive about arthritis and now see it as only a small part of me.'

Shelley Hayward



FEELING GOOD

Finding ways to look good is a real confidence boost, but you don't have to do it all the time, says **Shelley Hayward**

Feeling good about how you look and feel will let your confidence shine out from your personality and everything that you have inside you.

Learning that you have arthritis gives a great knock to your confidence as you may feel that people will look at you differently. You may put on weight because your joints hurt and you can't do enough exercise. You could also lose weight because of your medication and other factors.

The key thing to remember is that over time you can rebuild your confidence. The more you learn about your arthritis, the more you will learn about yourself. With arthritis, you have good days and bad days. I am a girl that loves shopping. I don't mind whether it is for clothes or jewellery, as long as I can shop. But shopping on a bad day



Shelley Hayward (19) has had arthritis since she was 14. She is training to be a primary school teacher

can knock my confidence and make my bad day worse. On the other hand, if I go shopping on a good day, then it boosts my confidence.

Dieting is something that is widely talked about among the celebrities. As a teenage girl with arthritis, I totally understand that it can be quite hard to find a balance. I take dieting into account and I am sensible about what I eat. I exercise

Being confident and comfortable about the way I look is important to me





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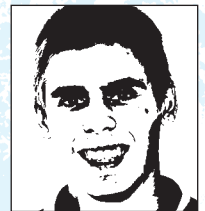
regularly as it relieves the stiffness in my joints and helps to control my weight.

Being confident and comfortable about the way I look is important to me, as it is what others see at the beginning of the day. For example, if I turn up in trackies and a hoody to college then my friends will know that I am having a bad day and know how to deal with that. However, if I arrive at college in shorts and a really nice top, then they know that I am having a good day and my confidence is high. I find the best way to feel good about myself is to have the confidence to go out and say that I know I look good – and therefore my confidence shines out.’ ■

Dan Proctor suggests you do what you need to feel good

I don't get myself down about arthritis. I try to be myself and try my hardest in everything I do to make me feel like I never had arthritis at all. If you do feel down, let your friends, family and school or college acquaintances know so they can help you out and maybe even help you relax if that's what you want.

Wear the clothes that feel comfortable and don't worry if people will start stereotyping you for what you wear, as long as your clothes or shoes are going to make your life easier.’ ■



Dan Proctor (18) has had juvenile arthritis since he was 10. He is doing a national diploma in public services and hoping to join the police

HAVING A LIFE

Doing one or two things really well is very satisfying and saves our energy says
Kate Fleetham

‘People often take on too much, over-exert themselves, and fall at the final hurdle. Being in your teens and early 20’s is an exhilarating time with limitless opportunities and exciting prospects.

It’s all too easy to be over confident and take on too much, especially within the limits of arthritis. This is not to say that having arthritis means you can’t live your life to the full; it’s just important to concentrate on your goals, and not those of your peers. In the same way, it’s sensible to know how much alcohol you can tolerate, and not to compete with your friends. Rather than attempting to get involved with everything, why not concentrate on a couple of things you are really passionate about, alongside any compulsory commitments you have.

For me this meant focusing on my degree but also volunteering

with Girl Guiding once a week. I want to work with children in the future, so gaining some experience in this field was essential. There were other things I would have liked to have done, such as helping to run the art society, but I realised it was important not to spread myself too thinly. Not taking on too much means that during bad times and flare-ups I can still cope reasonably well and not feel guilty for letting anyone down. While in a good week I can finish everything with ease and have the spare time to visit an art gallery, go shopping or spend an extra night with my friends.’ ■



Kate Fleetham (21) was recently diagnosed with rheumatoid arthritis after four years of symptoms. She is studying art history

Doing a few things well makes it much easier to cope



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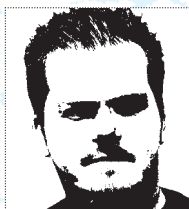


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Niall McLaughlin tells how he was able to turn a setback into a positive change of direction

I always wanted to be playing some kind of sport or cycling when I was a child and I never wanted to be indoors. When I was diagnosed with arthritis at the age of 12 this changed as I could not be the active child I used to be.

Music had been a secondary interest for me as I had taken violin lessons and was always fascinated when going through my parents' record collection. Unfortunately,



Niall McLaughlin (26) has had juvenile arthritis since he was 12. He is starting a degree in music

Finding something you are good at can lead you in a new direction

arthritis meant I had to give up the violin too, because my wrist prevented me from holding the instrument.

