



A Day With Sam



ARTHRITIS CARE

*Empowering
people with arthritis.*

A Day With Sam



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 10 and Samantha who is eight. Although we all think 'children do not get arthritis', by the age of 13 months Samantha had developed juvenile 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 to 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 assessed by many young people and children with arthritis, and was updated in 2010.

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

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.

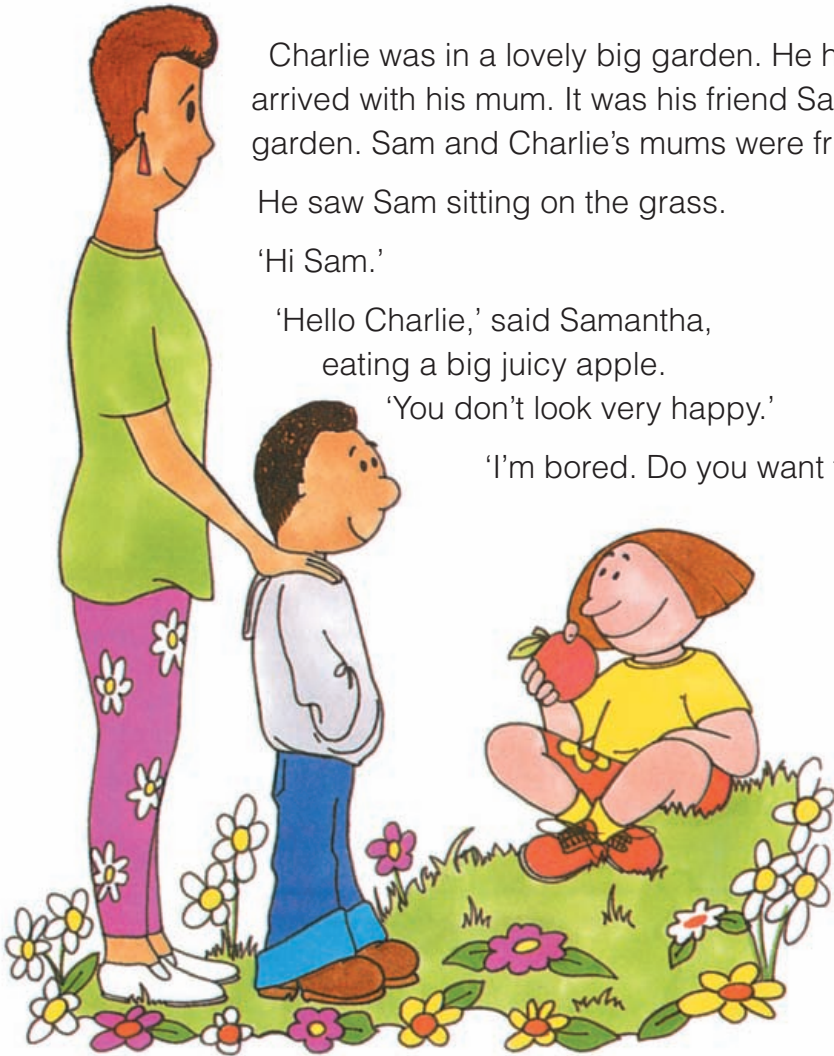
He saw Sam sitting on the grass.

'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.



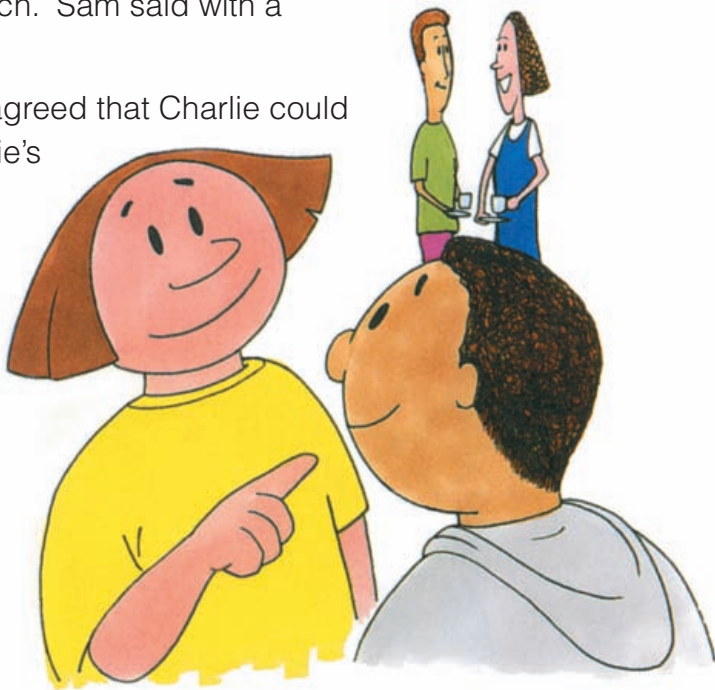
'Tell you what,' grinned Sam, 'Would you like to come too? I'll show you around. It can get boring at the hospital but I can tell you stories about what happens to me there.'

