



Explaining Puberty

Learning the rules

Changing
perspective

Living with
Moyamoya





**Down's
Syndrome
Scotland**

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Charity number SC011012

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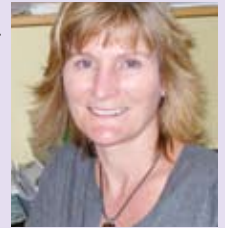
Articles in this newsletter reflect the opinions of the contributors. These are not necessarily the views of Down's Syndrome Scotland.

Down's Syndrome Scotland is a partner organisation in the Scottish Consortium for Learning Disabilities (SCLD).

Cover photo: David and Claire enjoying his 9th birthday outing

**Don't forget
Down's Syndrome
Awareness Week
8th - 14th June**

Lou Marsden
Senior Information Worker



Editorial



Over the years, a common debate in the charity has been the fact that we often focus on people with Down's syndrome who are very able, to promote our organisation and raise awareness. Recently, a member of our Training Team, Natasha was

featured on STV's 5.30 show; a short film of Natasha at college was followed by a studio interview in which she talked about her experience of having Down's syndrome. Natasha was great, taking it all in her stride and if she had any nerves, she kept them well under control. I am sure that she made many viewers reassess their opinion about Down's syndrome.

I firmly believe that we have to show the achievements of our members with Down's syndrome in order to challenge common misconceptions and continue to develop a positive public perception. Many newspaper articles still use negative and emotive statements such as 'suffers from' and 'mental age of' and we have to ensure that the public have the opportunity to see that these statements are not truly reflective of the lives of our members.

However, it is equally important for us to ensure that our members with Down's syndrome who have higher support needs are represented by the organisation and that their needs influence the areas of work that we undertake. Every child and adult with Down's syndrome is an achiever, whilst some accomplishments may be more news worthy than others; every success however great or small is significant.

We are establishing a focus group of parents whose sons and daughters do have higher support needs, in order that we fully understand the current issues affecting their lives and that their ideas can help to direct our future work. Please give me a call if you would like to be part of this group, which will have its first meeting in June.

*Regards
Lou.*

“he has the same interest in the opposite sex as any other heterosexual man of his age”

Pandora Summerfield
Chief Executive



Comment

Did you see the piece on BBC3 recently about Otto Baxter and his mum Lucy? It certainly provoked lots of discussion amongst the staff team here!

Otto is a man on a mission. At 21 years old, he has the same interest in the opposite sex as any other heterosexual man of his age. “I’m on a mission to find a girlfriend” he says “my reason is, I want to have sex. I’m looking for girlfriends everywhere.” The telly piece followed Otto as he pursued his mission, in nightclubs, at a singles salsa evening, at a dating agency for people with learning disabilities and over lunch with a female friend who also has Down’s syndrome. We watched as Otto chatted up women in these differing situations; with very little inhibition he would declare his love for the woman he was dancing with and ask her to be his girlfriend, the camera closely watching her face for her response. No doubt, careful editing of the film by the programme makers made this look as stark as possible. It was very noticeable how the female friend he had lunch with was just as forthright with him, unlike the other women he propositioned. Much of our discussion at work focussed on how and what Otto had said to the women he met and how it was only the woman with Down’s syndrome who told him straight how she felt. She knew he wanted a relationship with her, but she also knew she wasn’t ready and so wasn’t prepared to move

their relationship on from being just friends. What came across very strongly to all of us was how Otto was on the hunt for sex rather than a relationship/love and that this somewhat predatory approach was having exactly the opposite effect to that which he sought.

His mum, Lucy had also taken up many column inches in a variety of newspapers, where she talked about how she was prepared to pay for Otto to travel to Amsterdam and access the services of a prostitute. As you can imagine this prompted a mixed response from the public; some felt she was exploiting her son for her own media profile and that she was not helping him to realise that some people in our society go through life without the experience of an intimate, sexual relationship. Others felt she should be applauded for instigating a long overdue debate about a specific aspect of the expectations of people that society is now embracing rather than shutting away out of sight.

Puberty and sexuality are things that all parents of a child with Down’s syndrome will face at some time and we hope that the articles in this edition will help.

Pandora.

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Strangers

Explaining Puberty

by Karen Garrott
Family & Young People's Officer

The majority of children and young people with Down's syndrome go through the same developmental processes as their peers, including that stage, dreaded by many parents, puberty.