This led me to playing around with my sister's keyboard and eventually the guitar. I spent a lot of my spare time practising and composing my own music. I attended local classes in music and song writing, and I developed a real passion for music. I found myself on a more level playing field with other people as my condition did not matter. The disadvantages are that during rehearsals I have to sit down a lot, but playing a light and easy-to-hold instrument like the guitar does not create many problems. I now have an HND in music performance and will be starting a degree at university next year.

If I had not been diagnosed with arthritis I am almost certain I would not have such a musical life. The hobby I developed to substitute playing field sports has now become a full-time pursuit. I still occasionally take part in some sport by attending the local snooker club and try to keep fit at the gym.' ■

Did you know that...

you might be surprised by what you find you are good at?

TOP

Sometimes you just need to do something that might make you feel happy.

Dan Proctor

Being assertive about your needs and communicating them clearly is the best thing you can do.

Clare Allen

Having arthritis makes you more able to handle things as you have already had to deal with stuff in your life.

Dan Fielding

When going out with your friends, ask them to help you to look and feel good, and to boost your confidence.

Shelley Hayward

Get yourself a wonderful group of friends who love and support you. Independence doesn't have to mean doing it all by yourself.

Rosie Buttery

When I am feeling down I think positively about what I have got. There's a lot more to me than the physical side.

Rionah McNichol



TIPS

**A piece of hard won wisdom from each
Breakout writer**

Spend time with your friends and family, even if it's just going for a coffee at the local café.

Emma Wells

Your arthritis doesn't control you – you control it. Know your limits but never let yourself be stopped from doing anything you want to do. With help and support, anything is possible.

Jane Perks

If I'm going to a concert I'll relax and take it easy before the concert – as well as during and after it.

James Chamberlain

Having friends, family, a boyfriend, doctors and a counsellor to talk to has been just as helpful as any medication.

Kate Fleetham

I think the important thing is to be happy being yourself and this will shine through any problems you may have.

Suzie Forster



FITNESS

Move it or lose it, says James Chamberlain. It really works

‘When I was first diagnosed I could hardly walk for six weeks. That was the hardest time. My muscles became weak but I found that exercise helped a lot. I’m always doing something.

Swimming is really, really good. I used to swim before I got arthritis, then I started again after doing hydrotherapy. That really helped and I started building it up again. I now swim for an hour and a half at a time, and work as a lifeguard too.

Here’s a tip: the exercises that physiotherapists give you really help. I do them at least every couple of days, and have done from the time I was diagnosed.

It was hard at first because my muscles were really bad and got

tired, but I just kept doing them. I’ve always been quite good at sport, and started a hockey team at school and went on tour last year. I play football in the park with friends. Although I do a lot, I still need to pace myself. When I’m playing, the coaches will watch me and tell me to take a break if they see I’m getting tired. You’ve got to try to rest, but at the same time, try to exercise as much as you can to keep the muscles from getting too weak.’ ■

Did you know that...

exercising can help slow down the effects of arthritis by building up muscle strength, and increasing your mobility and flexibility?



James Chamberlain has had juvenile arthritis since he was eight. He is planning to study music technology and management

FIRST

Sport is possible if you adapt, says **Dan Fielding**

I have always played a lot of sport. Even when my hip was hurting I would go out and play football, and when I had a flare-up, if I saw a football I would be onto it straight away and kicking it about.

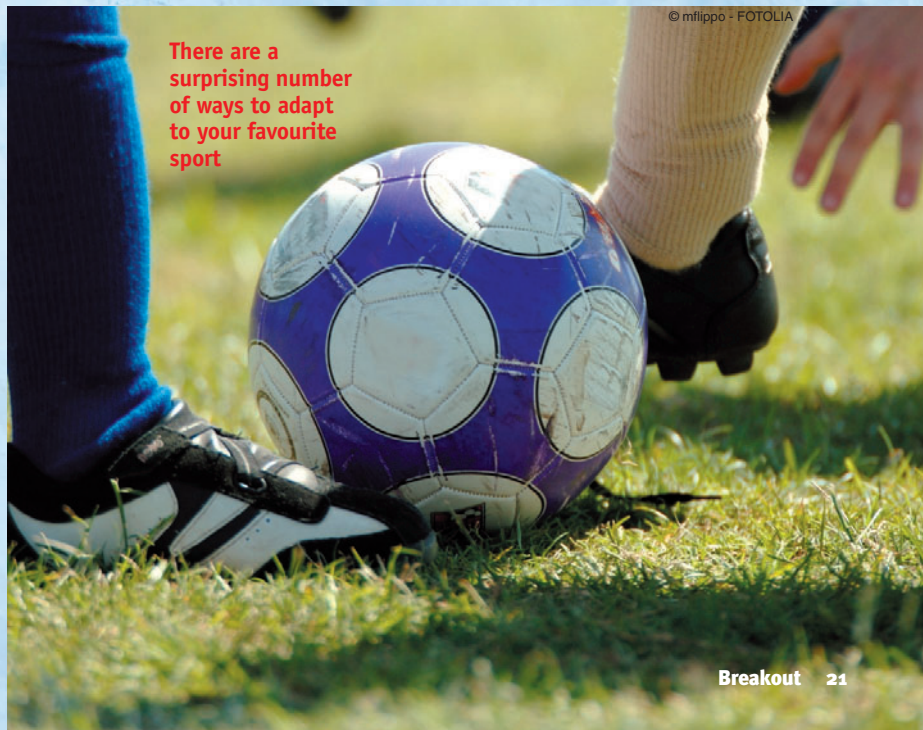
I'd pay for it in the night and the next day though. Football is very good exercise because it works your muscles and your mind. It really keeps you on your toes. You know it's good exercise because you get

