ISSN: 1366-0209

December 2008
No. 39

A-T Society News

The Ataxia-Telangiectasia Society

Ataxia-Telangiectasia is a rare, genetic, neurodegenerative disease which affects many parts of the body and causes severe disability.

The A-T Society was established in 1989 and is committed to helping, supporting and advising families affected by A-T. The Society aims to alleviate the distress and suffering that A-T causes by working to improve quality of life now and in the future. We do this through funding research, supporting families, working to improve clinical management, and raising awareness.

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Editor’s Comments

Once again, many thanks to all contributors. The copy date for the next issue is 1 April 2009
Please send comments, ideas, articles and pictures to the newsletter editor:

Beatrice Prokofiev
17 Park Manor, London Road, Brighton, East Sussex, BN1 6YP
01273 746462

email b_prokofiev@yahoo.co.uk

If you would like to receive this newsletter by email as a pdf file, please let us know.

A-T Society
IACR-Rothamsted
Harpenden, Herts AL5 2JQ

tel 01582 760733 fax 01582 760162
atsociety@btconnect.com
website: atsociety.org.uk

Registered Charity No.1105528

Cover picture:Glasgow Men’s 10K Run
From left to right, with Maria and Ben: Martin Doherty, Joe Farrell, Greg Starling, Sean McLaughlin

News from the Society

I am delighted to inform you that following an application by the A-T Society and Nottingham University Hospitals NHS Trust, the Health Minister has decided that from 1st April 2009 the A-T Clinic, Nottingham, will be funded on a national basis by the National Commissioning Group for Highly Specialised Services on behalf of the NHS.

This will enable us to develop the clinic and as a result you will see some changes:

- Each patient will be offered a regular review appointment every two to three years.
- Instead of being invited to a one day clinic, patients will be invited for a two day clinic and will be able to stay overnight at the popular Patient Hotel, not on a hospital ward.
- Moving to a two day multi-disciplinary clinic will give you more time with each of the clinicians and therapists and for any necessary tests and investigations.
- The frequency and number of clinics held per year will gradually increase.
- The clinic will also include AOA1 patients and those with "A-T Like" disorder.
- Referrals for newly diagnosed patients may be made through the Society or directly to Dr M. Suri, Consultant Geneticist, A-T National Clinic, Nottingham City Hospital.

Bear with us please as it will take a little while for the new arrangements to settle down.

The Papworth Clinic will continue to run alongside the Nottingham Clinic and take referrals for those over the age of 16.

This marks a significant step forward in advancing the clinical management of A-T and therefore the quality of life and length of life of all those who have the condition.

My thanks go to all those who worked so hard on the application namely all of the clinic team including Professor Taylor, University of Birmingham but in particular Dr Mohnish Suri and Vincent Poupard.

Soon we will have a new website! Jo Child has been working for several months now updating the content and the project is presently with a web designer. We are very excited as it will look very professional, colourful and upbeat. Our thanks go to Jo for her steadfast dedication and commitment not only to this task BUT also for the newsletter as sadly this will be Jo's last edition. She will be handing over to Beatrice Prokofiev whom some of you may already know as her brother Rupert has A-T.

Jo has looked after the newsletter for eight years and made it into a publication that we are all very proud of. She will continue to remain as a trustee.

We are very pleased to welcome Dr Emma Ross who was co-opted to the board of trustees in June. You can read Emma's profile on page 5. Welcome to both Emma and Beatrice. It is lovely to have some young blood on board. Next year we celebrate our 20th Anniversary. We began in 1989 when a group of 13 families came together in Birmingham and decided to form a charity to raise funds for A-T research and to support each other.

Wouldn't it be wonderful if there was no need for the Society in 20 years' time because a cure has been found for A-T? Help us get there. If you do not financially support us on a regular basis already please do so. Give us the tools to get on with the job and help make us redundant by 2029 if not sooner. Thank you.

Maureen Poupard
Hon. Secretary

Is the recession affecting the A-T Society?

As you are aware, the UK is now entering what is technically a recession.

We, like many other charities, are experiencing a falling-off in our income but with no corresponding reduction in the calls on our services. In fact we see signs of increased demand. It is important, therefore, that our income from fundraising compensates, at least in part, for the reduction we are experiencing in donations from grant-giving trusts. Please continue to support us in whatever way you can.

No amount is too small (or too large!) to make a difference.

Research Update: Immune Study

At the Family Day in May 2008, Dr Liz McDermott spoke about a study of immunity in people with A-T.

This is a summary of her talk.

Individuals with A-T can have problems with the immune system but this is very variable.

We used information gained from the Nottingham A-T Clinic to try and understand better the problems with the immune system and why some individuals had more problems than others.

We looked at the infection history, immunology blood tests and type of mutations in 80 patients who had visited the clinic over the last few years. We found that those individuals who had mutations resulting in no ATM protein activity were more likely to have recurrent chest infections and poorer immunology tests.

