

Care Time

Spring 2011



Mum Wins Struggle For Diagnosis

Saiid Salat is a bubbly five year old, living life to the full and enjoying school, but his life has not always been so straightforward. Saiid has spent much of his short life in hospital, whilst experts battled to find out the causes of his complex health problems.

"I knew something was not right with Saiid very soon after he was born," explained his mother, Iman. "He wasn't developing like other babies but no-one believed me until, at last, he was referred to a genetic consultant at the Royal United Hospital."

Saiid was finally diagnosed just a year ago with 3M Syndrome, an extremely rare genetic disorder.

"Thanks goodness the health visitor at my GP Surgery in Widcombe took me seriously," said Iman. "She was the only person who listened to me, and because of her referral to the hospital, Saiid now gets the healthcare he needs."

Saiid attends Three Ways School in Bath, which he loves. As well as lessons and playtime, he receives specialist care such as speech therapy and physiotherapy to help him catch up with other children.

"When Saiid was ill, I had too much to deal with and I just couldn't manage anymore," said Iman. "I was struggling to get the help I needed, but I contacted the Carers' Centre and have been helped so much by their friendly team. They are always able to come to see me if I have complex forms to fill in, and they've made sure I am receiving all the support and benefits I need to help me look after my son. I'd have been lost without them."



Care Time now an e-newsletter...

Care Time is now available as an e-newsletter. If you want to help us reduce our postage and printing costs, as well as help save the planet, please send us your name, address and email address to info@banescarerscentre.org.uk and we will ensure you receive Care Time, Carers' Updates and What's On electronically.

Pippa's Got the Write Idea

Pippa and Andrew Hawkins live in the beautiful village of Chew Stoke in North East Somerset. The couple were looking forward to retirement, rest and relaxation after a lifetime of teaching - until Andrew was diagnosed with Parkinson's Disease.

"Most diseases change a person," said Andrew. "And Parkinson's has definitely changed me. I am more difficult to live with now, and that's very hard for both of us."

The couple have been married for forty years, and for the last ten, Pippa has taken on a caring role for her husband as his condition has deteriorated.

"The balance of our relationship has completely changed," explained Pippa.

"I feel it's impossible to fulfill the role in my mind of a perfect carer, so I just do the best I can."

Pippa first heard about the Carers' Centre eight years ago, but didn't ask for the help she really needed until she started to receive one to one support from the team.

"It was a big step for me, but when I did ask for help it made such a difference," said Pippa. "I could email, phone or have a visit anytime. I had some brilliant advice from Alison, a Support Manager, to get myself a special place away from caring. A place that was just mine, where I could study and have some time to myself."

Granny Pip Finds Love in Stoke Newington

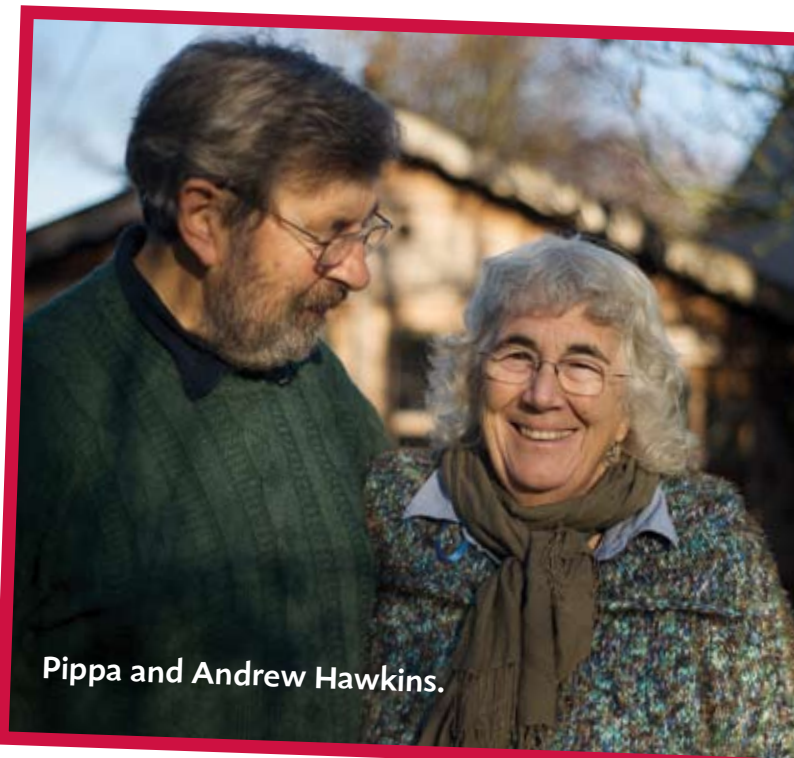
Bath to Paddington, Paddington to Kings Cross. I ring the bell - you sit snug on her hip - lean your head towards me like a king. Lips find soft hair, hand brushes hand - you cling to her, eyes wary.

