



A Day With Sam



ARTHRITIS CARE

*Empowering
people with arthritis.*

A Day With Sam



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A personal message from the author, Debbie Hunsley, to all parents who have children with arthritis

Welcome to my story for young children with arthritis. My name is Debbie. I am married with two children; Craig who is ten and Samantha who is eight. Although we all know 'children do not get arthritis', by the age of 13 months old Samantha had developed juvenile chronic arthritis. Our world was turned upside down. We did not know which way to turn and we read everything we could on the subject to try and understand what was happening to our daughter.

It soon became apparent that although there is plenty of literature available for adults with arthritis, there is very little written for children.

As Samantha grew older she started to ask questions about her arthritis. Questions which we found very hard to answer in a way she would understand. We also wanted answers that would encourage her and not diminish her confidence as a child with a medical condition.

It was then that I decided to write her a story all about the treatment she had to have for her condition. I wrote it in simple words with all the facts she needed to know. I felt that once Samantha understood, she would take on the challenge of her arthritis so much better.

I believe this is true for any child with arthritis and I hope this booklet will take away some of the initial fears and unknowns about having the condition.

Debbie Hunsley.

How to use this booklet

This booklet is designed for adults to read aloud to children with arthritis in the seven and under age group. It can also be used to help siblings and friends of a child with arthritis understand the challenges the child will face. The pictures can be used to support an understanding of the text. At the back of the booklet is a list of useful addresses and a glossary that adults can read out to help young children with arthritis understand the medical terms they will hear and the titles of the people they will see.

Why Arthritis Care produced the booklet

Arthritis Care's main objective in publishing this booklet was to enable younger children to understand what might happen to them as a child with arthritis. We also want to encourage these children to feel good about their bodies and develop identities, meeting the reality of arthritis in their lives with confidence. We hope it can play a small part in preventing in them the clichéd and discouraging idea that they must be 'brave victims'. Thousands of children below the age of 16 have arthritis. It is not just an 'old person's' condition. We believe these children need to be supported as ordinary, everyday 'normal' children. Some children have arthritis...some children do not.

This booklet was written by a mother of a child with arthritis; the text was edited and added to by an adult who has had arthritis since the age of two. It was also put through an assessment process before publication which involved many young people and children with arthritis.

Arthritis Care hopes it gives information and encouragement to your child with arthritis.

Penny Boot, Editor

A Day With Sam



Charlie was in a lovely big garden. He had just arrived with his mum. It was his friend Samantha's garden. Sam and Charlie's mums were friends.

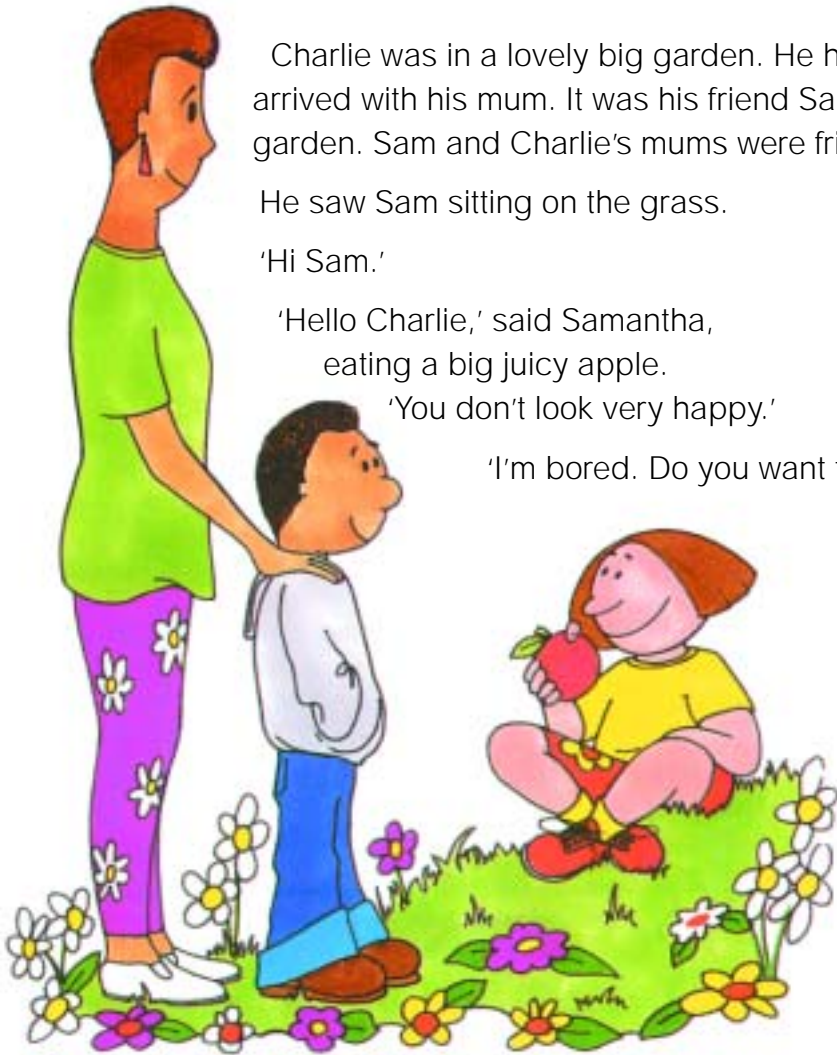
He saw Sam sitting on the grass.