For example, individuals with mutations resulting in no ATM protein activity were more likely to have low/undetectable IgA levels (one type of immunoglobulin or antibody), low pneumococcal antibody levels (pneumococcus is a common bug involved in chest infections) and low T lymphocytes (these are cells involved in the organisation of the immune system).

This is the first study in A-T looking at the immune system and mutation-type. Identifying and treating any immune system problem quickly reduces the risk of developing long term damage from repeated infections such as lung disease from repeated chest infections.

This knowledge should help identify those individuals most at risk of immune system problems who therefore require early assessment by an immunologist.

> *This is the first study in A-T looking at the immune system and mutation-type.*

This study was recently published in Clinical and Experimental Immunology, August 2008. The work was carried out by Emily Staples, A Reiman, P J Byrd, Susan Ritchie, Malcolm Taylor, Graham Davies and myself.

Dr Liz McDermott
Nottingham University Hospitals
NHS Trust

In Memoriam

We are very sorry to announce the deaths of two young people with A-T.

Phillip McCann died in May.
Ryan Lecky died in September.

We send our condolences to their families.

We now have a Memory Book of children with A-T who have died.
If anybody would like a copy please contact Maureen, at the A-T office, on 01582 760733.

NewTrustee

My name is Emma Ross and I am a research lecturer at Brunel University in London.

My first involvement with the A-T Society was through my sister, Michele, who had AT. I remember the Society being a big and important part of our lives as my sister grew up with the condition. Sadly, Michele passed away in January 2005, aged 29.

It gives me great pleasure to become involved with the A-T Society once again, in the role of Trustee. Along with other Trustees, I hope to develop the A-T research strategy and promote a diversity of research into A-T, such that we can not only make advances medically, but also in non-pharmacological treatments and interventions, and into improving quality of life for those with A-T.

Because my research interest is human physiology, in particular, neural and muscular physiology, I also hope to conduct some of my own research with A-T patients over the coming years. I look forward to meeting as many of you as possible in the future.

“Carers can’t afford to be ill” - Carers Week 2008

The Neurological Alliance promoted national Carers Week in June along with 10 national charities. This year some of our families were invited to share their thoughts and kindly gave an insight into their experience of being a carer.

The aim of Carers Week is to recognise and celebrate the contribution made by carers, to campaign for better support and services for carers, and to promote policies and best practice that can improve carers’ quality of life. The focus of Carers Week 2008 was on reminding carers to look after their own health and well-being, and how important this is for them and the person for whom they care.

In parliament the Secretary of State for Health was urged to promote the local implementation of the National Service Framework for long term neurological conditions and to recommend the commissioning by Primary Care Trusts of specialist nurses for neurological conditions. These specialist nurses were described recently by the Parliamentary Under-Secretary for Health Services as ‘absolutely critical’ to quality care.

Mrs Wills and Paula Wills (mother and sister respectively, of Alexandra who has A-T) were invited to attend the parliamentary reception on 11 June 2008. Anne Begg MP, Carers Week Parliamentary Champion, opened the speeches. Those present - carers, MPs, Peers and invited charities - were given an insight into the need for support for carers and the importance of neurological nurses and access to them, and the work that is going on within parliament to support this.

As a parent or guardian it is easy to forget that some of the role provided for a child with A-T is that of a carer. Thank you to those who helped promote Carers Week and to all who submitted their thoughts.

Support and information for carers

CARERS UK **www.carersuk.org**
0808 808 7777
Counsel & Care **www.counselandcare.org.uk**
0845 300 7585

Picture*: clockwise from left - Dr Elizabeth Harrison, Chair of Ataxia UK; Mrs Wills; Lian Yarlett, representing the A-T Society; Paula Wills; Anne Begg MP; Alecia Yarlett.*

A much needed lift

Catherine, Paula and Ian at Vitalise

Vitalise Holidays, Summer 2008

In the summer, 14 young people with A-T had a week's holiday funded by the A-T Society. This was the first time we'd organised a group holiday and it was a huge success.

Vitalise is a charity providing holidays for disabled people, offering activities and outings, supported by volunteers and professional carers.

Catherine, Emily and Russell were among the seven who went to Nottingham and here are some of their enthusiastic comments:

Catherine:
"It was a great opportunity to meet and talk with other people of similar ages as well as doing things together. The carers and volunteers made the holiday extra special by involving and encouraging us to participate in activities. This was a much needed break for me as well as my parents – it gave me a much needed lift."

Emily:
"The Skylarks holiday in Nottingham was very busy but fun. I thought my volunteer was very good and we did something nearly every day. It was made better by the fact Catherine was there and the other people with A-T."

Russell:
"I was very nervous when I arrived but excited as this was my first holiday away on my own for a long time with people my own age. But very soon I settled in and my stay was brilliant. I was looked after very very well as everyone was really kind and helpful. All the things we did were great and I really enjoyed the week. Thank you for the chance to go on this holiday and a special thanks to my helpers who were great."