'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.



'Instead of my joints working together, they get puffy and hot,' Sam announced. '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.



'Okay,' Charlie nodded slowly, 'I think I know what you mean now about joints.'

Sam carried on: 'If I have been very stiff in my joints the doctor might give me some new medicine to try.'

'I often see the nurse as well. She is a special nurse who knows all about my arthritis and looks at all my joints. She is very nice and says I can ask her anything I want to. The first time my knee was sore we had lots of things we wanted to know and the nurse helped us. She also talks to me and my mum about my medicines and shows me how to take them.'

'Do you have to take medicine every day,' asked Charlie?

'Yes I do, and sometimes at school. My nurse may visit me at home or at school so that everyone knows about my arthritis and how they can help.'

'I want a special nurse too,' Charlie said.

'Sometimes I will go to the physio lady,' Sam said, remembering more things to tell Charlie.

'The what lady?' he exclaimed, 'The fizzy lady?' The words were very confusing.

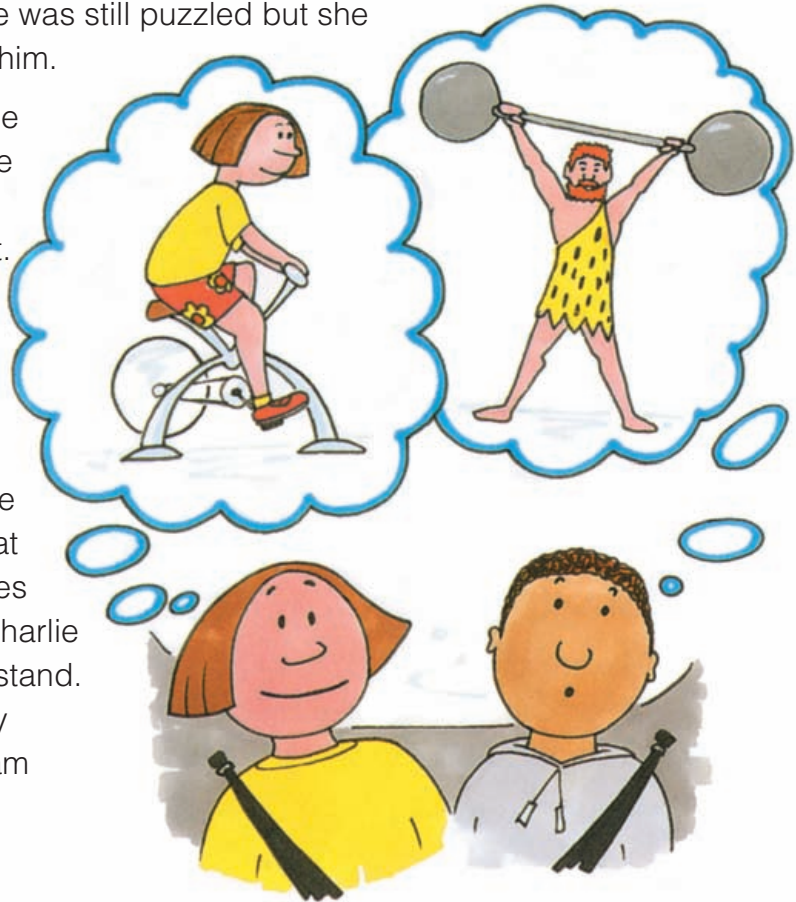
Sam laughed. She knew the words were hard to understand when you first heard them. But Sam knew them all by heart now.

'Physio treatment helps me with my joints too,' Sam grinned. She knew Charlie was still puzzled but she wanted to tease him.

