Richmond AID
Advice and Information on Disability

Disability News

Issue 46 Summer 2015

Not Seen, Not Heard:

Talking Hidden Disability

Undiagnosed: Invisible

A personal account of Hidden disability

Samantha Cleasby

"The go to gal for a quote about IBD, poo issues and invisible disabilities"

Travel through Time with Richmond Buddies

RUGBY FOOTBALL UNION Sponsored by the Rugby Football Union

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Pictured above: Richmond AID's staff, trustees, volunteers and clients were treated to an inspirational speech from 19 year old wheelchair racer Toby Gold and entertainment from the Avenue Club Choir at our 2015 AGM in March (Photography by Andrew Harris)

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Welcome to Summer edition of **Disability News!**

In February I read a blog post doing the rounds on social media called "*Dear Lady who tutted at me using the disabled loos"* written by a young Mum from Sheffield, Samantha Cleasby. Samantha's blog was a simple story but one that struck a chord with people around the world. In this blog Samantha, diagnosed with Ulcerative Colitis in 2003, tells of how she felt "humiliated, angry and upset" after a women tutted at her, whilst other have berated her, for using the disabled facilities. The lack of a visible disability was enough for this women to assume she was, in Samantha's own words, a "lazy cow".

This story brought to life the prejudices and misunderstanding that affect people with invisible disabilities everyday. Samantha was judged because people did not understand her condition. Similarly, from the young man labelled lazy because his line-manager doesn't understand fatigue or the kid with dyscalculia who is called stupid by classmates, people face prejudices or misunderstandings everyday as a result of their own hidden disabilities.

In this edition of *Disability News* we explore the issue of Hidden (or invisible) disability. We lead with an interview with Samantha Cleasby who tells us about why she wrote her blog and the positive reaction she has received from it. Our regular contributor, Justine Nagaur tells her own fascinating story of invisible disability- both her struggles and the inner strength she is gaining.

We also look at changes taking place at Richmond AID and keep you up to date with our Summer Events Calendar.

Enjoy the summer sun all!

Lewis Garland

***Disability News* Editor**

"We all need to talk about disability more, especially invisible disabilities and inform and educate society that we exist"

Samantha Cleasby

In February Samantha Cleasby gained national attention with her blog *to the lady who loudly tutted at me for using the disabled loos,* lucidly highlighting the everyday prejudices she has faced due to her hidden disability, a severe form of Inflammatory Bowel Disease. In this achingly honest "open letter" Samantha's managed to put into words, and make relatable, some of the key issues facing people with hidden disabilities. This month *Disability News* spoke to Samantha about what persuaded her to write such a personal article, the reaction she has received and how the attention she has gained has affected her life.

Was the incident in your blog an isolated event or have you encountered similar reactions?

"It was not an isolated incident. As someone who looks healthy I have faced judgments many times. Having people tutting, staring angrily or loudly saying to the person next to them 'SOME people should be ashamed for using disabled toilets when they don't need to!' while looking at me. Part of me feels like facing up to these people and explaining my issues, but the other part thinks 'why should I explain my personal medical needs to a total stranger!'"

A lot of people may feel embarrassed about addressing these issues publically. What were your thoughts while writing your blog?

"I have been writing about my illness for two years now so it has become normal for me to talk about the embarrassing parts of my life. I forget that my words will be read by thousands of people a week and get a reminder when a mum in the school yard mentions she has read my blog. It is embarrassing to talk about incontinence, illness and poo! But on the whole the response I have back is so amazing that it makes me carry on. I get messages telling me that I have changed someone's life, that my blog has made it easier for them to open up to their family and friends. Whilst I am doing some good in the world I will carry on".

"The only thing I do worry about is what my children think. If I am writing about something particularly intimate, I run it by them to get their opinion. They have never vetoed a post. YET!!"

Why do you think this article got so much attention?

"I think it was because everyone could see themselves in the story, either as the person who has been humiliated and judged or as the person who was doing the judging. I had so many people messaging me to apologise and say that they have been that person tutting before thinking they were stopping someone blagging the accessible loos and defending the "genuinely disabled".

The comments below your blogs are filled with messages of support and people giving their own stories. Have you been moved by any of these responses?

"I am blown away by the amount of people who have shared their own stories. The response was so huge that it made me realise the size of the issue and it prompted me to start the *More Than Meets The Eye* campaign about invisible disabilities."