Rupert and Natalie had positive things to say about Sandpipers in Southport, where they spent their week:

Rupert:
"It was nice to have a holiday with some activities planned (not too over crowded with them) and almost completely all young people.

It gave me independence - a different sort of independence from Uni where I'm really on my own – because there were plenty of people in the building but I could choose what I wanted to do and always find there were people to help me do them. I also enjoyed having enough free time so I could go to the cinema, swim in the pool.

So thank you for supporting me to go there."

Natalie:
"Thank you so much for arranging for me to go on the Vitalise holiday to Southport. I loved it; I had a great time. It was so much fun, I made loads of new friends and hopefully we're going to stay in touch."

Sandpipers, Southport

> *"Opportunities like this holiday at Skylarks and the A-T youth meetings are worthwhile things to do. It provides the opportunity to socially interact with other people, but it also helps to feel not alone, part of society. Thank you."*
>
> **Catherine**

Skylarks, Nottingham

Vitalise has five accessible Centres in Southampton, Cornwall, Essex, Nottingham and Southport.
www.vitalise.org.uk
0845 345 1972

Spotlight on Fundraising

Running, cycling, walking, dancing, playing music, organising coffee mornings, filling collecting tins - people have been raising money for the A-T Society in a wonderful variety of ways. In this edition of the newsletter we're putting the spotlight on our fantastic fundraisers who've been working hard, raising money, and - we think - having some fun too. It's thanks to their efforts that the Society can support families and fund research into A-T.

Coffee Break Money and CollectingTins

Thanks to Philip Horne and his colleagues at Morrish & Partners, Welwyn Garden City who regularly support us by making donations for their tea, coffee and biscuits at work. Also to Monica Horne, Harpenden who has a collection tin at home. She regularly brings us the contents.

Tributes in Lieu of Flowers

Ms Stender kindly remembered her recently departed friend Joan Holgate by sending a donation to the Society in her memory.

Golden Wedding

£85 was received in lieu of presents in celebration of Tom and Monica Horne's Golden Wedding Anniversary.

Bridgnorth Walk

Between them the Evans family, the Hughes family and Chloe and Josh Hand (pictured left) recently raised £1,510 for the Society on the 22 mile Bridgnorth Walk.

Team Leader Lloyd Evans said, "The walk starts from Bridgnorth in the heart of the Shropshire countryside and goes along the Ludlow Road to the village of Cleobury North and then up to the summit of Brown Clee Hill, before descending via the village of Ditton Priors back to Bridgnorth.Despite a strong wind and one or two blistered feet, our team finished the walk."

Many thanks to those stalwart walkers and also to Nick, Joy, Rachel and James Ferguson for their inspiration and support.

(Photo below: from left to right, Becky Hughes, Liz Hughes, Tim Hughes, Chloe Hand, Chloe Evans, Josh Hand, Lloyd Evans and Matthew Evans).

Coffee Morning

A Coffee Morning on International Ataxia Awareness Day held by Lian Yarlett raised £1,350!

Not Quite Written Off...

Staff at Tesco's, Chatham raised £220 by selling written-off goods.

Rattle tins

St John's Social Club, Luton collected £32.60 in their rattle tin and the customers of The Black Horse Public House, Great Missenden collected £62.13.

Plant Sales

Mrs D Hammond raised £70 through sales of plants including strawberry plants and hand-made cards.

School Show

Our Lady of Victories School in Putney raised £500 from their performance of "Hoodwinked".

Northern Rock Cyclone

Katy Luke (left, with Karen Biancardi, right) says:

"We were very lucky to have good cycling weather - fair, not wet or windy.

It was quite an event with lots of serious lycra clad cyclists who swooshed past us as they went on the long route - 100 miles, into the Borders. We took our 31 miles steadily and I was pleased that I had done quite a bit of training for it - no punctures and not too saddle sore at the end!"

Karen and Katy raised £335.

Golf Day

A Golf Day in aid of the Society at the Marriott-Tudor Seniors' Golf Club raised £1,300.

...and another Collecting Box

Mrs Wills made £50 from her collecting box.

Recycle4Charity.co.uk

The Recycle4Charity scheme is working very well and has raised over £500 this year.

Keep it up!

Ask us for more envelopes for relatives and friends.

Mayor's Chosen Charity

We are very pleased that Councillor Bert Pawle, Mayor of St Albans District Council, has made the Society one of three charities he will be supporting during his mayoral year.

The Mayor is pictured right with two young dancers from the show "A Measure of Scotch" (see next page).

Art Exhibition

An Art Exhibition organised by Original Art Solutions (www.orginalartsolutions.com) was held during Heritage Weekend, 13 & 14th September, in the Council Chamber at the Civic Centre, St Albans District Council with a private view on the Friday evening. Thanks to Councillor Bert Pawle, Mayor of St Albans, Ramon Anderson of Original Art Solutions (who donated a painting for the prize draw) and Alison Ord of St Albans District Council, £800 was raised for the Society.