really tired when you start playing after having had a break.

I've got some mates who I play basketball with, and I recently started doing weight training. Because of my arthritis I have been quite skinny but my doctor has said that I can start doing weights. I have been taught some special techniques to adapt my lifting so I don't put too much pressure on my elbows and shoulders.' ■



Dan Fielding (18) has had juvenile arthritis since he was two. He is studying information technology



There are a surprising number of ways to adapt to your favourite sport

Being open about arthritis means being open to other people, says **James Chamberlain**

I help out on Arthritis Care's young people's workshops. Arthritis is not all bad. I really encourage people on the courses to be open to making friends and be ready to talk about the ways arthritis affects them.

Above all, stay positive and try to get support from people because once you have support, you can start to feel better about yourself. My friends and family have been the best support.

Trying to get on with things is

Trying to get on with things is the approach that works best

the approach that works best, rather than sitting around thinking about arthritis. It was

hard to talk about

arthritis at first. Once I had been able to talk to other young people with it, talking about it to my friends was much easier. Most of them knew about it anyway, but now they know my limits and if I start to get tired when we're out, they will suggest I go home. It's a bit frustrating, but I know that's how it is.' ■



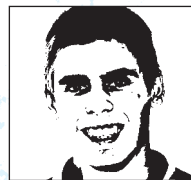
James Chamberlain has had juvenile arthritis since he was eight. He is planning to study music technology and management

HOW FRIENDS CAN HELP

Being yourself helps others to make friends with you, advises **Dan Proctor**

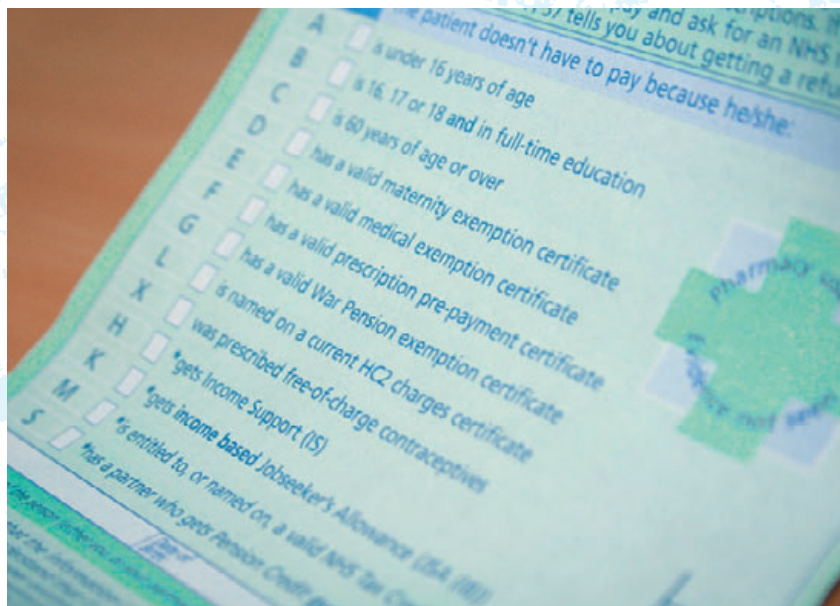
I find that you just need to be yourself to develop a good relationship with someone. People that you have recently formed a relationship with, or have as a friend or partner, can really help you to deal with your life as it happens.

When you get to know someone, make sure that they are going to be a real friend and that you can stand by them. Don't be shy to say hello to new people at college, school or maybe university, as it's easy to make friends.' ■



Dan Proctor (18) has had juvenile arthritis since he was 10. He is doing a national diploma in public services and hopes to join the police

Find out what you are entitled to



Rosie Buttery found that there is more support than you might think

The truth is that I hate having to ask for help. I have a strong desire to be independent because all my life I have been told what to do – and that's when people don't rush in and do things for me. So how do I survive living away from home?