"One response that really struck a chord was from a mum of a little girl who was born prematurely. The girl has incontinence issues and they need to use an accessible toilet to change and clean her. She said "She was born at 26 weeks and had to have part of her bowel removed. We use disabled toilets and the disgusting glares and tuts we get are unreal. I refuse to explain my daughter's complex health issues with strangers so they usually waltz off believing they've put the world to rights. In actual fact they've just made a disabled little girl and her family much more anxious about going out."

"That last line says it all for me. I tell people that the best thing that can happen if you call out someone you *think* is using something for disabled people irresponsibly is that you are right and you *might* shame them into not doing it again. The worst thing that can happen is you are wrong and you may just crush a persons spirit, you might make them feel life is just too tough to be out in public, you might just make their life a lot more difficult."

Do you have any advice for people with IBD or any other hidden disabilities who may face prejudices or lack of understanding?

"We all need to talk about disability more, especially invisible disabilities and inform and educate society that we exist! It is so hard when you feel embarrassed and humiliated but you can make your voice heard and explain that you have specific needs that can't be easily seen."

"I believe most people who are judging do so because they think they are speaking out for people with disabilities and would be upset to find out they are doing more harm than good. If we can kindly explain, perhaps we can change the mindset of society."

"If anyone wants to share their story with me, I will put it on my #MoreThanMeetsTheEye page, or they can share it on social media using this hashtag."

How has the attention you received affected your own life?

"I have become the voice of poo! The go to gal for a quote about IBD, poo issues and invisible disabilities. And I love it!! I have been writing for a couple of years and so it is great to get a bigger audience. Everything I do is to make life better for others, I share my story on my blog, do public speaking and write for others in the hope that I can make a difference to #stoppoobeingtaboo and teach people that there is #MoreThanMeetsTheEye".

"I am writing a book and feel very blessed to have these opportunities in my life. When I was in a hospital bed after major surgery 18 months ago, I thought my life was over. I was at my lowest point and I started my blog as a form of therapy, a cathartic release of everything I was feeling. For it to have gone viral and now be read in 220 countries around the world is amazing. I am really proud that I have used this difficult time in my life and turned it into something positive that can help others."

To find out more about Samantha Cleasby's campaigns and to read her blog visit: <u>www.sobadass.me</u>

Undiagnosed:Invisible

Justine Nuguar

I have suffered with an invisible illness for over four years. In less than a year I went from living a healthy, active life to being bed-bound for months. With no apparent source or 'name' to put to your illness people do not understand. Now, though not on the road to 'recovery', for this is a chronic illness, I am more positive about my future.

When the pain started the doctors sent me for various scans. These did not show any cause. I was put on a cocktail of drugs; at one point I was taking over 20 pills per day. I had days of vomiting and passing out and I was left incoherent and incapable of looking after my children or experiencing family life.

I soon became bed bound. All of my physical senses were heightened. I reached a point where wearing clothing was painful. Even having my youngest place his little arm around my waist hurt.

Initially, these changes were extremely hard. My husband had to take up the reigns of being mother, father and bread-winner. I had the pressure of knowing he was losing income due to having to take time out to shop, take the children to schools, clubs etc. I had the psychological fall-out of dealing with children who were scared- mummy suddenly couldn't move. As I had not lived long in my area at this time I did not have a network of close friends. I felt completely isolated.

I did not know at this point that there are many groups that can help with activities from shopping to helping to manage isolation. This would have helped both practically and psychologically. It is very hard for a reasonably young woman with no visible illness to feel justified in taking up the valuable time of others. In hindsight I was as deserving as anyone else.

The problem with an invisible (in my case undiagnosed) illness is that, because people cannot 'see' it (there is no badge saying "I have a disability") they find it hard to understand or respond. There are hurdles to overcome which sometimes require a shield to be worn.

When I eventually began to socialise people assumed I was better. I found myself constantly explaining myself. This is hard when you do not understand fully yourself and when you are facing an uphill battle to remain positive.

It was wonderful to get out again and travel on the bus but this also had its issues. I need to ensure that I am near enough to home in case of a flare up. Moreover, sitting is an issue for me so I often stand in the middle section. I have experienced confused and even annoyed ‘looks’ from passengers when the bus is busy and I am jostling among the prams, not sitting down when seats become free.