Maureen Poupard (just recognisable in the picture below) says: "The photo was taken just before the private view so it all looks rather quiet but at least you can see the paintings in all their glory!"

A Measure of Scotch

On Saturday 11th October, the 125 dancers (from tots to grannies) of the Harpenden Hiel'n'Toe club jigged their way to raising more than £2,000 for the Society.

Giving the Boot to A-T

Jen, David and Doreen Owens manning the stall at the car boot sale, Winfrith Village Pre-school Fete.
After attending 2 car boot sales they made £215 for the Society. Not bad for cast-offs!

Thanks to the Owens family.

Wayne's Waddle and Kaid's Walk

£710 was raised by Jo Betts through "Wayne's Waddle".

Friends and relatives of the Betts family organised Kaid's Walk on Sunday 22nd June raising £1,282.08! (photo below).

Rocking the night away

Jamie Ion organised Blackhall Mill Rock Night gig with bands "Lay to Waste" and "Emily n Kathryn" on 28th July at Blackhall Mill Community Centre, Gateshead, and raised £57.75.

Cheque this...

The Lynn Family in Northern Ireland raised £552 as a result of several fund-raising events including a coffee morning and 2 sponsored walks.

Great North Run

Marion Wilson ran on our behalf taking just 2 hours 26 minutes 53 seconds and raising £175 to boot despite the weather. Thank you Marion.

No Women Allowed... at the Glasgow Men's 10K!

Eight men including four teachers from St Columba's High School, Gouroc, ran for A-T with a great show of comradeship from the teachers as they finished together in 1 hour and 10 seconds. The men are hoping to repeat their success next year but with a faster time.

The Glasgow 10K raised £3,076 in total. Left: Eric Begg, Barry Jones, Paul Gordon, Brian Gordon.

Glasgow runners with Maria and Ben: Martin Doherty, Joe Farrell, Greg Starling and Sean McLaughlin.

No Men Allowed...at the Adidas Women's Challenge!

5K Women's Challenge

Left to right: Harriet Goldsack, Sarah Welsh, Francesca Owens, and Fleur Loveless, together with Spencer Owens at the Adidas 5K Women's Challenge, Hyde Park, Sunday 7th September.

The girls raised £606.10 for the charity. Thanks girls, and we hope the blisters have well and truly gone!

Thanks also to Maureen Jenkins who raised £188 and Maureen Ainsworth who raised £86.

Have the adventure of a lifetime with a Charity Challenge

Do you feel like having a bit of an adventure whilst raising funds for the A-T Society?

Then look no further.

Working In partnership with Charity Challenge we can organise a range of challenging events. Whether you fancy treks, bike rides, mountain climbs, horse riding or white water rafting, you're sure to find something a little out of the ordinary to get the adrenalin going.

Charity Challenge operate worldwide, so your adventure can be as extreme and far away as you like. You can do a cycle ride from London to Paris, climb the dizzying heights of Mount Kilimanjaro in Tanzania, or experience a trek along one of the eight wonders of the world – The Great Wall of China.

The choice is yours.

Interested?

Then speak to Angie in the office. tel: 01582 760733

Are you embracing the world of online social networking?

Joining websites like Facebook and Myspace not only encourages social interaction, allowing you to build a personal profile, communicate with friends and join groups, but can also help raise awareness on important issues, giving everyone a space to voice their opinions and share their views. Joining online communities can be particularly useful for those who don't often get out to meet people.

Facebook currently has over 70 million active users around the world, with 8 million from the UK. Why not see what all the fuss is about and see how you can get involved?

Contact a Family online

Contact a Family, the charity for families with disabled children, has just launched its own group and profile on a range of social networking websites including Facebook, Myspace and Bebo. They're helping parent support groups do the same, as part of a project funded by the Department for Children, Schools and Families.

They've also opened a virtual advice service, on the innovative internet site called Second Life. 13 million people are registered on this site, where they can create a character and move and talk with others in a virtual 3D world. The online office is now open every Wednesday from 10am-4pm, staffed by a Contact a Family adviser. There you can access a wide range of publications and meet other 'avatars' (virtual people).

Some useful links:

www.facebook.com – build your own personal profile, send messages, find old friends and make new ones, join and create groups, share photos and videos. Easy to use.

www.myspace.com – Similar to Facebook, but also great for finding bands, sharing music and writing/checking out blogs.

www.youtube.com – search a huge database of videos; you can add them too.

www.bebo.com - Allows users to share photos with music, and blogs, and draw on members' White Boards.

www.secondlife.com - 3D virtual world where users can socialise, connect and create using voice and text chat.

Friends Email List

The A-T Society's Friends Email List is for anyone over the age of 12 who has A-T. Ages range from 13 to 52. Whether you live in the UK or abroad, you can contact anyone on the list and make new friends.