'Hi Sam.'

'Hello Charlie,' said Samantha,
eating a big juicy apple.

'You don't look very happy.'

'I'm bored. Do you want to play?'



'Well, I've got a busy day today. I've got to go to the hospital,' replied Sam.

'What for? Are you ill?' asked Charlie. He couldn't help being a bit nosy about his friend.

'I've got to see the doctor about my arthritis,' Sam told him. She knew he wouldn't understand but she thought it might be fun to tease him.

'Oh, I see,' said Charlie. As Sam had guessed, he looked very confused.



'Tell you what,' grinned Sam, 'Would you like to come too? I'll show you around. It can get boring at the hospital but I can tell you stories about what happens to me there.'

'Can I really come?' asked Charlie. 'It should be fun if we are together.'

'We'll go and ask shall we? My mum said we would be going to the hospital after they had finished their coffee. Let's go and stop them chatting too much.' Sam said with a cheeky smile.

Samantha's mum agreed that Charlie could go with them, if Charlie's mum didn't mind.

'I don't mind at all.' laughed Charlie's mum. 'But you will be very good, won't you Charlie? I expect Sam is used to going now so she knows all about how to behave.'



Before Sam, Charlie and Sam's mum could go to the hospital, Sam had to take some medicine.

'Do you like that?' asked Charlie.

'No, not really, but if I don't take it I can get poorly,' frowned Sam.

'Why?' asked Charlie. He was getting confused again.

'Because I have arthritis,' said Sam. But she knew the word would puzzle him.

'What's arffi-iffus?' said Charlie, trying to get this new word right.

'Ar-thri-tis,' Sam said slowly to help him understand. 'It's something that is happening inside me, mostly in my arms and legs. It makes me stiff and ill sometimes.'

'Why?' asked Charlie. He wanted to know more.



'It's a mistake really,' Sam announced, glad to see mum was putting the medicine away. 'Instead of my joints working together, they get puffy and hot. Then they can hurt.'

'Oh I see.' Charlie bit his lip, and pointed to her knee, trying harder to understand. 'Is it hot now?'

'No, because my medicine helps my body to work better,' Sam said. She looked around and saw her mum saying goodbye to Charlie's mum. 'Some medicine might not taste nice. But it really helps me so I don't mind it anymore.'



Sam and Charlie heard Sam's mum calling for them to get into the car.

They looked at each other and grinned, climbing into the back seat. At last they were off! Sam's mum secured their seat-belts and they began the drive to the hospital.



During the journey Sam told Charlie about all the people she had to see at the hospital, usually on lots of different days.

'First I have to see my doctor. She looks at my joints to see how I am doing,' Sam explained.

'What are these joints you keep talking about?'

Charlie had never heard so many new words all at once.

'They are where your bones meet together so they can bend. You know, like your knees.' Sam pointed to them, swinging them to show him.



'I'll tell you a little bit. She helps me make my muscles stronger, even if my joints are sore. It's so my joints don't get worse from having weak muscles. Muscles are all around your joints. They make the joints move,' Sam explained.