My condition is very much “do something at the time and pay for it later”. It does not necessarily stop me immediately but often leaves me rolling around in pain later. People don’t see this. Being determined not to let my pain stop me, I do things I shouldn't and then I am expected to do them again. There is also the issue of unpredictability. One day I am good, the next not. People set parameters for you based on what they see you doing assuming you can do it again if you did it once. Its tricky explaining that it does not work like this.

I would love to go food shopping but I cannot push a trolley or carry the bags home or to a car. I have recently found that supermarkets provide assistance with pushing your trolley, packing and bringing your food home. However I have yet to explore this. It is not pride that stops me using this service, but a sense of “will they look at me and think I don’t need it, will I have to justify myself to get the help needed?”. Maybe I should be stronger but for now I have not had the courage to ask, so again my husband picks up the pieces and I miss out on something I used to enjoy.

On a positive note, I have recently spent three weeks at a pain management programme. It was hard, there were days when I would have done anything not to return to the clinic. I chronicled my journey through my blog. However, despite these ups and downs, in the end I took two very important things away with me: knowledge and empowerment.

I have felt nervous whilst writing this article; concerned about how people reading this might react. That is what a lot of having an invisible illness is about; the misunderstandings, miscommunications and complexities of living with a hidden problem.

Though I do not know what caused my ‘invisible illness’, I now understand it better. Attending the pain management programme has given me the confidence to talk about it in a more open way. It has allowed me to ask for things and make better judgements on what is right for my health. It is a learning curve; it is a journey, one I am still finding my feet with, but a positive road for the future.

You can read Justine’s blog here: ponderingwords.wordpress.com/.

Hidden Disability and ASC

An ASC (autism spectrum condition) is a lifelong developmental condition affecting the way a person communicates and relates to others. The term spectrum implies that the condition of autism varies in severity, depending on the individual. It ranges from classic autism, which is more pronounced and where accompanying learning disabilities are more likely, through to social communication difficulties, where individuals have difficulties using spoken and written language and give inappropriate responses in conversation because they find it hard to understand the ‘hidden’ rules of social interaction. Additionally, someone with an ASC may have difficulties processing sensory information. This means that their senses of hearing, sight, smell, taste and touch react to stimuli differently. They can become overwhelmed by lights, sounds and smells or they can be seemingly insensitive to pain, yet oversensitive to light touch.

“You meet one person with an ASC, you've met one person with an ASC"

How can you spot someone with an ASC? They don't usually look different, there are no obvious signs that they have a disability. Therein, unfortunately, lies the snag. People on the spectrum can be very good at masking their problems and occasionally, when faced with a challenging situation such as heavy social demands or sensory overload, their reactions can shock or cause concern. Someone who looks the same as everyone else, and sometimes even manages to 'act the part' enough to 'fit in', can be vulnerable. People can misunderstand them and think they are 'strange' or worse. For children this can lead to bullying and, for adults, harassment or isolation. So what's the solution? One of the NAS's mottos is "Accept difference, not indifference". Another is "You meet one person with an ASC, you've met one person with an ASC". The solution is accepting that everyone is different in their own way; understanding that people can perceive and experience life and everyday situations differently and that sometimes a 'disability' is a 'different ability'. The solution is tolerance.

Laura Lennuyeux-Comnene
Richmond NAS Branch manager

Travelling through Time

"...Look at this! You can tell by the expression on this statue's' face that he was a warrior, the romans would often make their statues say something about the person, or about what the person wanted to be seen as…."

I nod along, making the right noises to ensure Basim doesn't catch on to my embarrassing lack of knowledge. I am learning far more from him today than from any of the explanatory labels that the British Museum have on offer.

This is Basim's tenth trip with his Travel Buddy, Lauren. *Richmond Travel Buddies f*irst met Basim last summer. Although initially reserved, Basim came to life with the idea that these trips would allow him to visit new museums and sites. He was particularly excited that, in the longer term, with the right travel skills under his belt, he may even be able to visit London's many museums independently.

The following week Basim began meeting with his Buddy, Lauren, a caring, wide-grinned student from St Mary's University. The pair initially practised local routes useful to Basim's daily life. These included travelling from Whitton to Isleworth for West Thames College and onward to Richmond for Basim's work experience with Mencap. Over this time, Basim learnt to read timetables, maps, and identify stops and signs. He grew used to making unexpected changes and even began to develop his own itineraries using TFL's route planner.