Firstly, there is a lot of financial help out there. I get housing benefit, Disabled Student Allowance and free travel on public transport with a London Freedom Pass. Being on a low income I also get free NHS prescriptions. It's not easy being a student but with careful planning you can get by.

You can also get Disability Living Allowance to pay for someone to do the cooking, cleaning and shopping, but if you are wilful like me it may be easier to move in with a bunch

Did you know that...

you may be eligible for a wide range of benefits and support if you are disabled?

of friends who understand and support you. If I'm having a bad day they are quite happy to do a bit of vacuuming in exchange for a cup of tea and a natter. As long as you pace yourself and ask for help when you need it, the tasks get done.

Remember to take your medication and attend your hospital appointments, eat healthily and keep up the exercise regime. It sounds silly but it really is the best advice. You have to look after yourself and that doesn't have to mean compromising your life. If you feel well you will enjoy adulthood and all the trials and tribulations that come with it so much more.' ■



Rosie Buttery (22) has had juvenile arthritis since she was a baby. She has just finished a psychology degree

BECOMING INDEPENDENT

Going away to university was hard work but very worthwhile says Jane Perks

Independence is important, no matter how bad the arthritis. When I told my dad I was going to live in university halls of residence, he insisted that it would be easier for me to live at home, saying that friends wouldn't be able to offer as much support as family. I managed to explain to him how important it was to me that I lived away.

We went through as many of his concerns as possible and I even suggested ways to prove things to him, such as cooking him a meal each week. By the time I was ready to move to university he had slowly come round to the idea. At first he phoned every day to check how I was, but now this is once a week. Whenever I have a flare-up he still suggests that I come home, but to be fair to him it's normally followed with a "but you aren't going to do that are you?"

Living independently has been fantastic

It's hard for parents because they care for you and their children moving out of the home is a scary time for them. When their child has a chronic illness this worry is magnified by 10. I think if you asked my dad now he would admit that living independently has been fantastic for me. Just remember to be firm with your family and say "look, I need to do this". Eventually they will realise how much something is important to you and, like most families, help and support you. ■

Did you know that...

if you get the higher rate Disability Living Allowance you can start learning to drive at 16 – if you can afford the insurance?



Jane Perks (21) has had rheumatoid arthritis since she was 13, and is at university





Emma Wells suggests a few details to look at when moving out of home

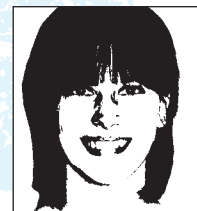
Make sure you can use all household items in your new home

When I decided to move into my own place I wanted a ground floor property so I wouldn't have to worry about the stairs in future. I made sure that I did my packing over two weeks so as not to do too much. I packed a separate bag with things I would need for a couple of days such as clothes and dishes, so that I wouldn't have to unpack everything straight away.

Mum and dad loaded the boxes into the van for me. I was moving into an unfurnished property and didn't realise just how much I would need to consider. I needed sofas, a cooker, a fridge and other things. I went to local shops and made sure I tried out everything

before I bought it to make sure I could use it comfortably. Things such as cookers need to be tried out before buying them because you need to be able to open doors comfortably, turn the knobs and preferably not have to bend down too much. Another item that took me a while to find was a sofa. It needed to be comfortable and also slightly raised so I could easily get up from it.

Social services did an assessment of my home and gave me loads of gadgets to help make independent living easier. It took a lot of time and planning but I'm happy that I made the decision to move out. My family are still close by if I need any help.' ■



Emma Wells (23) has had rheumatoid arthritis since she was 17, and is working towards her NVQ in business administration

PREPARING TO TRAVEL

Clare Allen gives some good advice on transporting medications and pacing yourself well

I'd always dreamt of travelling to Africa and Malaysia, but as I'm on methotrexate and etanercept, immunisations were out of the question. I had to re-think my options and decided on New Zealand and Australia.

I was able to get four months supply of medication from the NHS. Because it has to be kept between 3-8°C I bought two cold chain packaging boxes (£25 each) and ordered a travel-size sharps container. For blood tests I had to go to the local hospital's A&E department with a letter from my hospital specifying the tests I needed and why.

When travelling, my partner and I established "the two night rule," meaning that everywhere we went we stayed for at least two nights, so we could have one day doing activities or just exploring and one day resting. This also meant I had a flexible enough window to receive my medication, which was couriered to me weekly from relatives.