'What does she do, Sam?' Charlie jumped up and down on his seat.

'I think I'll tell you that story later,' Sam laughed again.

'Please, please Sam. Tell me what the fizzy lady does for your joints.' Charlie wanted to understand. He pulled a sulky face because Sam wouldn't tell him.



Sam was sorry to see him look unhappy. '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.'



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 do a scan of your knees,' said the doctor, looking at Sam and then her mum, 'Just to see how they're coming along. It won't hurt, and you will be able to see inside yourself on a television screen – like when doctors look at a baby in mummy's tummy. Some people call it a jelly scan, because we put jelly on your skin to help us see the picture on the TV screen.'

As they said goodbye to the doctor, Sam was thinking that Charlie wouldn't understand about scans. But she was surprised to see him smiling.

'Sam, I saw inside myself once,' he laughed. 'When I fell off my swing and hurt my arm, Dad took me to the hospital and a lady took a special photo of my arm with a big X-ray machine.'

'That's right, Charlie,' Sam's mum smiled. 'When Sam has scans, the doctor can look at them and see what is happening inside, where the arthritis is making her joints sore. The scans don't hurt, but Samantha's joints can feel a little bit sore when the lady asks

her to hold them still. You know what they ask you to do though, don't you Sam?'

'Oh yes. I try and keep still for the scan so it's done quickly,' Sam nodded. 'But Charlie, you've never told me about your arm before. Was it broken?'

'No, it was all right. Dad and I came straight home.' Charlie felt happy that he knew about scans because they were like his X-rays.

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



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

'The what lady?' Charlie was very confused.

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

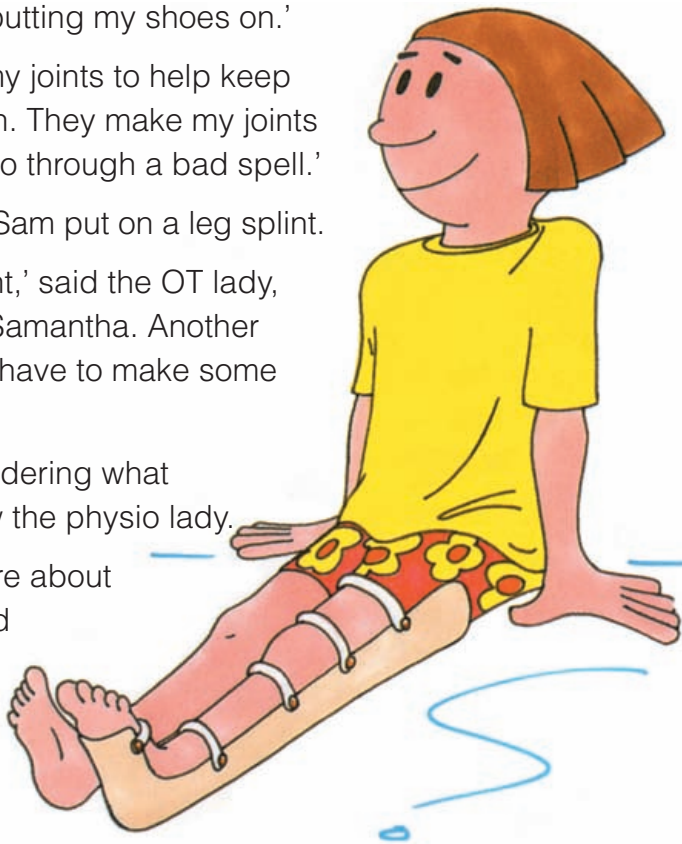
'Splints go around my joints to help keep them in a good position. They make my joints feel better when they go through a bad spell.'

Charlie watched as Sam put on a leg splint.

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

Charlie was still wondering what Sam did when she saw the physio lady.

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



'No, not yet,' Sam's mum laughed. 'Sam has to go for an eye test.'

'Does arthritis make your eyes sore too?' Charlie asked Sam.

'No, but it can upset them so I have to have them checked,' said Sam.

They went into a room and Sam sat down next to a machine which looked like a telescope on a special stand. A doctor asked Sam to look into the machine, and then looked into her eyes with a light. 'Your eyes look fine,' said the doctor, 'so we'll see you again in a few months.'

'What are we doing now?' Charlie asked Sam.