On the floor, I try a game. Jack, can you see Spot? No response. I try hiding Spot, say, Where's Spot?

You shrug your shoulders, eyes smile, finger points. Your Spo...floats through the air and I stop breathing. You bring the book with holes, warm body next to mine. One apple, two pears... sumptuous butterfly. Your hand flutters its goodbye just as my taxi comes.

King's Cross to Paddington, Paddington to Bath.

Poem by Pippa Hawkins



Pippa and Andrew Hawkins.

Pippa built herself a cosy shed in the garden, which she has beautifully furnished and decorated, and uses as a space for study and relaxation - yet she's just a few feet away from Andrew if he needs her.

"Thanks to my hideaway, I've completed a Diploma in Creative Writing and now I have started a part-time Masters Degree at Swansea University. Andrew is starting to have some help from paid care workers for the first time, which is a big step and means I can get to my course without worrying about him."

"I love Pippa's shed," said Andrew. "It's warm and cosy, with its own woodburner and comfy sofas. I am so proud of what Pippa's achieved, her writing is excellent; I often read her stories and poems and really enjoy them."

Pippa has now become a Trustee at the Carers' Centre and is a member of the new Neuro-Carers Support Group. For more information contact the Carers' Centre on 01761 431388

Jim's Journey From Councillor To Carer

Eighty six year old Jim Lingard has been caring for his wife, Peg, who is 82, for many years.

"Peg has always needed caring for," said Jim. "She had a part time job as a telephonist, but her asthma was sometimes really bad; it was a constant worry. Last year, she was diagnosed with Alzheimer's Disease as well which was a blow."

Jim recently attended the Carers' Rights Day event in Bath, organised by the Carers' Centre. Having been active in local politics, Jim was interested to hear what guest speaker Malcolm Hanney, Deputy Leader of Bath and North East Somerset Council, had to say in support of services for carers.



Former Councillor Jim Lingard, with his wife Peg who has Alzheimer's Disease.

"I decided to give up my political career as Peg was not well and I needed to spend more time looking after her," said Jim.

Jim became active in local politics in 1978 after he was voted Labour Councillor for Wansdyke, he was elected to Avon County Council in 1989 and to Bath and North East Somerset Council until he retired in 2003.

Deputy Council Leader Hears Carers' Concerns

A major event, hosted by the Carers' Centre, brought more than seventy carers of all ages together with top Council and NHS officials to have their say in how local spending cuts could affect them.

Keynote speaker at the Carers' Rights Day event was Malcolm Hanney, Deputy Leader of the Council and Chairman of NHS Bath and North East Somerset. "Our Council prepared itself well in advance of the cuts, and we are in a much better position than most other authorities," said Councillor Hanney