I wanted to minimise the time I was carrying my bag around so we drove around the North Island of New Zealand and got a tour



Clare Allen found that extra time to rest made travelling enjoyable

bus around the South Island. This meant that we were transported door-to-door and just had to carry our bags from the car/bus to our hostel rooms. In Australia we flew between the east coast cities but a little extra research meant we found places to stay on the train route to the airports or took advantage of hostels' free airport pick-up services.' ■



Clare Allen (20) has had rheumatoid arthritis since she was 13. She is doing a geography degree

Did you know that...

vaccines made from live organisms are not safe if you are taking methotrexate and several other disease-modifying treatments? The drugs can interfere with your response to the vaccine. Vaccines made from killed organisms, on the other hand, are safe.

EQUIPPED FOR UNIVERSITY

There is plenty of funding and help available for the asking, as **Kate Fleetham** discovered

My occupational therapist said on my first visit after starting university: “It’s not you that’s disabled; it’s your university that can make you disabled.” I didn’t want second best just because I have arthritis, so I contacted the university’s dyslexia and disability support unit (most universities have an equivalent).

You couldn’t believe how useful the disability support officer was. He helped me to apply for the Disabled Students Allowance which provided me with a new laptop and printer, voice-activated software to make essay writing easier, a fully adjustable computer chair, and even extra money for books. I wouldn’t have been able to afford these as I couldn’t cope with a part-time job on top of my studies.

My friends were rather jealous, and

we had a lot of fun training the voice-recognition program. I was also encouraged to speak to my tutors – with support from the disability officer if they didn’t understand or weren’t accommodating – but they were amazing.

Missing lectures because of hospital appointments was no longer a problem, and I was always granted an extension on an essay if I asked. They even made sure all my seminar rooms and lecture theatres were on the ground floor so

I didn’t have to deal with the stairs. It’s really important that you’re open and honest and not embarrassed about arthritis or worried about being a nuisance. The university staff are there to support you, they want you to be a success. That doesn’t mean struggling along in silence.’ ■



Kate Fleetham (21) was recently diagnosed with rheumatoid arthritis after four years of symptoms. She is studying art history

Did you know that...

there are lots of sources of financial support aimed to help disabled students? Check out: www.direct.gov.uk/studentfinance

SUCCESS AT UNIVERSITY

Support varies, so choose your university with care, says Clare Allen



Clare Allen (20) has had rheumatoid arthritis since she was 13. She is doing a geography degree

The most important consideration is to choose a subject that is challenging but not too physically demanding for you. I am doing a geography degree and often go on field trips which means I have had to utilise all of the support and understanding available to be able to take part.

This has included funding from my local education authority through the Disabled Students Allowance for a laptop, printer, voice recognition software, recording devices and an allowance for extra photocopying and textbooks. As well, I get support from the student services department at my university with alternative exam arrangements, extra time, deadline extensions and extra library services, such as a browser to bring things to me.

The most important element in my choice of university was to find one with a good combination of support and academic credentials. They are all obliged to give the

Find a university with a good combination of support and academic credentials

same level of care but I found this doesn't always happen.

Deciding whether to go to a city-based or campus-based university is important, and I chose a campus university within a city. If you live on campus, you either need to live close to your department or know that there is a campus bus to get you there. Choice of room is important. Sharing a bathroom with another student rather than each person having their own, can be the best solution as it usually means you have more bedroom space for physiotherapy exercises and extra equipment, and also a "bathroom buddy" to help you out if need be. ■

Did you know that...

if you don't get on with your course you should be able to swap to something you are more interested in? Ask your tutor if you are in doubt.



© Stephen Coburn - Fotolia.com

Rosie Buttery describes some of the support you can get for arthritis at university

Colleges and universities must support disabled students, and there is a lot of help if you ask

‘When I first started applying to universities I was really scared that I would not be able to cope with all the challenges of a degree. I had already found the demands of my A-level courses too much and had to take a year out to let my body recover, but I was really surprised by how easily the student support teams resolved all my fears. Every aspect of university life was covered, from essays to exams.

Getting Disabled Students Allowance and access to learning grants means that I can support myself. Housing benefit is very useful as I can't work and study because I need to save my energy.

Exam stress can cause my arthritis to flare, but I am allowed to do my

exams in a smaller room on a computer, where I can take rest breaks as necessary and get 25 per cent more time to support my slower writing style. If I was ever unable to write, the university would let me dictate my exams verbally. The library service has specialist computers for disabled students and a book collection service where they will gather all the books you require and bring them to you. The student accommodation office also made sure that I had a ground floor room in the nearest halls, with accessible ensuite and organised mail delivery to my door (rather than the post room).