Basim and his family are delighted by the strides he has taken. Basim has said, "I feel that I can confidently travel anywhere I need to using buses and trains". Mohammed, Basim's father has echoed these sentiments: "The Travel Buddy scheme has been a blessing for Basim. It has been an enjoyable learning experience. His confidence in using public transport has increased by leaps and bounds and he is not afraid to travel on his own now. He has made a big transition from a kid who was afraid to venture out on his own to someone who confidently takes buses and different routes. This new found independence has been a big gain for Basim."

Lauren has been equally enthusiastic about her experiences: "I absolutely loved the Buddy scheme. The transport system can be tricky, it is important that anyone should be able to use it effectively. Since I met Basim he has gained significant amounts of confidence and is now planning his own journeys! For me, this is the best reward of all. I love the satisfaction of being able to improve others lives, so that they are able to go about their errands without any trouble. I have made lovely friends as part of this scheme too. I would recommend this to anyone! Thank you Richmond AID, for such a life changing experience!"

Six months after meeting Basim, here we stand beneath the great glass-roofed court of the British Museum, fulfilling an ambition he had spoken of in our first meeting. Lauren and Basim chat about an upcoming trip to Greenwich whilst glancing over the museum map looking for Ancient Mesopotamia. In this moment I realise, as I prepare to pass Richmond Buddies into the capable hands of our new Buddy Scheme Coordinator, that I am hugely proud of what Richmond Travel Buddies have achieved so far and excited about its future.– **Lewis Garland**

Hi! My name is Amanpreet (Aman for short) and I'm the new Travel Buddy Coordinator. As Lewis ends his article with a real sense of pride in the achievements of the buddy scheme, I am reminded of the immense cumulative power of seemingly small acts. I am SO excited to be taking on this project; as a young person, gaining the ability to travel independently unlocks a world of possibility. As a volunteer, the personal and social gains of sharing ourselves with others can contribute more to our lives – and to our world - than we bargained for. What an absolute privilege to be a part of something with such wonderful possibilities.

To find out more about getting a Travel Buddy or volunteering for Richmond Travel Buddies please contact A.Ahluwalia@richmondaid.org.uk

Summer Events

RAID Drama Workshops

This summer Richmond AID, in collaboration with NCS with the Challenge, are putting on free Drama Workshops for young people under the age of 25. Workshops and performances will take place in as yet TBC venues in Kingston and Richmond on:

- **29th-30th July in the afternoon**
- **19th August, 12 (Midday) 3:30pm**

If you're interested please e-mail Aman or Jess:

a.ahluwalia@richmondaid.org.uk
J.lawn@richmondaid.org.uk

Otakar Kraus Music Trust (OKMT)

13th June: Drum workshop from 12 (Midday) - 6pm. Church Road (Twickenham Club) - part of Learning Disability Awareness Week

19th June: OKMT Music School Performance to end Mencap week at Langdon Centrem 4pm- part of Learning Disability Awareness Week.

18th July: Music School/OKMT Summer Party at UR Church, Twickenham Green

ADHD group evening pub social

July 21st, **7pm-9pm**, The Slug & Lettuce. 22-28, High Street, Unit 6, Charter Quay, Kingston, KT1 1HL ADHD Richmond in partnership with Kingston Carers ADHD Group are organizing a pub social evening. Come along for an informal chat. Although mainly for parents and carers of those who have ADHD, the doors are open to all! To confirm your attendance email ADHD Richmond: info@adhdrichmond.org

Live in Ham? Want to know more about the Kingston Aviation Factory which built Sopworth and Harrier planes? Find out more at Ham Library on 10.7.15 at 11.00 – with refreshments. Rsvp to f.berry@richmondaid.org.uk

RISE
Richmond upon Thames Inclusive Sport and Exercise

Canoeing

A new weekly inclusive canoe club for adults aged 16 and over.

The session is open to individuals of all experience levels. If you have specific support needs please contact us before the course to arrange for appropriate support where possible.

Mondays

10.00-11.00am

1 June- 6 July

Course cost: £45.00

Participants must be able to swim and be confident in water.