If you haven't already received a copy of this and would like one, then please contact Kay in the office.

Sex and Personal Relationships

Reproduced from Target MD, August 2008 issue, with the kind permission of the Muscular Dystrophy Campaign

Being diagnosed with a neuromuscular condition in adulthood, or attempting to come to terms with the progression of an existing condition, is emotionally challenging and raises many questions for those affected. Sex (actual or desired) and personal relationships (again, actual or desired) are a very important part of many people's lives but this is an area often ignored by professionals leaving individuals with many unanswered questions. In this article we attempt to address these questions and help people feel better able to discuss their concerns with those close to them and with any professionals supporting them.

Most (but not all) people with a neuromuscular condition have normal sexual function and desire – a fact often not appreciated by others. Disability caused by weakness may make having sex more difficult and some people may find they have additional psychological issues to contend with.

Louise Hastings, Principal Genetics Counsellor at the Centre for Life in Newcastle has worked with hundreds of people with a neuromuscular condition. She talked about sex and relationships in a presentation at a Limb Girdle muscular dystrophy conference back in 2003. Louise spoke about neuromuscular conditions causing changes in body shape and weight, changes to the appearance of the muscles and changes to walking style and gait and she looked at how this can alter a person's "body image" affecting self confidence and raising questions such as: "Does my partner still fancy me?"

We all try to cope with difficult situations differently and often in a relationship one person wants to talk things through and the other doesn't feel able to. This can cause enormous stress. There is no right or wrong way to feel – just the way you do feel. Take your time, respect one another and try to show your care through actions if words are hard. If necessary seek professional help (with or without your partner) to find a way forward you feel comfortable with. Your GP or an organisation like Relate can be very helpful.

It is important to recognise that whilst we are shaped by our experiences you are the same person you were before your diagnosis – and those close to you are likely to continue to love you for the reasons they always have even if they too struggle with the challenges of the situation.

Sometimes disability can impact on the role you feel you have traditionally held within your relationship or family. For example, some may see part of the role of a husband as that of a provider (more so in some societies and cultures than others) and if disability impacts on the ability to work this can undermine the "role" held and affect feelings of self esteem and sexual performance. Try to recognise that roles can, and do, change over time. There are no rights or wrongs in this and each of us has to find the role that works best for us in our individual circumstances and relationships.

Care needs are often a concern – both for the person with the disability and for their partner. Not everyone has the capacity or desire to be a "carer" and open, non-judgemental discussion can be enormously helpful here. Different people bring different strengths to their relationships – someone who is not good at the practical side of care provision may be a great organiser and can use these talents to arrange a care package that works. Some people will be keen to separate their care needs from their needs as a lover/partner and doing so may help maintain sexual mystery and desire as well as lessen feelings of vulnerability. For other couples the provision of personal care support from the able bodied partner may bring added closeness. Try to work out what is right for the two of you and if necessary involve outside agencies to reach workable solutions and to obtain the support required.

As one man in his 30s with FSH muscular dystrophy said "My wife is my wife, not my carer and this can be difficult. We do have emotional conflicts but we also have a strong marriage. The main thing we have to deal with is change but we put our heads together to overcome problems."

The fact that society often sees adults with disabilities as asexual is reinforced when professionals suggest housing adaptations or equipment that don't take this side of life into account. One gentleman with Becker muscular dystrophy married a lady with two teenagers and the couple went on to have a child together. Prior to his marriage he had lived in a small adapted bungalow. On requesting a housing transfer he was told that he was not a priority as he "hadn't warned them he might get married and have a family." The bungalow had been allocated to him fifteen years prior to his marriage!

Another gentleman, who was in his late 70s and had been married over 50 years, said the thing he missed most now that he had to sleep alone downstairs in a single, electrically adjustable bed was "the marital bedroom and sex - or at least that night time kiss and cuddle."

Of course, not everybody with a neuromuscular condition is in a relationship. Finding love and a sexual partner can be challenging for us all and may seem more so to someone with a disability. All the usual advice about taking a positive approach applies here – it is a quality which attracts others. Keep active and try to maintain a social life – preferably one where you meet new people. One website with lots of advice about finding a partner (and about sex and relationships and the impact a disability can have on them) is **www.outsiders.org.uk**

Some people will be concerned about how their disability might impact on their ability to have a sexual relationship. Muscle weakness, inability to move the body easily and contractures can all make the physical act of intercourse problematic. As always, good communication is the key. Bob Mauro, a man in his late 50s with polio is quoted on www.accessibility.com.au in their set of articles on "sex and disability." He points out that engaging in sexual activity when you have a disability requires the four Ts "Time, Trust, Trying and Talk." Another tip is to "focus on the process not the outcome."