I really enjoyed my time at university and there has never been an obstacle that couldn't be overcome by just asking for help. ■



Rosie Buttery (22) has had juvenile arthritis since she was a baby. She has just finished a psychology degree

GOING OUT

Rionah McNichol says that her determination to do things really took her places

'Not wanting to be different from anyone else was a big issue for me when socialising with friends. I just wanted to go out with my friends and dance and have fun. I was determined to live my life fully and in many ways my

It took a lot for me not to go out somewhere

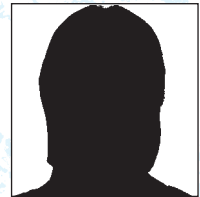
life came before my arthritis. That was thanks to going on Arthritis Care's young people's workshops, and my rheumatologist who would tell me to take my medications and go out and enjoy myself while I was young.

Obviously when I was really ill I couldn't go out, but it took a lot for me to not go somewhere. So I went to sleepovers to watch DVDs, and to school discos. I even went on a school trip to Italy. This was a big thing for me and I was worried about all the walking, but the teachers were very supportive. I was so determined to go – I was sore and



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aching after being out all day, but I did it. Pubs haven't been an issue because I'm not really interested in drinking – perhaps that made it easier for my parents to stand back and let me do more of my own thing once I was 18.' ■



Rionah McNichol (25) has had juvenile arthritis since she was 10. She is doing a social work degree and wants to work with young disabled people

Did you know that...

you can get a third off most rail fares with a Young Person's Railcard or you can buy a disabled person's railcard?



© Jérôme Cools - Fotolia.com

Going out just takes a bit of extra planning, says **Niall McLaughlin**

Choosing somewhere where there is seating is important, as many clubs do not have adequate seating or any seating at all. When going to gigs it is necessary to get seated tickets, which can be a problem if friends want to stand. If you are sore and you are getting pushed into all night it will put a dampener on it, so this is something I am always aware of.

I will try to get into a venue before it gets too busy, though this can be a challenge sometimes as people will want to finish eating take-aways. By the time you get your transport sorted it is late, although good friends who know your situation will always be understanding.

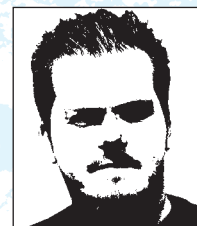
Taxis or lifts home are always

important as public transport at night in my area doesn't exist. I live 20 miles from the city so when I am out there and staying with friends it is important to always have transport arranged beforehand. High demand for taxis in the city mean you are sometimes faced with the choice of waiting around in the cold for an hour or two, or walking a few miles. It is important when you are out to not drink too much. You don't want the risk of falling down or getting into a violent situation that could be dangerous.' ■

Did you know that...

with a bit of research you can find places that are easy to access?

It can be tempting to overdo things on a night out



Niall McLaughlin (26) has had juvenile arthritis since he was 12. He is starting a degree in music

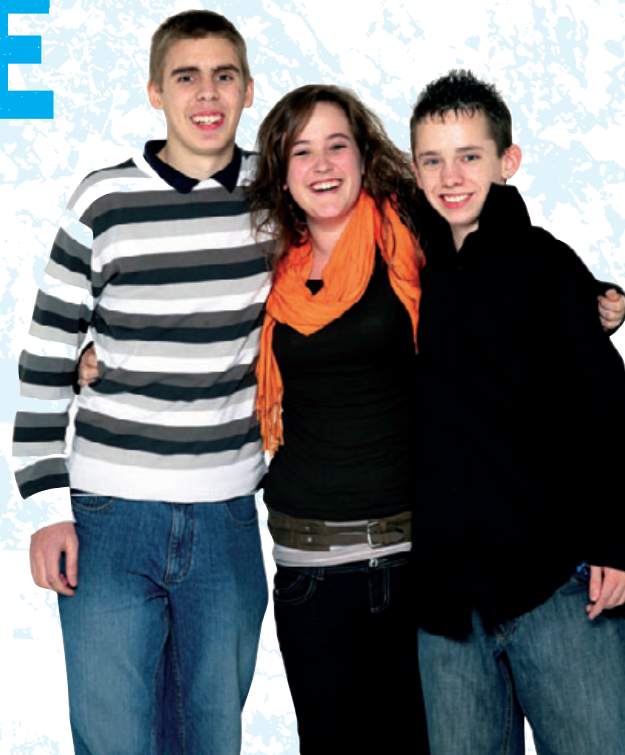
FRIENDS AND MORE

Kate Fleetham says when it comes to your arthritis, other people follow your lead

I'm sure you've heard it a million times, but it really is important to remember that everyone is as anxious and desperate to make new friends as you are. Get talking to everybody and anybody, make 100 acquaintances in a month and then you have the rest of your life to choose which ones become friends.