Young people with Down's syndrome will use the same tactics as any other teenager to help them gain an element of control over their own lives, including manipulating others to get what they want.

Often by the time a young person with Down's syndrome reaches puberty they have just managed to gain an element of independence with daily living skills. It can be a worrying time for parents as they begin to notice changes in their son or daughter's body. The privacy issues that surround these changes, both at home and at school need to be addressed. It is helpful to discuss these concerns with the school so that issues surrounding puberty can be built into the Individual Education Programme (IEP).

As a young person with Down's syndrome begins to go through the changes that occur during puberty, like any other young person they will begin to exhibit many mood swings. This is due to the hormonal changes that begin to occur in the body, even as early as 7 years old. This can be a very confusing time for young people with Down's syndrome. It is important that they are supported both at home and at school to understand the changes that are beginning to happen in their

body as well as the changes that will occur over time. This can be a challenge when the young person may be a chronological age of 12 years old but emotionally still be at a developmental stage of a younger child. It is important that this is taken into account when considering what a young person will understand.

You will find that you have to explain puberty many times.

The 'green hands and the red hands' (pictures one and two) are a great way of explaining where it is ok to touch either yourself or others in public places. It can be turned into a fun game and because it is very visual it is a great way of helping the young person to understand social behaviour. You can expand the topic by asking the young person questions or explaining where it would be acceptable to touch certain parts of their body.

The Hug circle (picture 3) is a way of helping the young person to understand acceptable ways of approaching people. It is also a very important way of explaining the dangers of talking to strangers. The young person can colour in the circle before putting the word cards onto the different areas of the circle. It can then be put up either in the classroom or the young person's bedroom

“Marie was very aware that something had happened to her.”

Living with Moyamoya

On 30th May 2008, I had a telephone call from my daughter Marie's school informing me that she wasn't well. When I arrived to collect Marie, I noticed that the left side of her face looked different and that she was finding it very difficult to speak. As I helped Marie to walk, she needed to lean very heavily on me and we didn't get very far before I had to help her to sit on the floor and call an ambulance.

At the hospital Marie had no feeling in her left side and couldn't form her words. She was incontinent and I had to assure the hospital staff that this was due to whatever was happening to Marie, not because she had Down's syndrome as they had assumed. A CT scan showed that there was damage to Marie's brain possibly caused by Epilepsy. During the following week Marie slept for long periods, could not walk, was incontinent, could not form words and could not feed herself. Marie complained of a pins and needles sensation in her left side, her left hand faced outwards whilst her left foot faced in. Marie was very aware that something had happened to her. At the end of the week she had a MRI scan at Stirling, this revealed that the damage to her brain was the equivalent of a head-on collision.

I spoke to a local GP who mentioned the possibility of Moyamoya and I did some research about the disease and it seemed to be the likely cause, however the hospital did not agree although they did confirm that Marie had suffered two strokes. Finally, after four months, an Angiogram confirmed that it was Moyamoya which is a rare and progressive disorder caused by blocked arteries in the base of the brain (basal ganglia). It affects mainly children but can also occur in adults. The first symptom is usually a stroke or recurrent transient ischemic attacks (TIAs, also known as mini strokes). The attacks often result in muscular weakness or paralysis affecting one side of the body or seizures.

Marie lost feeling in both her left arm and leg and for a while spent most of the time in her wheelchair. Marie receives physiotherapy and speech therapy extensively, due to the decline of her mental and physical abilities

by Michelle Lochrie,
parent, Stenhousemuir

caused by her strokes and TIAs. In addition, Marie developed dysphagia which means that her muscles for chewing and swallowing have been weakened by the strokes. This was very worrying as chest infections can occur when food and liquids go down the wrong way and meant that Marie had to eat a soft diet. However, thanks to a spray which helps her to create saliva, Marie can now eat normal foods and feed herself.

The first few months were extremely worrying and difficult because Moyamoya is so rare, it took 4 months to diagnose. However there is recognition that the sooner it is treated the better the outcome for the patient. Treatment is not widely available and involves surgery to suture the affected arteries and encourage new blood flow to the brain. As with any surgery there is a risk, but I understood that without it, Marie's future looked very bleak. I found out that there is a specialist working in Newcastle and was able to persuade the consultant at Stirling to refer Marie.