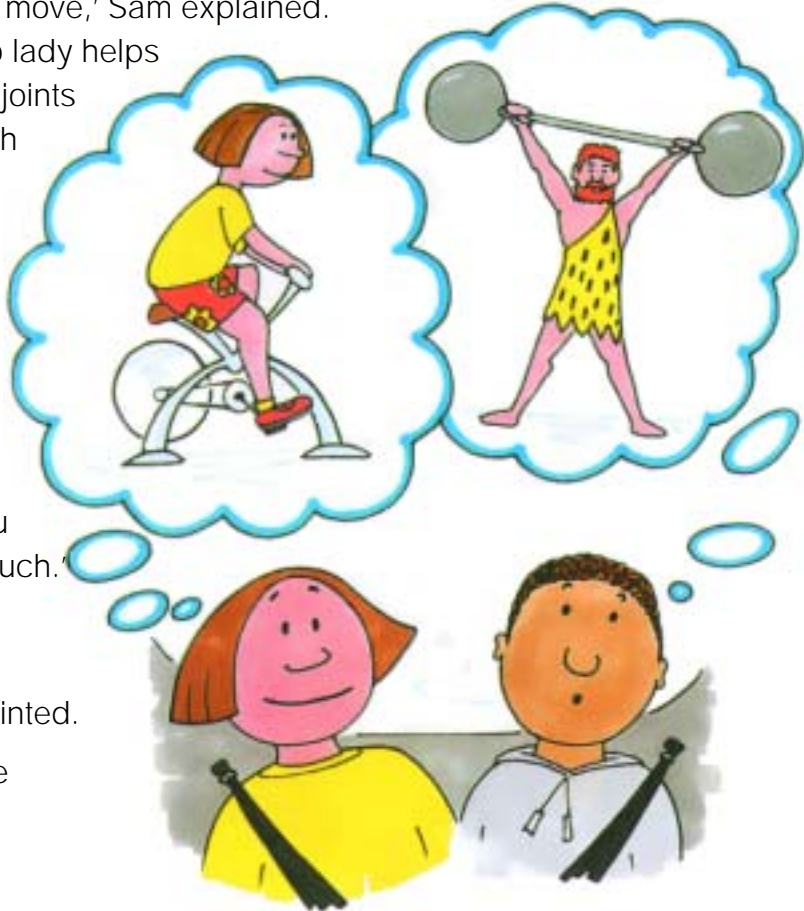
'And the physio lady helps me to keep my joints moving as much as possible. This will keep them working.'

Now Charlie smiled.

'Sam, that's good, isn't it? That means you won't hurt so much.'

Sam looked out of the car window and pointed.

'Look, we are nearly there!'



When they arrived at the hospital mum hurried them along.

'Wow. It's big,' gasped Charlie looking around the hospital buildings and all the colourful signs pointing everywhere.

'Yes, it is big. But you'll soon get used to it,' Sam's mum held onto their hands. 'Now, this way to the doctor's.'

Lots of people passed them and some waved at Sam.

'Because I come for lots of check-ups on my arthritis, I get to know people at the hospital,' Sam smiled.



Charlie sat very quietly while the doctor looked at Sam's knees and other joints. Sam's mum and the doctor seemed to talk a lot and use some very big words that Charlie didn't understand. Charlie wondered if they would see the fizzy lady today. He was thinking about what it could be that she would do to help Sam and her stiff joints. He was very curious to find out.

Sam didn't mind seeing the doctor. She had met her so often now she wasn't frightened any more. The doctor listened to Sam and tried to understand Sam's problems.

'Next time you come to see me, I might have some X-rays taken of your knees,' said the doctor, looking at Sam and then her mum, 'Just to see how they're coming along.'



'Tell Charlie where we are off to now,' said Sam's mum.

'The OT man,' Sam replied, smiling at Charlie. She knew he would be puzzled again.

'The what man?' Charlie was very confused.

'The occupational therapy man makes splints and helps me manage things I might find hard because of my stiff joints. Things like putting my shoes on.'

Sam reminded Charlie about arthritis. She explained that when your joints are sore, you have to wear splints.



'Splints go around my joints to help keep them in a good position. They make my joints feel better when they go through a bad spell.'

The OT room was full of funny shaped things. Some were long and shaped like legs, others were small and looked like hands. There were lots of other things in the room. Charlie couldn't work out what they might be.