LOTTERY FUNDED | SPORT ENGLAND

Royal Canoe Club

Trowlock Way, Trowlock Island, Teddington TW11 9QY

For more information, or to sign up, please contact the Sports Development Team on 020 8831 6181, email: rise@richmond.gov.uk

SPORTS DEVELOPMENT

2000RISE

Richmond NAS Coffee Morning- in association with Me Too & Co

- **Friday 19th June, 10.30am-12pm**
- **Friday 17th July, 10.30am-12pm**

St. Stephen's Crossway Centre. 306, Richmond Road, East Twickenham. TW1 2PD creche facility available - places need to be booke. Email info@metooandco.org.uk or phone 07946 646033

RISE
Richmond upon Thames Inclusive Sport and Exercise

Dance and Drama

Mondays 13 April - 20 July (not 4 or 25 May), 6-7pm

Hampton Sports & Fitness Centre, Age range: 16+yrs Course cost: £46.80

Tennis

Mondays 20 April - 13 July (not 4 or 25 May), 6-7 pm

Barn Elms Sports Trust, Age range: 16+yrs Session cost: £5.00 R/C, £5.50

Swimming

Wednesdays 1-3pm

Teddington Pools & Fitness Centre

Age range: 16+yrs Cost: £1

Multi-Sports

Saturdays 25 April - 18 July (not 30 May)

10.30-11.30am

Shene Sports & Fitness Centre

Age range: 11 - 25 yrs, cost: £4.70 R/C, £5.40

...and many more activities!

If you would like to attend any of these activities or for more details, please contact the Sports Development Team, on 020 8831 6181 email: rise@richmond.gov.uk

www.richmond.gov.uk/RISE

And finally, RAID are bidding another fond farewell, this time to our friend, colleague and resident thespian Lena Vantol. Lena has been Richmond AID's Children and Families Coordinator for thee years, making a huge difference to families she has worked with. In the words of one parent: "Lena…was able to let me talk, listen to my needs and unjumble me! Lena directed me to the appropriate organisations and helped fill out forms that were required. Her knowledge and advice are priceless" and another "Lena was very supportive, explaining the process step by step very clearly. She made a very nervous mum relaxed"

Richmond AID
Advice and Information on Disability

OUR SERVICES

ADVICE SERVICE Advice, information and guidance for disabled people, carers and professionals on subjects including housing, benefits, aids and adaptations, support services and more. This service is staffed by specialist Advisors and is available by phone, appointment, drop-in, email and SMS/text.

BENEFITS SERVICE Expert help and support from a team of Benefits Advisors with form-filling and advice on all aspects of benefit claims, appeals and general queries.

CHILDREN AND FAMILIES We support families with disabled children and ensure they are claiming and accessing all they are entitled to, and have information about services and activities.

YOUTH SERVICES Richmond AID has a number of services that support young disabled people moving into adulthood.

’Stepping Stones’ is a work experience project in the Richmond borough for young people with additional needs between ages 14 and 17.

We have two ‘Buddy Schemes’ in both Kingston and Richmond boroughs. These schemes match young disabled people (aged 14 to 25) with volunteer ‘Buddies’ who support the young people to access activities and opportunities in their local community.

EMPLOYMENT SUPPORT Helping disabled people into work, training or education. We offer one-to-one advice and guidance and a weekly job club supported by a team of specialist staff and volunteers. You can also access our range of toolkits and training for employers online.

SPADE GARDENING SPADE provides a gardening service to disabled and older people in Richmond Borough. This popular project is staffed by a team of committed volunteers.

COMMUNITY INVOLVEMENT Richmond AID promotes the interests of disabled people through various forums, meetings and groups. We have a range of opportunities for disabled people and carers to feed into shaping local services and the services of Richmond AID.

BUSINESS SERVICES We have a range of Disability Awareness and Employment training and we offer advice and support to employers on issues relating to disability and equality. We have experience working with large and small local businesses, including Kew Gardens and Richmond Housing Partnership.

VOLUNTEERING We have lots of volunteering opportunities, from advice, administration, editing and media to gardening and access work. Excellent training and support is provided for volunteers in a warm and friendly environment.

Other Formats: Disability News is available in a larger format or on tape. Please contact the Advice Service on 020 8831 6070 or text 07894 215 835.

Disclaimer: Although Richmond AID checks all information carefully, it cannot accept legal liability for any inaccuracy or omission. Richmond AID does not recommend any product nor do the views expressed in Disability News necessarily represent the views of the organisation.

INDEPENDENCE
AND CHOICE FOR
DISABLED PEOPLE

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