Marie had her first operation in April and it was a success with the new blood vessel working. Further tests will be done in the near future to assess whether a second operation on the right hand side will be carried out.

Michelle has spent many hours trying to find out more information about Moyamoya and wanted to draw it to our members' attention because there is a very slightly increased risk for children with Down's syndrome, particularly girls, to develop Moyamoya.

Moyamoya is a very difficult medical condition to deal with. Michelle saw her bright, young daughter lose some of her independence skills and mobility. However, the family did not just accept that this was how it was going to be, they worked hard with Marie to encourage her to regain her skills and to ensure that she remained a confident young woman. Even before her operation, Marie was recovering skills and with a mum like Michelle to support her, we are sure that she will continue to make good progress.

£ Fundraising

Hospital Saturday Fund



Down's Syndrome Scotland was one of 24 Scottish-based charities to receive a donation from the Hospital Saturday Fund at an event at Glasgow's City Chambers on 24 February. Pandora Summerfield accepted the £1,000 donation.

Popular television presenter Carol Smillie also accepted a donation on behalf of Yorkhill Children's Foundation. She spoke of her delight at supporting the event, where £32,000 was donated to 24 Scotland-based medical charities, hospices and hospitals.

"In a time when money is tight and charities are struggling it's great to see this level of support from the Hospital Saturday Fund. "It's nice to know that these donations from the Hospital Saturday Fund are going to local and national projects in Scotland and the money will be spent here."

The event was hosted by the Glasgow City Council, with Bailie John McLaughlin presiding.

Eggstraordinary!



Our thanks to Michele and Samantha from Scottish Gas who brought a car load of Easter eggs which we circulated far and wide. Pictured with our two tasters Sam and Rachel.

Paris Marathon



Our congratulations and thanks go to Allyson MacColl who raised £2,500 by running the Paris Marathon whilst modelling our new running vests!

Ayrshire Branch



Bob Gordon sends a wee bit of news from the Ayrshire branch.

'I have attached a photo of a cheque presentation for a donation we received from a chap called

Graeme Feldman (the young one in the back row). He raised £605.45 from a sponsored Bungee jump from the Transporter Bridge in Middlesbrough which he carried last August and frankly I think he is "aff his heid". Graeme has a sister called Karen who has Down's Syndrome (front row) and lives in Maybole in Ayrshire.

We held a very successful fundraiser function called stars in Disguise on the 21st of March in my local village hall allowing people to make a complete fool of themselves and raise a few quid in the process. Money raised went towards our weekend to the Arran outdoor centre for teenagers and young adults with Down's syndrome in April.'

Bupa 10k



Thanks to Alan Davidson who completed the Bupa 10k and raised £388.21 for us.

Learning the Rules

Learning about sexuality and the mechanics of sex is, as Karen has pointed out, an important part of growing up and taking your place in the adult world and there are many resources available to help young people with Down's syndrome learn. What is much more difficult to understand and master are the 'rules of engagement' with other people.

I remember some colleagues from a housing association developing a course about sexuality and relationships for their tenants. After very little response to their flyers, they were told in no uncertain terms that 'we've learned about that, we know what to do, we just need to learn about how to meet new people'. The course content was quickly changed into what became known as 'chat up training'. (Incidentally, as a follow on from this course, they started a dating service, the best advert being; 'fun and friendly guy seeks lovely lady for sex, possibly relationship!')

Seriously though, we recognise that young people with Down's syndrome don't tend to learn through the more informal routes of watching their peers, therefore they need to have concrete information so that they gain a clear understanding about what is and is not appropriate behaviour when meeting new people.

“young people with Down's syndrome don't tend to learn through the more informal routes of watching their peers, therefore they need to have concrete information”

by Lou Marsden - Senior Information Worker

In my experience, young people with Down's syndrome may not be aware of age differences between themselves and other people leading them to make inappropriate overtures to someone who is old enough to be their parent. Wearing a wedding ring is a clear sign that the person is off limits, however a young person with Down's syndrome may not think to check this and again risk embarrassment by trying to flirt with that person.

It is extremely difficult for people with Down's syndrome to understand when someone is politely trying to give them the brush off but could be quite devastating for them if the person had to be more forceful in their rejection. It is well documented that people with Down's syndrome respond very poorly to failure and we need to ensure that they are given the right support and information in this crucial aspect of their lives.