Join clubs and societies based on your interests and you're much more likely to find like-minded people. The most important lesson to learn (far more important than that pesky gam lecture) is that true friends are the ones who really care and understand. They are the ones that always remember you have arthritis, but never make an issue out of it.

While it's important to get home safely after going to a party, don't always insist you leave together. It's better not to give someone the opportunity to resent your illness. Besides, they will be much more willing to help with the lows if and when they come along. To some people arthritis would be seen as a



flaw, an imperfection, but to our true friends, we're perfect.

The same goes for more intimate relationships; your other half should always be a good friend as well as your lover, so supporting you through difficult times is essential. Remember that it's often difficult for someone so close to come to terms with your illness, but generally if you have a positive attitude about arthritis, then no one else will see it as a problem.' ■

Friends will support you through hard times and make good times better



Kate Fleetham (21) was recently diagnosed with rheumatoid arthritis after four years of symptoms. She is studying art history

Did you know that...

the best way to make friends is to take an interest in other people?



The other person is interested in you for who you are – it should stay that way

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Want a good date? Then focus on what you have in common with the other person, says **Shelley Hayward**

Forming new friendships and dating is hard for everyone, but if you have arthritis it can be extra hard. There are so many questions that can rush through your head when meeting a new person: “How are they going to react when I tell them about my arthritis?” I have had only a few people turn around and be completely rude about it and the friendship went no further.

I think that when forming a new friendship, the best thing is not to focus on your arthritis. If you do, the person will think it controls your life and that’s not what it should be like. Everybody has negative thoughts about the way they look, but sometimes it’s harder if you have arthritis as you may walk differently or hold

cutlery in a different way.

If you are on a date then that person has already seen past your arthritis, so the best thing to do is get rid of the negative thoughts and tell yourself that this person wants to be on a date with you because they like you for who you are. When going on a date, the best thing to do is to be yourself and focus again on what you and the other person have in common.

Looking and feeling good is a high priority when going out with your friends or going on a date, but the main thing to remember is that these people want to be with you because they like you for your other qualities. Your arthritis probably never crosses their minds.’ ■



Shelley Hayward (19) has had arthritis since she was 14. She is training to be a primary school teacher

Another person will see special things in you, as Suzie Forster found out

I was beginning to give up hope that I would meet the perfect guy. I'm not very confident when it comes to meeting new people and I'm quite conscious that I look very young for my age as well as having arthritis.

One day I went out for a coffee with my sister, brother and some friends. Somehow I ended up telling a story about an unfortunate but amusing event that happened that

week, and it had got everyone laughing. Later on, I heard that my brother's friend quite liked me and wanted to exchange numbers. It turned out that my strange sense of humour was one of the things that first attracted him.

At first I found it difficult asking him for help with things. I usually use my wheelchair when I go out but on our first proper date I didn't want to have to depend on him to push

Did you know that...

whether you are male or female, if you have sex when you are on methotrexate and several other disease-modifying treatments you should make sure you use protection as the drug can harm the development of a baby?

FINDING TRUE LOVE



me so I walked all the way from the car park to the restaurant with my crutches. It was quite a struggle so I was really relieved after the meal when he offered to go and get my chair from the car without me even asking. He obviously wasn't worried about it so I'm not sure why I was.

I didn't tell him everything about my arthritis all in one go, but instead I just got on with life and approached things that needed explaining as they arose. For example, I took my tablets when I needed to, and when

he saw my injections in the fridge I explained what they were for. I tried not to make a big issue of having arthritis and now he accepts it as just being part of me.

A few years on he has stuck by me through a couple of major operations and our relationship is stronger than ever as we plan our wedding. I think the important thing is to be happy being yourself. This will shine through above any problems you may have. Let people discover who you are and see that the arthritis is just a part of your life.' ■



Suzie Forster (25) was diagnosed with juvenile arthritis when she was six, and is a biology graduate

© Andrey Kiselev - Fotolia.com



A SOBERING THOUGHT

Being told you can't drink can be a challenge, says **Clare Allen**

Although you're not supposed to drink while taking methotrexate I must admit the reality of teenage life has meant that I have not always been able to stick to my better judgement. If you cannot go out at all, it is easy to become isolated and feel very down. You need to feel "normal" and included, and alcohol can not only numb the physical pain while you are out dancing but also the emotional stress that comes with having arthritis.

The practicality is that I don't drink the day before or after taking my methotrexate. I've come to terms with having to drink less than my friends and having a worse hangover the next day, and stopping if blood tests show my liver is in distress.