'I have a blood test next,' Sam explained to Charlie.

Charlie heard the word blood. He was nervous about what a test with blood could mean.

'When they do a blood test it helps the doctors to see how my arthritis is doing. They can check if the amount of medicine I take needs to be changed or not,' Sam tried to explain.

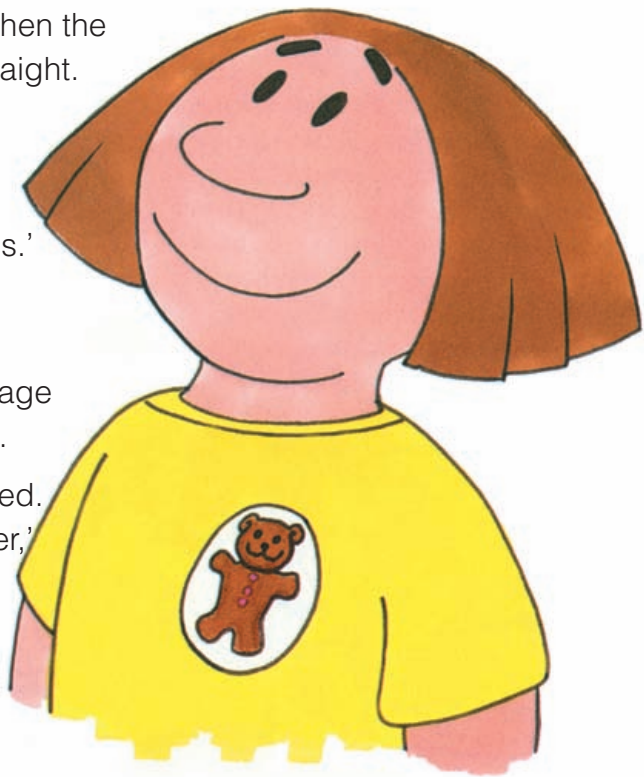
'You know an awful lot Sam,' Charlie sighed as they walked into another room.

A lady said hello to them all and asked Sam to hold her sleeve up. A band was placed around Sam's arm and some blood was taken out from one of her veins through a tiny needle.

'At first I was worried that it would hurt, but the lady uses magic cream that numbs the skin so that I can't feel the needle,' Sam told him. 'When I first had to come for these blood tests I thought that my elbow joint would hurt when the lady asked me to keep it straight. But I've got used to it. It's just something that has to happen to help the doctor know more about my arthritis.'

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.



'You're very brave,' said Charlie. 'I hate needles.'

'It's okay,' said Sam. 'Once, when a lot of my joints were very sore, they made me sleepy and put needles into my joints to make them better.'

'Did it hurt?' said Charlie, looking scared.

'Not too much,' said Sam. 'My joints still felt stiff, but they got better very fast and I could ride my bike again.'

'You've got used to so many things, Sam,' said Charlie, feeling very proud of her.

Sam remembered her promise to tell him about going to see the physio lady.

'When I get to the physio room I might meet some friends who have arthritis too. Physio treatment can be a bit boring, but you get used to it.'

'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.' 'What do you do on the mat, Sam?' Charlie really was fascinated by the physio treatment.

'The physio lady tells us what to do, but really I know it off by heart now,' said Sam. 'We have to pull our legs up and down. And the physio lady says "Wiggle your toes."' Charlie laughed as he imagined Sam and her friends doing this.

'And what happens next, Sam?'

'We move our arms. The physio lady gets us to make big circles with them. Then she says "Make those fingers wriggle just like little worms."'

They all laughed together as Sam held her hands up and wriggled her fingers.