Medication can affect sexual function and desire. Dr David Hilton-Jones, Director of the Oxford Muscle Centre says:

"Many drugs, even at appropriate therapeutic doses, can have an adverse effect on aspects of normal sexual function. It is impossible to be comprehensive and if you think that there is any possibility of a connection you should discuss it with the relevant doctor. Some times the association is obvious, for example loss of the ability to gain or maintain an erection shortly after starting a new drug, but the effect may be more insidious.

The mechanisms of sexual dysfunction are varied. Loss of penile erection can be caused by a wide range of drugs, including those used for treating high blood pressure and other heart conditions (such as cardiomyopathy in muscular dystrophy). Many drugs can affect libido including those used for treating psychiatric issues (which in themselves may, of course, affect sexual function) and epilepsy.
If in doubt, ask."

If you are concerned about heart or respiratory issues talk to your specialist and ask about the affect these may have (or not have) on your sex life. Everybody's situation will be different so personal advice is essential. The American Muscular Dystrophy Association says:

"Sexual intercourse generally uses about as much energy as walking three miles an hour, and that can be a strain for people with weakened respiratory or cardiac muscles. Some positions require less energy than others so experiment. Many people find a side lying position easier.
Of course, respiratory and cardiac problems should be evaluated and treated by a doctor – for the sake of your sex life – and your life."

All sexual choices are personal. As in the able bodied population some people will seek same sex relationships much or all of the time. For many people sex

outside a loving relationship is not an option whilst this may be something others seek or decide to pay for. The important thing is to ensure that your choices are right for you.
As Bob Mauro who was cited earlier says: "If you are in a relationship that puts you at odds with your sexual identity you should look elsewhere for someone to love and to love you."

Young people

Young people who have grown up with a progressive disability or who have a disability acquired in childhood, face very different challenges to adults who were able bodied in childhood.

There are challenges around parents and other adults accepting that sexual issues are relevant for them and that sexual desire will exist. Advising a young person "not to think about it" or to "concentrate on other things" will not be helpful. Their thoughts and feelings need to be respected and listened to and a positive attitude towards their concerns taken. Work together to seek answers whilst accepting that sometimes there are no easy answers. Respect the fact that your child may choose (as all teenagers often will) to seek advice, information and support (often without your knowledge) from their friends or from professionals rather than from within the family. As a parent you can help by ensuring that open discussion is encouraged and sources of professional help identified.

Resources

The Muscular Dystrophy Campaign is not in a position to recommend other organisations or services but the following list is provided for your information:

Outsiders:
This is an organisation of disabled people for disabled people and is open to all aged 16 or over. The website contains a huge amount of information (much of it very explicit) and publishes some leaflets including: "Physical disability and sexual intercourse", "Practical sex tips for disabled people" and "Sex and your partner with a disability."
www.outsiders.org.uk
020 7354 8291
BCM Box Lovely,
London, WC1N 3XX

Relate:
Relate can offer advice to people experiencing relationship difficulties including sexual problems. It offers a telephone and e mail counselling service as well as the traditional face to face option. Advice on common difficulties is published on its website and an online book ordering service covering relevant topics is available.
www.relate.org.uk
0845 456 1310

Relate Scotland:
www.couplecounselling.org
0845 119 6088

British Association for Sexual and Relationship Therapy:
A national charity for sexual relationship counselling.
Lists locally based advisers on its website.
www.basrt.org.uk
020 8543 2707

www.bbc.co.uk/ouch/lifefiles/sex_disability.shtml - on line diaries/personal stories

www.tlc-trust.org.uk – a site sponsored by sex workers and campaigners connecting them to disabled people

www.accessibility.com.au has an interesting series of articles on sex and disability. To find these type "sex" into the search function.

The following fact sheets published by the Muscular Dystrophy Campaign (address below) may be helpful:

"Organisations that provide information, advice and support on personal relationships and sexuality"
"Pregnancy and reproduction in muscle disorders"

And from the Campaign's new adult self management pack:
"Sex and relationships"
"Emotional support"

Muscular Dystrophy Campaign
61 Southwark Street
London
SE1 0HL

Information and Support Line:
0800 652 6352 (freephone)

T: 020 7803 4800
F: 020 7401 3495
info@muscular-dystrophy.org
www.muscular-dystrophy.org

Help for families

One Plus One, the relationship charity, has produced a report which explores the issues faced by parents of disabled children and the effects this has on their relationship. The research shows that parents of children with disabilities are more likely to experience relationship distress. The support services are often inconsistent so some parents are not getting the support they need, often resulting in even more stress for these families.