As usual, it falls to parents to teach their young adult about behaving in a socially acceptable way and encouraging them to go out and develop friendships and relationships. Young people need to know about meeting new people and making friends and what the boundaries in the early days of a friendship are. In her book 'People Skills for Young Adults', Marianne Csoti suggests that discussion takes place using the following questions; What can you do to get to know this person? What could go wrong? What should you do to create a good impression? What will the other person need to do to make a good impression? This helps the young person to practice beforehand and talk about different scenarios that might happen.

Farewell and Thank you to Sheenagh

The next issue is how young people with Down's syndrome get to meet new friends. Parents are often called upon to provide transport and then have to take a back seat or go off and amuse themselves for a few hours until the social event has finished. Most parents would not wish to be responsible for their son or daughter's social life but many young people with Down's syndrome would miss out if it wasn't for their help. Debate continues about whether social events specifically for people with learning disabilities are appropriate given the inclusion agenda, however I understand that Enable Scotland's monthly disco is always full! People need access to a variety of social activities in order to have a chance to meet all sorts of other people.

Last year Enable Scotland in partnership with C-Change and Altrum set up Dates-n-Mates. This dating agency provides matched dates and activities to support people to make friends and perhaps relationships. Activities take place on a monthly basis in the Glasgow area and membership is open to anyone aged 18 or over with a learning disability. A fantastic launch party was held and the service is providing people with learning disabilities the opportunity to take part in a wide range of activities and to be supported and encouraged to make new friends and possibly develop a special relationship. It is hoped that Dates-n-Mates will be rolled out across Scotland over the next 3 years; there is clearly a great demand out there.

If you would like more information about Dates-n-Mates contact 0141 418 7147.

People Skills for Young Adults by Marianne Csoti is available to loan from the library.

Sheenagh Hardie has been a valued volunteer at the office for the past 10 years but is now leaving us to concentrate on her other work commitments. Sheenagh undertook a great many tasks whilst working with us and was particularly interested in helping us to create resources.

Everyone enjoyed the chance to wish her well at her leaving do in May. We wish her a very happy future.



“Willie was content with company, content with himself and untroubled by life”

Changing Perspective

Fifty years ago in Glasgow people who had Down's syndrome were called derogatory names. They certainly were not integrated and were only seen when they travelled on grey buses to whatever was their daily destination. The term special school in the 1950s and 60s did not denote anything positive, but I realise now that this was a form of eugenic apartheid.

My first experience of a boy with Down's syndrome was in 1956, I was aged about six and he would come around the school playground fence during morning or afternoon break and bellow at us. We shouted abuse at him and he bellowed back. Sometimes he would have a stick or a length of runner hose which he swished in anger and frustration at us. My view at the time was be careful, he looks dangerous.

I met Willie, a man with Down's syndrome in his 20s or possibly 30s, when my gang were aged 12. Our world was defined by how far you could ride your bike, which gave us a territory of 50 square miles of city and countryside. The world was our oyster. Willie had a bike too; his was a black classic single cog with upright handlebars, old-fashioned brakes and full mudguards like a policeman's bike. We had colourful bikes with drop handlebars, 10 speed gears, complex cantilever brakes and no mudguards at all.

Willie was dressed like a man of fifty, short-sleeved jersey over a long-sleeved flannel shirt of grey or brown and a tweed jacket and flat cap. He wore grey flannel long trousers and needed bicycle clips to guard them from his bicycle chain. We wore sporty clothes, short trousers, short-sleeved shirts and no hats! The differences were obvious.

by Brian MacIver

Willie was slim; he had calm shining eyes and a ready smile. He simply sat near us on several occasions as we rested up after a bike ride, in a field near our homes. On each occasion he came and sat a little closer until we had gotten used to him.

'Hiya, what's your name' was finally asked. 'Willie' he replied. At that age, Willie has a double meaning 'big Willie, wee Willie or Oor Willie'? we asked with cackling laughter. 'Just Willie' he replied in innocence. 'Ok Willie, want to cycle to the park with us?', 'yes please' he replied.

And so this man with Down's syndrome was accepted into the gang. During the 2 months of the summer holidays we saw Willie many times. He cycled with us, listened to us and sometimes spoke of himself. He lived at home with his family. He could help with gardening and earned money from time to time working in people's gardens. He was a gentle, quiet man. Willie was content with company, content with himself and untroubled by life.