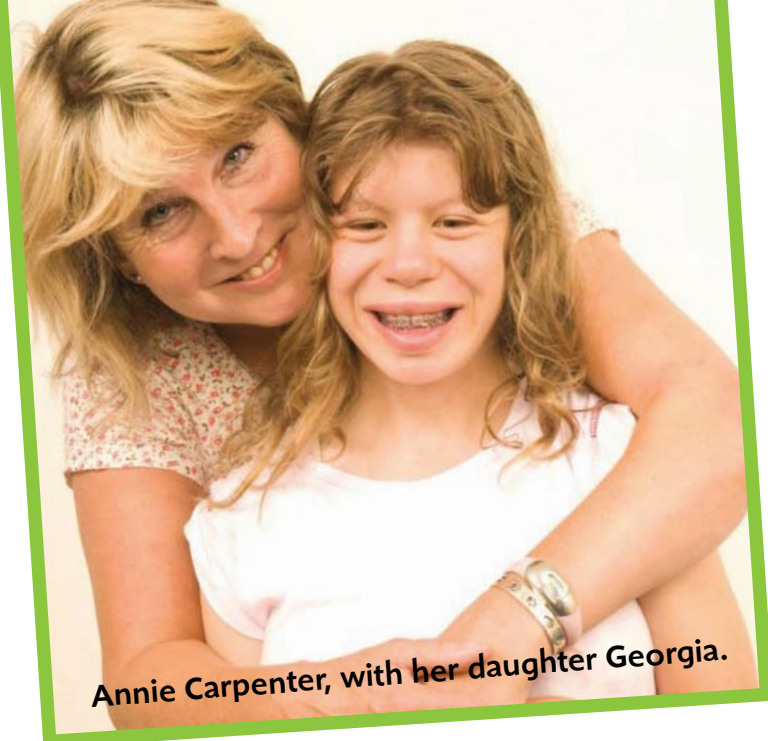
"I know from today that carers often feel very alone."



"They need support and help, breaks and space away from caring and someone to turn to when needed. Carers are highly valued, they save the country huge amounts of money by taking care of people who can't look after themselves. Providing good, supportive services for carers makes complete financial sense."

Annie Wants A Fair Deal For Disabled Children

Annie Carpenter wants to make a difference for disabled children in mainstream school. Her experience in caring for her daughter, Georgia, means she knows first hand what it can be like to see your child miss out at school because they have a disability.



Annie Carpenter, with her daughter Georgia.

"I got involved in Parent Carers Aiming High (PCAH) through an event I went to organised by the Carers' Centre," said Annie. "They were looking for parent carers who wanted to improve services and help others.

"My problem was that because Georgia was at mainstream school, she was missing out on opportunities like speech therapy, which she'd have got if she went to a special school. We really had to fight for what she needed and that's not right – disabled children should receive the support they need whatever school they go to."

By getting involved with PCAH, Annie can use her experiences to influence and improve services for disabled children.

"Now Georgia is at Hayesfield Girls' School in Bath and we are very impressed with the support she receives," said Annie. "Her education is really focused on her needs."

Parent Carers Aiming High is looking for more parent carers to get involved, especially parents

of children with physical disabilities, sensory impairment or life long conditions.

"The parent carers group wouldn't have succeeded without the help and friendliness of the team at the Carers' Centre and certainly wouldn't have kept going without their input," added Annie.

"I don't hold back now when I've got something to say; if you are the parent of a disabled child, having your voice heard is essential. Through PCAH we can bring about change for the better for our kids, and those in the future."



For more information, contact the Carers' Centre on **01761 431388**

New Carers' Service At RUH

A new Drop In service has been launched by the Carers' Centre at the Combe Ward in Bath's Royal United Hospital. Every Thursday and Saturday between 2.00pm and 4.00pm, carers can meet with a member of the Carers' Centre team for information, help and advice.

Jackie Short, from the Centre, explained. "We are trying to identify carers who have slipped through the net and aren't getting all the help they need in their caring role. These people often don't realise they are carers and can miss out on vital services."

A working partnership between the Wiltshire Carers' Centre and the Carers' Centre Bath and North East Somerset, the Drop In hopes to attract people from throughout the region who are visiting relatives on the Combe Ward.



Jackie Short from the Carers' Centre

Jackie added, "By bringing the services of both Carers' Centres out into the community, we hope to be able to help more people to access all the support they are entitled to."

Launch Of Website For Carers

A major virtual resource for carers in Bath and North East Somerset has been launched at www.banescarerscentre.org.uk. The new website is an instant online solution to providing information and easy self-referral for carers to access help and support from the area's Carers' Centre.

Bath-based website entrepreneurs, Float Design, helped the Centre to realise its ambitions to bring a complete online package for all carers, health professionals, businesses and volunteers across the area.

"Our website is fully accessible for all, with additional resources for people with learning disabilities and visual impairments," said Centre Chief Executive, Sonia Hutchison. "It even has a chatroom where carers can get together at any time of the day or night and offer help and support to each other."

She added, "Our events calendar is a major part of the site. Every month we have a programme of activities and training to help carers in the area to take a break, learn a new skill, make new friends and get involved in helping to influence the development of local services."