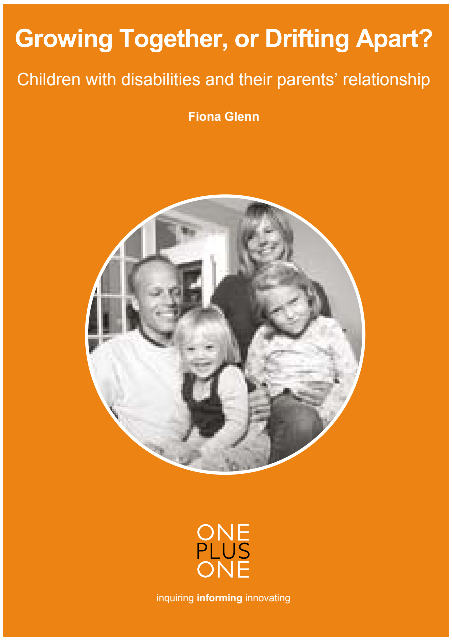
Help for the couple relationship is a crucial strand of parenting support that has often been overlooked, yet it's well proven that when parents get along, their children benefit from more effective parenting and closer relationships with each parent.

One Plus One's involvement in producing the report has encouraged them to make resources available to parents via the web.

www.thecoupleconnection.net is an interactive, self-help site aims to provide couples with resources and practical tools that will enable them to improve their relationship.

One Plus One have also produced a relationship guide in partnership with Contact a Family, which offers information and ideas on family relationships to parents with a disabled child.

The full report and information guide can be downloaded here: http://www.oneplusone.org.uk/PUBS/Index.php



Growing Together, or Drifting Apart?

Children with disabilities and their parents' relationship

Fiona Glenn

ONE
PLUS
ONE

inquiring **informing** innovating

Sibs UK

Sibs is a UK charity for people who grow up with a disabled brother or sister. The charity recognises that siblings have specific needs at different stages of their lives that often require attention, including relief of anxiety and strategies for coping.

Sibs aims to enhance the lives of siblings by providing them with information, advice and support. They also offer advice to parents on how they can give their sibling child enough attention and communicate the disability to them.

Sibs run a wide range of conferences and workshops around the UK. Full details of these events and dates can be found on their website

www.sibs.org.uk

Sibs
Meadowfield
Oxenhope
West Yorkshire
BD22 9JD

01535 645453

A Dream Come True for Helen

Dreams Come True is a national charity which organises special experiences for young people with life limiting conditions. To find out more, contact Kay at the A-T Office.

Hello - my name is Helen Carter, I'm 15 years old and I've just come back from Disneyland Paris.

The Dreams Come True team sent me and my mam and dad there. It was fabulous. We didn't have to wait in any queues – being in a wheelchair has its advantages – and the staff there were great.

We went to all the parks in the four days we were there. I went on Big Thunder Mountain, Indiana Jones Rollercoaster, a flight simulator and a 3D show, saw the parade and even a sight-seeing tour of Paris by night. The Sequoia Lodge where we stayed was excellent for wheelchairs, a lot of room, but the bathroom was a bit difficult. Access round the park and on most of the rides was very good.

Helen the Rock Star...

The day before I went to Disneyland I opened an open air pop concert in Durham. My pal from Butterwick Hospice and Durham University had me on stage first, singing two Cascada songs! It was awesome!

Soon I'm off to London with the school to see Billy Elliot and We Will Rock You. Hopefully we're going on the London Eye, to the London Dungeon and Thorpe Park too.

Enjoying the open air

Emily sent us this picture of herself and her mum when they went to Exmoor.

Gliding along...

Have you ever fancied taking a cruise through the English countryside?

The Canal Boat project is a registered charity established in 1989 to provide affordable opportunities for anyone with a disability or their carers, charities and community groups, to experience the joy of cruising the inland waterways. From half a day to a week or more, their fleet of accessible boats is perfect for day trips, weekend breaks and holidays. You can be captain for the day, or let a qualified skipper take the helm.

The boats are based on the River Stort in Harlow, easy to get to by road or rail.

For day trips, there's a choice of two boats, the larger of which provides state-of-the-art facilities for up to 12 people.

Two other boats are equipped for overnight stays, allowing you to venture further afield. The local towns of Bishop's Stortford, Hertford and Waltham Abbey are all within reach on a weekend cruise.

For a longer journey, you could chug all the way to London and back.

For more information look on the websites:

www.canalboat.org.uk
for day trips

www.lockviewcanalholidays.org.uk
for short breaks and holidays

Or phone 01279 424444 for a brochure, then arrange a visit to view the boats and meet the Canal Boat Project to discuss your requirements.

Thanks for the trike!

Sophie Lynn, aged 10, on her trike, which was paid for from the A-T Society's Support Fund.

Sophie's mother, Pauline, writes:

"May I take this opportunity on behalf of Sophie and all her family in thanking the A-T Society for funding her trike, which is giving her immense enjoyment."

VAT Relief for disabled people

Gary Bromwich takes you through some simple steps to save money

Buying a new vehicle? Having building work carried out? Or purchasing adaptations? Then STOP!!! Go no further until you have viewed this website: **www.hmrc.gov.uk** This is a rare opportunity to actually NOT have to pay tax.