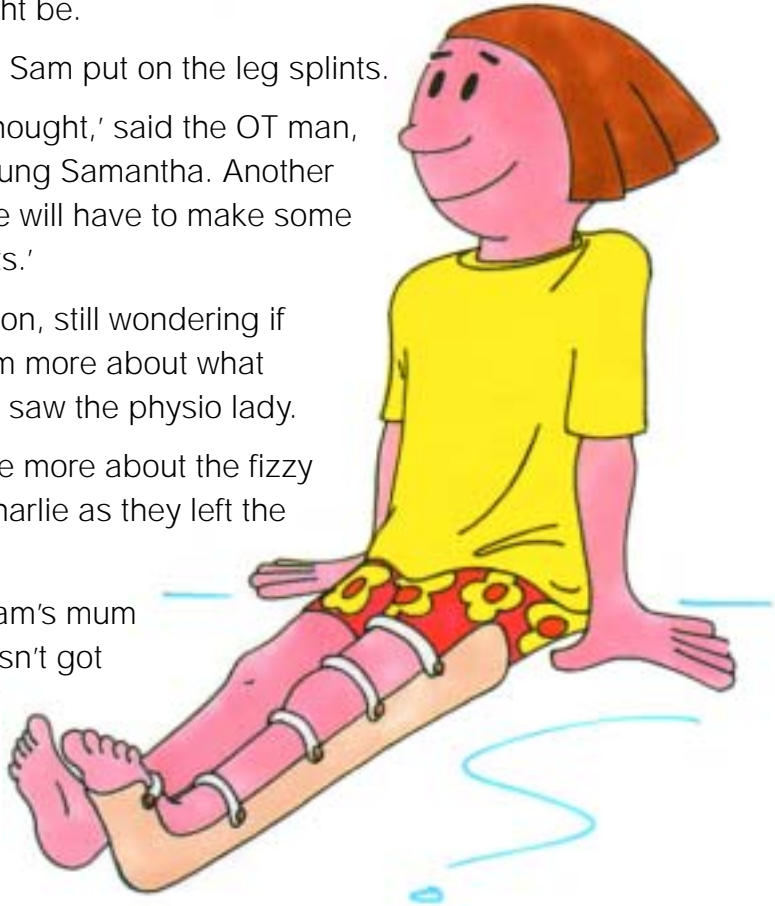
He watched as Sam put on the leg splints.

'Yes, just as I thought,' said the OT man, 'You've grown, young Samantha. Another few weeks and we will have to make some new, bigger splints.'

Charlie looked on, still wondering if Sam would tell him more about what she did when she saw the physio lady.

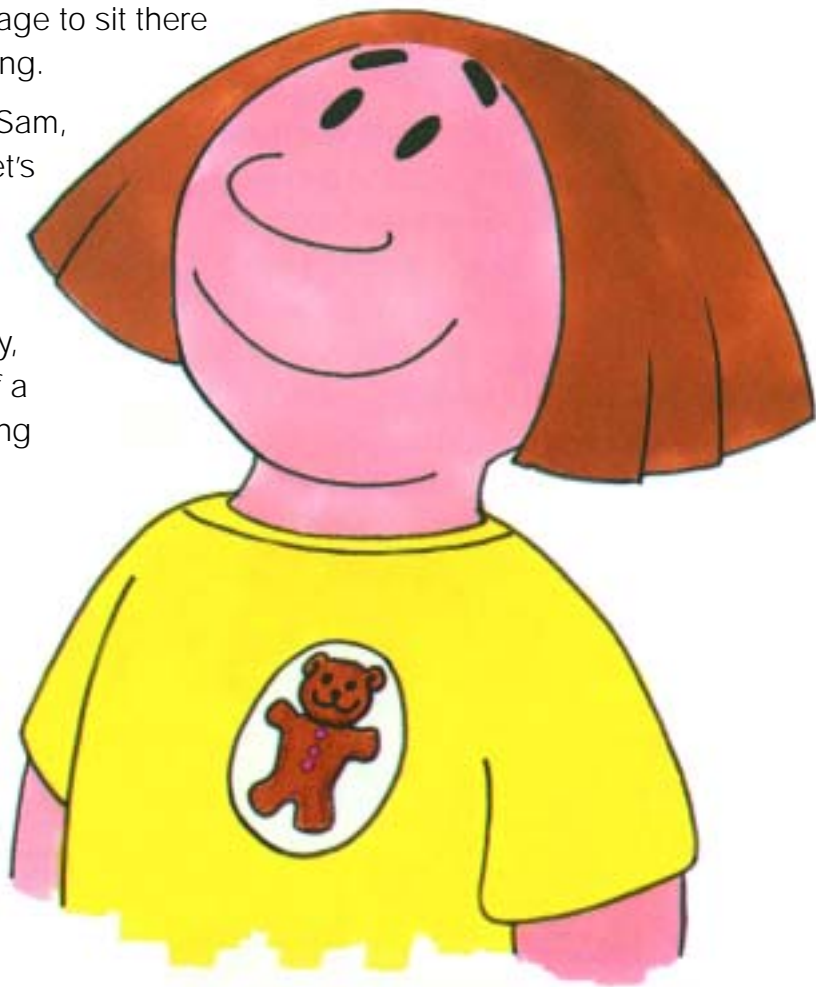
'Can you tell me more about the fizzy lady?' pleaded Charlie as they left the OT man's room.