We never saw Willie after that summer, our summers changed to more grown up pursuits, from bikes to scooters, from boys to girls, from days to evenings. So, fifty years on I can't remember the faces or names of the old gang, but I still remember Willie.

Brian wrote to us after being inspired by the recent Shifting Perspectives exhibition, he is uncle of Joe whom he describes as 'a wonderful young man

Notice Board

Parent's Focus group

We are establishing a focus group of parents whose sons and daughters have higher support needs, in order that we fully understand the current issues affecting their lives and that their ideas can help to direct our future work.

The first meeting will be on Friday 19th June, 10.30 – 12 at the office, Balgreen Road. If you would like to be part of this group please contact Lou on 0131 313 4225 or email lou@dsscotland.org.uk

Dear Down's Syndrome Scotland

Why is it so difficult for people with learning disabilities, who need support when using transport or to access social activities and events? I was in touch with The Playhouse recently when I found out that people who use wheelchairs were allowed to take their carer in for free while people like my daughter Emma were not. I had written to the General Manager and got nowhere but eventually I phoned the Wheelchair phoneline and with their intervention people like Emma now get the same concessions as those who use wheelchairs.

Helen Bryce

New website launch Monday 8th June

Work continues on the development of the new website which will 'go live' on Monday 8th June as part of Down's Syndrome Awareness Week. If you have photographs or personal stories that you are willing to publish on the site, please send them to lou@dsscotland.org.uk

At a recent Keycom open day I was chatting to a charity called Pass IT On who sell refurbished computers. I thought this could be of interest to families who are looking to buy computer equipment inexpensively.

They hold regular public sales in Edinburgh on the first Saturday of every month.

Please see their website for more details
www.passitoncomputers.co.uk

Kind regards, Sheila

Causeway Prospects

Ivy Blair has recently been appointed as the first Scottish worker for Causeway Prospects, a small non-denominational charity supporting churches who want to be more inclusive in their welcome for people with a learning disability.

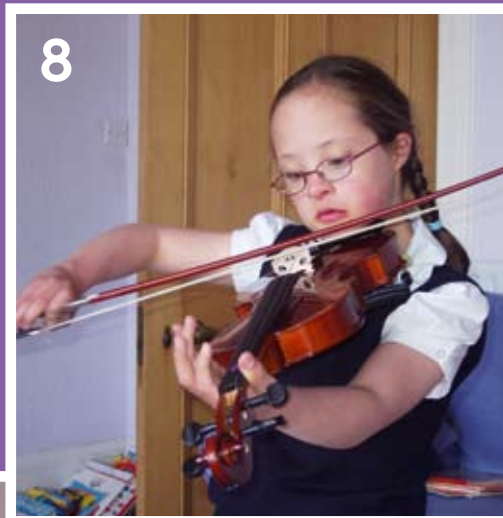
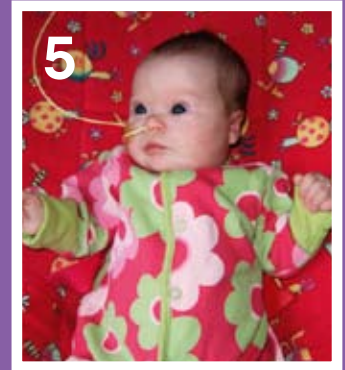
This work is done by

- Raising the awareness of the needs of people with a learning disability
- Offering support and resources to churches, groups and individuals
- Developing opportunities for people with a learning disability to fully participate in the life of their local church.
- Providing training opportunities.

Currently there are 13 local groups attached to churches in Scotland from Aberdeen to Ayr and potential for many more. Groups have their own character and way of doing things to reflect their local community but using simple language, learning together, singing, friendship and fun are core to all groups.

For further information of the work of Causeway Prospects in Scotland please contact Ivy Blair 07827 939 520 ivyb@prospects.org.uk www.prospects.org.uk

Summer gallery



- 1 Marcus
- 2 Central branch activities group
- 3 Claire and her new nephew
- 4 Jennifer

- 5 Baby Emma
- 6 Alison's 21st birthday limo ride
- 7 Jonathon the party animal
- 8 Olwyn
- 9 Aaryan



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