'We might play with a ball which means we get to exercise at the same

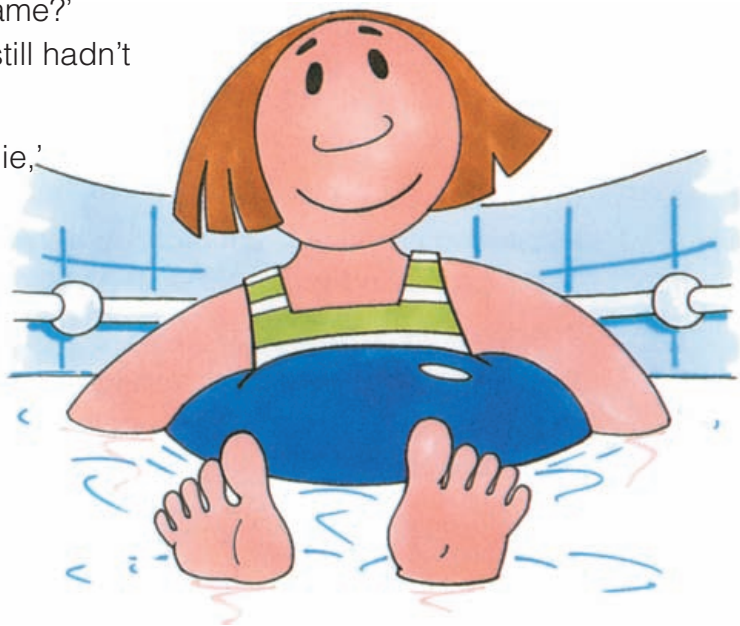


time,' Sam said, thinking how funny it was that Charlie wanted to know all about her physio treatment.

On some days going to physio was fun. It helped her joints. On other days the physio lady made her move joints that hurt. But mum helped Sam to understand, and she was getting used to all the things that happened to her at the hospital because she had arthritis.

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

'Sometimes, Charlie,' said Sam. 'And the word is PHYSIO. Now 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 having a bath in a small swimming pool and it's 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.

'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.

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 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 help you to move in many different ways. Strong muscles help sore joints to keep working.

Nurse – the person at the hospital who helps you to understand your arthritis, helps with your medicines, and sometimes does your blood tests.

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 makes splints for your joints, if you need them.

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.

Scans – a way of seeing inside your body. They are used to see what is going on with your arthritis around your sore joints. They are used regularly and show different things than X-rays. Ultrasound is being used increasingly.

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 – X-rays are special photographs, usually taken with a big machine, which can see into your body to look at your bones. 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

Call our free confidential helpline called The Source, for young people with arthritis: Freephone 0800 800 2000 (10am-4pm weekdays), or email

TheSource@arthritiscare.org.uk

www.arthritiscare.org.uk

See back cover for more information on our services.

Arthritis Research UK

Funds medical research and produces information.

Copeman House, St Mary's Court,

St Mary's Gate, Chesterfield,

Derbyshire S41 7TD

Tel: 01246 558033

www.arthritisresearchuk.org

Action for Sick Children

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

32b Buxton Road, High Lane,

Stockport SK6 8BH

Tel: 0800 0744 519

www.actionforsickchildren.org

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: 0800 800 5793

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: 01263 822161

www.break-charity.org

Children's Chronic Arthritis Association (CCAA)

Support group for families of children with arthritis.

Ground floor office

Amber Gate, City Wall Road

Worcester WR1 2AH

Tel: 01905 745595

www.ccaa.org.uk

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

Family Fund

(Joseph Rowntree Memorial Trust)

Offers grants for families with severely disabled children.

Unit 4, Alpha Court, Monks Cross Drive
Huntingdon, York YO32 9WN
Tel: 0845 130 45 42
www.familyfund.org.uk

Family Holiday Association

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

16 Mortimer Street,
London W1T 3JL
Tel: 020 7436 3304
email: info@fhaonline.org.uk
www.fhaonline.org.uk

National Childrens' Bureau

Provides information on children and disability issues

8 Wakley Street
London EC1V 7QE
Tel: 020 7843 6008
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, Essex CM24 8AJ
Tel: 0845 077 4055
www.network81.org

Our booklets are reviewed every 12-18 months. Please check our website for up-to-date information and reference sources or call 020 7380 6577.

Arthritis Care is the UK's largest organisation working with and for all people who have arthritis. We provide a number of resources to support young people and their families:

- The Source – a helpline service that offers confidential information and support for young people with arthritis and their families. Call free on 0808 808 2000 (10am-4pm weekdays) or email TheSource@arthritiscare.org.uk
- our website (www.arthritiscare.org.uk) has sections for young people and for parents
- online discussion forums for young people and for parents
- a range of personal development and confidence building workshops and weekends.



Published by Arthritis Care,
18 Stephenson Way, London NW1 2HD

Last reviewed November 2010 ACR019
Registered Charity Nos. 206563 and SC038693

ISBN 978-1-903419-465

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