The pain factor is harder to deal with, dosing yourself up on painkillers and anti-inflammatories is the sensible thing to do, but



Clare Allen (20) has had rheumatoid arthritis since she was 13. She is doing a geography degree

I don't drink the day before or after taking medication

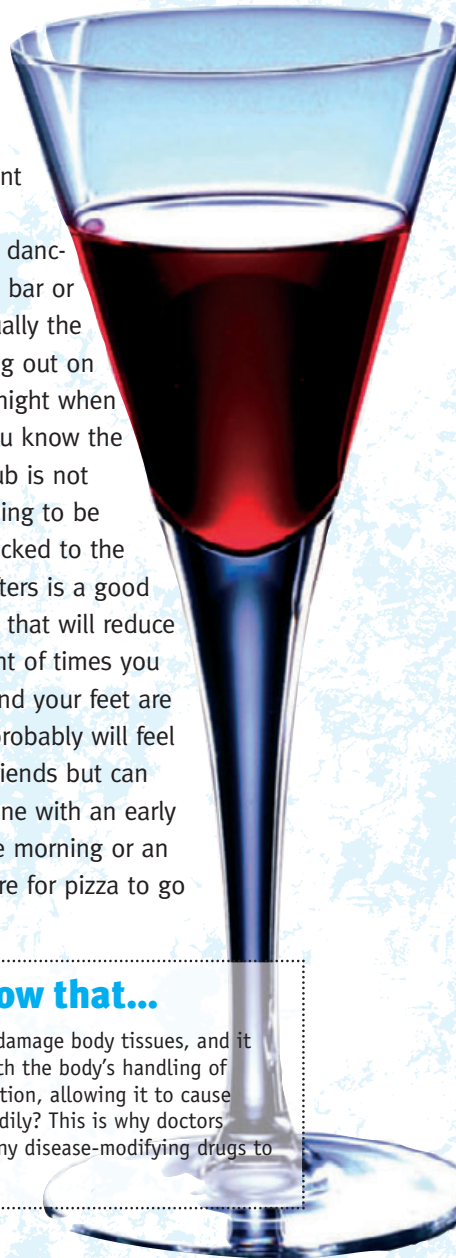
of course this impacts on the amount you should drink. Switching between dancing, leaning on the bar or sitting down is usually the safest option. Going out on

a night when you know the club is not going to be packed to the rafters is a good idea that will reduce

the amount of times you are bumped into and your feet are stomped on. You probably will feel tired before your friends but can usually find someone with an early lecture, work in the morning or an overwhelming desire for pizza to go home early.' ■

Did you know that...

alcohol can directly damage body tissues, and it can also interfere with the body's handling of your arthritis medication, allowing it to cause side effects more readily? This is why doctors advise people on many disease-modifying drugs to avoid alcohol.



SOURCES OF SUPPORT

ARTHRITIS CARE

www.arthritiscare.org.uk

Arthritis Care has lots of useful resources:

- You can chat to other young people with arthritis through the discussion forums on our website:
www.arthritiscare.org.uk/forums
- Call our free confidential helpline called The Source, for young people with arthritis: Freephone 0808 808 2000 (10am–4pm weekdays, or email TheSource@arthritiscare.org.uk)
- There are weekend workshops offering a range of personal development and confidence building activities for young people with arthritis
- Read back issues of *No Limits* magazine for 15-20 year olds online.
- There is a young person's section on our website with information on keeping healthy, drugs, study, relationships and much more: www.arthritiscare.org.uk/LivingwithArthritis/Youngpeople

OTHER RESOURCES

General and health

Arthritis Research UK funds medical research into arthritis and provides information:

www.arthritisresearchuk.org

Directgov has useful information for young people:

www.direct.gov.uk/en/YoungPeople

Information for young people with arthritis:

www.dreamteam-uk.org

General information for young people:

www.thesite.org

Health information for young people:

www.youthhealthtalk.org

The Beeb's disability website:

www.bbc.co.uk/ouch

The Government's health information website:

www.nhs.uk

Cars and scooters

Cars and powered wheelchairs provided through the Motability scheme:

www.motability.co.uk

Prescription costs

www.ppa.org.uk/ppc

Education and work

Skill at Disability Alliance provides very useful guides on disability rights and sources of funding:

www.disabilityalliance.org/skill.htm

Sexual health

www.brook.org.uk

www.fpa.org.uk

Travel

www.fitfortravel.nhs.uk

www.16-25railcard.co.uk

Our information is regularly reviewed. This booklet will be reviewed in 2013. Please check our website for up-to-date information and reference sources or call 020 7380 6577.



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