VAT reductions are available for many disabled purchases, products or projects. As ever it's not easy to find these reductions, or even understand them when you have.

There are great savings to be had. For example, if you purchase an adapted vehicle for a wheelchair user from the dealer, you get VAT relief on the whole vehicle. But if you purchase the vehicle and *then* have the adaptations fitted, you only get VAT relief on the adaptations. A few thousand pounds' difference in some cases. I am no expert but that is my understanding of the information offered on the site. I have in the past contacted their helpline, and they were surprisingly helpful.

Anyway here goes!
Enter www.hmrc.gov.uk.
In the search box type "disabled"

Pick second option V1-7 Chapter 12: VAT reliefs for disabled people and download the document. This section then details the procedures and criteria regarding VAT exemption or reduction for items ranging from beds to vehicles and computers and adapted vehicles.

Obviously please check the website and if in doubt confirm any reliefs with HMRC themselves, you don't want the taxman after you.

Good luck and remember: a few minutes spent wading through bureaucracy may save you a few quid.

In brief

Scoliosis and A-T

If you are aware that surgery to correct scoliosis is being considered for a person with A-T, could you contact Maureen or Kay at the office please on 01582 760733. It is of great importance that the orthopaedic surgeon discusses the case with the A-T clinical team prior to any operation.

Keep us up to date!

If you move house, don't forget to tell us at the A-T Society, so that you won't miss out on mailings. And if you want to stop receiving the newsletter, please let us know.

Incapacity Benefit

Incapacity Benefit is being replaced by Employment and Support Allowance (ESA) for new claimants. People already receiving Incapacity Benefit will continue on this for the time being. If you have any queries regarding this new benefit please contact Kay in the office.

Elifar Foundation

The Elifar Foundation, mentioned in the last newsletter, is a grant giving organisation. They can help with the cost of holidays or equipment such as wheelchairs or special trikes. Contact them on 023 9226 7996 or by email: info@elifarfoundation.org.uk for more information and an application form.

Email Contact List

We have a list in the office of all those families who are happy to be contacted by email. If you are not already on this list and you do have an email address that you are happy to use, can you please let Kay know. We can then contact you with any up to date information in the world of A-T.

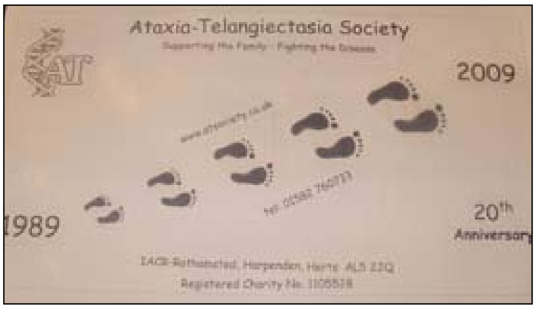
Spoke guards

A family has two virtually brand new spoke guards for 22" wheels. They are decorated with pictures of Winnie the Pooh. (The wheelchair owner feels they are too babyish for her now). If you would like them (free!!) please contact Kay in the office.

20th Anniversary Tea Towels

We can take the pressure out of all that Christmas buying!
We now have tea towels to commemorate our 20th anniversary which occurs next year.
The tea towel is white cotton and all printing is in blue.

At just £4 each they will make excellent Christmas presents whilst
raising awareness of the condition, the Society and funds all at the same time!



TEA TOWELS ORDER FORM (BLOCK CAPITALS PLEASE)

I would like to order ____________ *(number) 20th Anniversary Tea Towels*

Total cost of tea towels ____________

Post and packing ____________

Voluntary donation ____________

TOTAL £ ____________

NAME:

ADDRESS:

Postcode:

Postage & Packing

1 tea towel		*£0.45*
2	*"*	*£1.25*
3-6	*"*	*£1.51*
7-9	*"*	*£1.86*
10	*"*	*£2.21*

Cheques/postal orders payable to A-T Society please to accompany order. Send to:
A-T Society, IACR-Rothamsted, Harpenden, Herts, AL5 2JQ

Extras Wanted!

We want to recruit an extra

100

planned giving supporters!

By giving on a regular basis you will provide us with a secure income that will allow us to plan ahead.

Pledging just:
£3 per month = £36 per annum
£6 per month = £72 per annum
£10 per month = £120 per annum

100 people regularly giving £10 per month = £12,000 per annum!

With that we could
provide 6 new manual wheelchairs
or
send 12 young people with A-T on a Vitalise respite care holiday.

With an increased income we could do so much more.
Pledge what you can afford.
Even small amounts become large ones over time and everything helps!

Don't delay - do it today.

A planned giving form is enclosed with the Newsletter.
If you are already a regular giver -
THANK YOU
You are worth your weight in gold!

A-T Society, IACR-Rothamsted, Harpenden, Herts, AL5 2JQ
atsociety@btconnect.com
tel 01582 760 733 fax 01582 760 162
Reg Charity No 1105528