'No, not yet,' Sam's mum laughed. 'Sam hasn't got the time just now.'



Charlie wondered how Sam could keep so still. He didn't know if he could manage to sit there without fidgeting.

'Well done Sam, all finished. Let's give you a teddy sticker,' said the blood-test lady, pulling one off a roll and handing it to Sam.

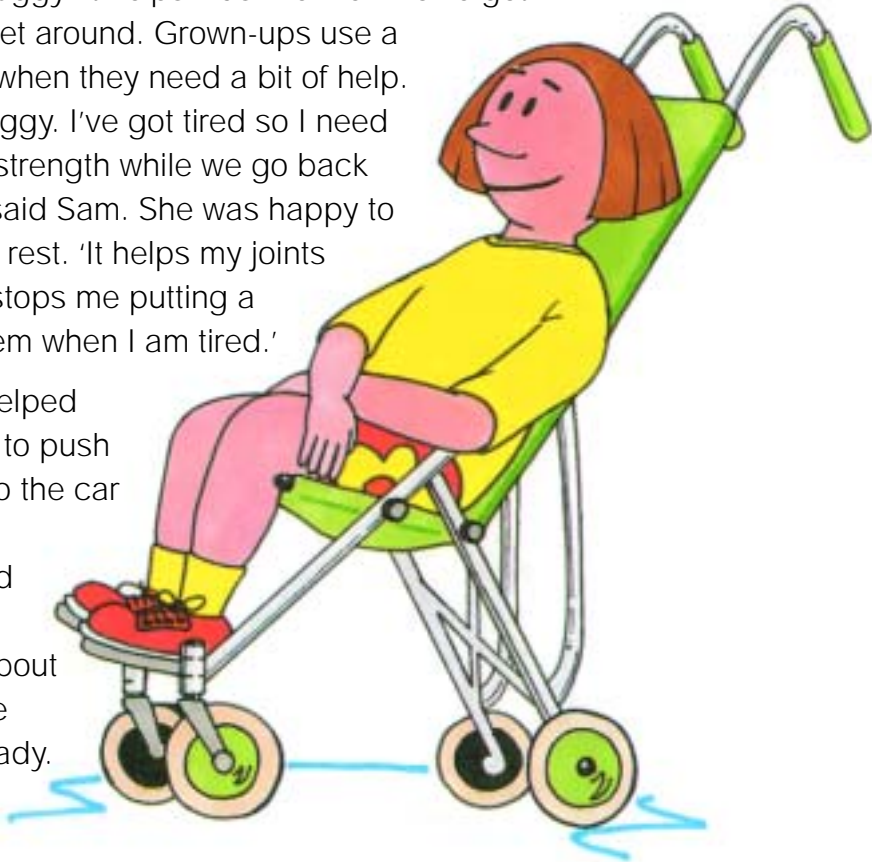


Charlie was curious when a hospital porter brought a buggy for Sam.

'What's that for?' he asked.

'It's my buggy. It helps kids like me who've got arthritis to get around. Grown-ups use a wheelchair when they need a bit of help. I use the buggy. I've got tired so I need to save my strength while we go back to the car,' said Sam. She was happy to be having a rest. 'It helps my joints because it stops me putting a strain on them when I am tired.'

Charlie helped Sam's mum to push the buggy to the car park. Sam remembered her promise to tell him about going to see the physio lady.



'The physio room is at the other end of the hospital. When I get there I might meet some friends who have arthritis too. Physio treatment can be a bit boring, but you get used to it.'