People visiting the site can book themselves onto these events, read about the experiences of other carers, catch up on news items and, importantly, refer themselves for help and support.

Gary Smith, from Saltford, was one of the carers who helped with the initial concepts of the site. He said,



Gary Smith, who helped develop the new Carers' Centre website, and his wife, Sue.

"The Carers' Centre website is a real opportunity for people who are carers in BANES. Finding out about others helps them feel less isolated, and I think it's a great idea to bring carers together through a chatroom as there is real support available from those who've been there and know how you feel."

New Keynsham Drop In Service

A new service for carers in Keynsham and Chew Valley has opened at the Keynsham Health Centre. Carers can now drop in on the first and third Tuesday of the month to see a member of the Carers' Centre team for help and advice.

Jo Grobler, from the Centre, explained. "We want carers to come along to find out about their rights, benefits they may be entitled to, employment, breaks away from caring, free counselling and all the other services of the Carers' Centre.

"Many people do not realise they are carers, or what they may be entitled to, so by having the Drop In Service in the Health Centre, we hope to find more people we can help."



Jo Grobler from the Carers' Centre is running the Carers' Drop In Service at Keynsham Health Centre, St Clements Road, Keynsham BS31 1AG.

The Drop In Service is free and no appointment is necessary.

Carers can find out when the next session is by telephoning the Carers' Centre on 01761 431388 or going online to www.banescarerscentre.org.uk

Funding Success For Sunday Fundays

Finding the opportunity to enjoy some fitness fun with the whole family can be difficult if you have a child with a disability.

The Carers' Centre has won funding for a series of weekly sport sessions for parent carers and their children to get fit, have fun and enjoy themselves at Bath Sports and Leisure Centre.

Dad, John Grady, has been coming along each week with Katy, who is 8, and 10 year old Toby, who has autistic spectrum disorder.

“This has been great for Toby, and for Katy too,” enthused John.

“Getting Toby to explore sport is hard because his behaviour can be very difficult. I go cycling and swimming with him, but these sessions mean we can meet new people, try out different sports, relax and all have fun together – and above all, Toby's able to just be himself.”

“I like coming here with Dad and Katy,” said Toby. “I do lots of running and today I scored a goal in football. I really like playing games like Stuck in The Mud too.”

Quartet
community foundation
for the west of england



John Grady with Katy and Toby.



“Sport Relief have funded these sessions through the Quartet Community Foundation,” explained Sonia Hutchison, Carers' Centre Chief Executive. “Jimmy Dean from Bath Rugby Foundation is running the sessions for us; he is very experienced in accessible sports and wants whole families to feel confident about enjoying getting fitter together.

“We have funding for ten sessions, and are busy trying to secure more funding to ensure they can continue.”

If you would like to join in the fun for free every Sunday 10.00am to 12 noon at Bath Sports and Leisure Centre, contact the Carers' Centre on 01761 431388

Funding News

The Churches Together Carol Service at Radstock Methodist Church raised over £100 for the Carers' Centre.

Quartet Express Fund provided £2,000 to fund the December and February Carers Together involvement forums.

The Nationwide Foundation has donated £4,778 to support older carers. The money will pay for fortnightly 'money surgeries' from April 2011, providing advice and advocacy on pensions, benefits, budgeting, finance and housing. These events will take place in Somer Housing Community Centres.

Carer Mary Allen made over 500 mince pies last Christmas and raised just under £200 from their sales.

The Co-operative Group and The Albert Hunt Trust have donated a total of £1,900 for carers' training in 2011.

Give Us a Break is funding activities for the Carers' Centre Two's Company events, the Carers for Each Other art workshops and the activities at the Carers Together involvement forums.

Positive partnerships with St James's Place Wealth Management and Stone King have developed to run useful information sessions for carers during the year.

London Calling For Robert

Carer, Robert Whiting, from Pensford in North East Somerset, was invited to give a presentation at the recent Learning Disability Today Exhibition at London's Business Design Centre. Robert is a member of the Carers for Each Other support group which regularly brings carers with learning disabilities together for mutual help and support at the Carers' Centre.

Lydia Clark, who works at the Centre, said, "Robert has become a member of the National Network of Carers with Learning Disabilities, and he was invited to share his experiences of support from the Carers' Centre at this major event."

Robert has made many new friends through his involvement with the Centre and the Network, and is a founding member of the Carers for Each Other support group, which meets every fortnight at the Carers' Centre.