'You've got used to so many things, Sam.' Charlie laughed, trying not to make the buggy wobble as he pushed it with Sam's mum.

'The physio room is called the gym,' Sam carried on as they moved down the corridor. 'Charlie, you've never seen such a big room.'

Charlie's eyes widened as he tried to imagine this huge room.

'The physio lady sorts out what exercises I will do. Sometimes a friend will do them at the same time.' Sam kept talking and laughed to see how amazed Charlie seemed. 'A big mat is brought out and we lie down on it.'



'Does your...your fizzy-time finish with the ball game?' asked Charlie, who still hadn't run out of questions.

'No, Charlie! And the word is PHYSIO. Next it's time for the hydro pool,' Sam said, with a big grin on her face.

'What is a hydro pool?' Charlie frowned.

Sam wanted to laugh again at how muddled he looked.

'The hydro pool is my favourite. It's like a small swimming-pool only very warm. It makes me feel very good.'

Sam smiled, thinking about how much she was looking forward to the next time in the hydro pool. She explained to Charlie how it helped all her joints, making it easy to move around in the water.



At last Charlie, Sam and Sam's mum left the hospital building and got into the car. They left the buggy just inside the door and Sam walked to the car easily after her rest from walking.

'Are we just going home now, Sam?' Charlie asked. He sounded a bit sad.

Sam's mum smiled at them both. She had planned a secret treat for them. Charlie's mum knew all about it too.

'Well, you've both been very good today so we'll have a picnic in the park before we go home,' Sam's mum said.

'Oh, yes please. Yummy.' shouted Sam and Charlie as they climbed into the back of the car.

They soon drove away from the big building. Sam and Charlie chatted for a while about what had happened during the visit to the hospital. Charlie felt he understood more about Sam's arthritis.

Soon they realised they were near the park. Sam and Charlie suddenly felt hungry and it was more exciting to forget about the hospital and to think about the picnic and all the tasty treats Sam's mum had planned for them.

THE END



New words you will hear at the hospital

For parents to read out and explain further if necessary.

Buggy – a special large pushchair used by children who have trouble walking a long way, to look after and rest their sore joints.

Crutches – crutches are special long sticks that you can lean on. This helps to stop you putting a big strain on very sore joints when you walk. This means you can still walk around but you won't be making your sore joints hurt even more. There are all sorts of crutches, which you lean on in different ways with your arms. The physio person will give you crutches if the doctor thinks you need them.

Disabled – if you have trouble moving around and sometimes use a buggy, a wheelchair or crutches, people might say you are disabled. It is not a bad thing to be disabled. All it means is that because you have arthritis, you might get around in a different way to other children who don't have arthritis, and that your body moves differently to theirs.

Juvenile idiopathic arthritis – one of the big names your doctor will call your arthritis.

Muscles – muscles are underneath your skin in all sorts of places. The muscles around your joints stretch to make you move in many different ways. Strong muscles help sore joints to keep working.

Occupational therapist – a person who helps you to manage things you do every day, like getting dressed easily and washing your face. These things might be harder to manage if you have arthritis. It is the occupational therapist who will usually make your splints. This person is called an OT for short.

Ophthalmologist – a special doctor who looks after problems you may have with your eyes.

Orthotist – a person who sometimes makes the splints that help your joints.

Paediatrician – a special doctor who looks after children who are ill.

Physiotherapist – a person who helps with your exercises. This person is called a physio for short. The treatment the physio gives you is called physiotherapy, and sometimes this is called physio for short too.

Rheumatologist – a special doctor who looks after lots of people with all sorts of arthritis. This is the doctor most children with arthritis will see.

Social worker – a person who helps the whole family with all sorts of things you might need help with. A social worker might sort out problems with managing at school, or they might make sure your mum and dad are getting the special money benefits you can sometimes have for a child with arthritis. There are lots of things social workers can help with.

Splints – splints are made to help your joints. They fit around them in different ways that will look after them, whether you are resting or moving about.

Veins – tubes that carry blood around inside your body. Everyone has veins.

Wheelchair – a different sort of chair with wheels, used a lot by adults who need help getting around. Children will use a small wheelchair sometimes instead of a buggy.

X-rays – there are lots of different kinds of X-rays for looking at all sorts of things inside your body. X-rays are special photographs, usually taken with a big machine, which can see into your body to look at your bones. This means the doctor can see what is going on with your arthritis around your sore joints. X-rays on your joints will not hurt unless your joints are feeling very stiff and the person in the X-ray room has to ask you to move them into positions that might be a bit hard.

Helpful organisations

FOR PARENTS OF A CHILD WITH ARTHRITIS

Arthritis Care

18 Stephenson Way

London NW1 2HD

Tel: 020 7380 6500

www.arthritiscare.org.uk

See back cover for more information on our services.

arc (Arthritis Research Campaign)

Funds medical research and produces information.

Copeman House, St Mary's Court,

St Mary's Gate, Chesterfield,

Derbyshire S41 7TD

Tel: 0870 8505000

www.arc.org.uk

Children's Chronic Arthritis Association (CCAA)

Support group for families of children with arthritis.

Ground floor office

Amber Gate, City Walls Road

Worcester WR1 2AH

Tel: 01905 745595

Choices

For families of children with arthritis.

PO Box 58, Hove,

East Sussex BN3 5WN

www.kidswitharthritis.org

Lady Hoare Trust for Physically Disabled Children

Now merged with Contact a Family.

Contact A Family

Gives information on access to services and family support through a freephone helpline. Brings together families with a disabled child through mutual support and self-help groups.

209-211 City Road

London EC1V 1JN

Tel: 0808 808 3555

www.cafamily.org.uk

Advisory Centre for Education (ACE)

Education advice centre to assist parents of children with special education needs.

1C Aberdeen Studios

22-24 Highbury Grove, London, N5 2DQ

Tel: 020 7704 3370

(advice line 2-5pm Mon-Fri)

www.ace-ed.org.uk

Break

Provides holidays and respite care for children and adults with learning disabilities and families with special needs

Davison House, 1 Montague Road

Sheringham NR26 8WN

Tel: 01623 822161

Fax: 01263 822181

www.break-charity.org.uk

Action for Sick Children

Works to ensure health services are planned for children. Supports parents of children in hospital.

8 Wakely Street, London EC1V 7QE

Tel: 020 7843 6444

Family Fund

(Joseph Rowntree Memorial Trust)

Offers grants for families with severely disabled children.

PO Box 50

York YO1 9ZX

Tel: 01904 621115

text phone: 01904 658085

info@familyfund.org.uk

Family Holiday Association

Grants for families of children with special needs to have a holiday

16 Mortimer Street,

London W1N 7RD

Tel: 020 7436 3304

email: info@fhaonline.org.uk

www.fhaonline.org.uk

In Touch Trust

Puts families of children with special needs in contact with each other.

10 Norman Road, Sale M33 3DF

Tel: 0161 905 2440

email: jworth@globalnet.co.uk

JOINTZ

Part of Arthritis Care. For parents of children with arthritis. Covers all N. Ireland.

7 Newtown Heights

Newtownards BT23 7YG

Tel: 028 9182 0369

National Childrens' Bureau

Provides information on children and disability issues

8 Wakely Street

London EC1V 7QE

Tel: 020 7843 6000

www.ncb.org.uk

Network 81

Advice on special needs education including assessment, statementing and negotiation with schools and local authorities.

1-7 Woodfield Terrace,

Stanstead CM24 8AJ

Tel: 01279 647415

Write Away

Penfriend club for children, young people and adults with special needs and their siblings, parents and carers.

1 Thorpe Close

London W10 5XL

Tel: 020 8964 4225

email: peter.howell@write-away.org

www.write-away.org

Arthritis Care is the largest UK-wide voluntary organisation working with and for all people with arthritis. We aim to promote independence and empower people with arthritis to live positive lives as well as raise awareness of the condition.

ARTHRITIS CARE:

- offers The Source, a helpline service for young people with arthritis by telephone, letter and email.
Freephone: 0808 808 2000 weekdays 10am-2pm.
Email: TheSource@arthritiscare.org.uk
- produces a range of helpful publications, including *No Limits* magazine for people aged 15-20, three times a year



- offers a range of personal development and confidence building training courses for young people with arthritis to enable them to be in control of their arthritis
- campaigns for greater awareness of the needs of all people with arthritis
- has a network of staff and volunteers across the UK, and has offices in England, Wales, Scotland and Northern Ireland. Phone 020 7380 6540 to find your nearest one.