Robert Whiting and Lydia Clark at London's Learning Disability Today Exhibition.

"I really enjoyed going to London with Lydia," said Robert.

"I was a little bit nervous, standing up in front of lots of people, but I must have been alright because everyone clapped when I finished my talk."

130 Attend Pub Lunch Treat

The Carers' Centre events programme has an exciting range of activities, workshops, support groups and social events for carers in the area. Every month, Two's Company events provide the opportunity for carers to have a break with the person they care for.

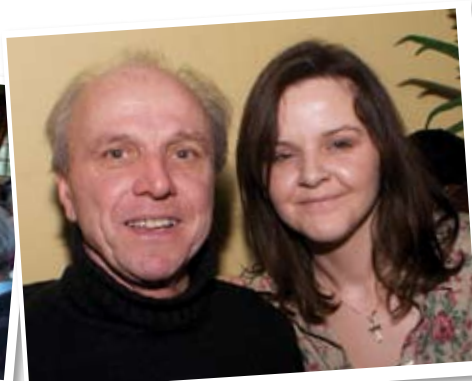
Give Us A Break, a project funded by the Department of Health, provides short breaks for carers and has funded some of these activities for the Carers' Centre, with recent pub lunches at the New Inn, Farmborough, attracting over 130 people.

"It's wonderful to get out together," said Valerie Owen, who cares for her husband, Ken.

"We come along to Two's Company events every month. We really don't get out much, but the Carers' Centre helps us with transport from their volunteer drivers which makes it possible for us to have an outing together."

Chris Jordan, who cares for his two daughters, said, "I've been on several outings with Two's Company, and it's lovely to be able to have a treat today with my daughter, Lavinia. I'm also looking forward to the trip to Bristol Docks in April to see Brunel's ss Great Britain."

For more information about what's on at the Carers' Centre visit www.banescarerscentre.org.uk



Chris Jordan and his daughter, Lavinia.



Brenda Reid and her daughter, Laura.

Carers' Centre In Partnership

Somer Community Housing Trust has won new funding to support older people in Bath and North East Somerset. The Older Persons' Independent Living Service means that people who need support will be able to get a range of services to help them live independently in their own homes.

Types of support range from having a simple personal 24-hour alarm to receiving daily well-being calls and home visits.

The new service will be delivered in partnership with Community Health and Social Care Services and the Carers' Centre Bath and North East Somerset, who will help ensure that support reaches carers too.

To find out more call **01225 366196** or visit www.somer.org.uk

Extra Help For Neuro-Carers

Extra help for carers of people with neurological conditions is being provided through a specialist support group launched by the Carers' Centre Bath and North East Somerset.



Neil Drinkwater from
the Carers' Centre.

Neil Drinkwater from the Centre explained, "We talk to carers about what they want, and they have asked us to provide this support group for them. People looking after someone with a neurological condition share many common experiences. Illnesses can vary widely in diagnosis, such as head injury, stroke or Parkinson's Disease, but the issues faced by the carer and how they feel about their situation can be the same."

Pippa Hawkins, from Chew Stoke in Somerset, cares for her husband, Andrew. "I'm really pleased to have joined the group; we get together and share our expertise and experiences," she said. "My husband has Parkinson's Disease and it's been great to meet others in similar situations and share ideas, offload and give each other support – as well as get help from the professionals involved."

The Neuro-Carers' Support Group meets regularly, and is the first of its kind in the area. Carers wanting to get involved can get in touch with Neil Drinkwater at the Carers' Centre on 01761 431388.

Neuro-Carers' Support Group Meetings:

Wednesday 9th March -
6:30pm to 8:30pm
Twerton Infants' School, Bath BA2 1QR

Wednesday 6th April -
2:30pm to 4:30pm
Parkside Children's Centre, Bath BA1 2NE

Desperately Seeking Treasurer

Do you have a sound background in finance and want to help the Carers' Centre? We are looking for a new volunteer Treasurer to oversee and monitor the financial matters of the charity, and report to the board of Trustees at regular intervals about the financial health of the organisation.

To find out more about this important role, and to apply, please go to www.banescarerscentre.org.uk and click Work For Us where full job description and application form is available, or alternatively call 01761 431388.

Contact the Carers' Centre

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