

ADULT SIBLING NEWSLETTER

Sibs

No 1 July 08

Welcome

Hello and welcome to our first newsletter for adult siblings. You are one of over a million adult siblings (of disabled people) in the UK—a significant yet hidden group, with many shared experiences and needs. One of the main things adult siblings tell me is that they feel isolated with their experiences. Through this newsletter we want you to read about the experiences of other adult siblings, to inform you of any relevant resources, and to give you the opportunity to contribute to the adult sibling community. Our next newsletter will be looking at making plans for future care, so please email me with your experiences on this topic by the end of September.



Monica McCaffrey, Director, Sibs

First ever UK conference for adult siblings

We will be holding our first conference for adult siblings on 11th November in London. I hope that many of you will join me for a very exciting programme of workshops.

Cognitive behavior therapy as an emotional coping strategy for adult siblings

Long-term emotional impact of disability upon adult siblings

Facilitating future care planning with adult siblings and their families

How adult siblings can influence service provision

Resources for adult siblings on practical aspects of planning future care

Getting the balance between caring and just being a brother or sister



Our keynote speaker on future planning is John Kramer. John is an adult sibling and chairs the US Sibling Leadership Network. At the end of the conference I will be facilitating a networking session for adult siblings so that you will be able to stay in touch with each other. This conference is for adult siblings, their parents, and service providers. The venue is St Albans Centre, Holborn, London. I look forward to seeing you there.

Download flyer at www.sibs.org.uk/events or call for one by post.

About Sibs

Sibs is the UK organisation for people who grow up with a disabled brother or sister.

Tel 01535 645453

Email info@sibs.org.uk

Website www.sibs.org.uk

In this issue

Margaret shares her experiences of getting to know other adult siblings

The National Carers' Strategy

Resources for adult siblings

Getting to know other siblings

I am the younger and only sibling of a brother with mild to moderate learning difficulties. He is married with two daughters in their teens. The eldest has inherited my brother's learning difficulties. The most poignant thing my brother has ever said to me was when his first-born was still tiny: 'Please, please don't let her be like me.' I felt so deeply the pain behind his words. Ever since I can remember, I have strongly identified with my brother and wanted to take away his pain. But I know I can't. I can only sit on the sidelines and cheer him on.

He struggles hard, lacking the confidence to negotiate many of life's everyday tasks, like ringing the bank or talking with officialdom of any sort. He is very lucky to have his wife's help in this but I know she does sometimes find her support role overwhelming. And with two teenagers in the house tensions can run high...

I love my brother, my nieces and my sister-in-law. I really enjoy being with them. But I do sometimes rail against the amount of time, energy and emotion I spend trying to be there for them. Discovering Sibs was a big relief for me. I first heard about it on Radio 4's 'Home Truths' a few years ago and immediately rang the information line. The sense of community I get from Sibs is the most important thing for me - the feeling of no longer being on my own.

Through Sibs I have found Sibnet - a worldwide email list for siblings. When I first signed up I logged on several times a day because I was so excited about reading news from other siblings. Sometimes I am awed by what stressful situations some other Sibnetters find themselves in - for example, having several brothers/sisters each with a range of disabilities - yet nonetheless they cope.

Other times I think 'Yes, that's me. I've been there too!' Like when one sib described how he gravitates to those with disabilities without even realising it and this can cause misunderstandings. That's me, too. During my daily shop at a street market when I was living overseas I always made a beeline for the stall owned by a man with one arm. It was not long before I realised he thought I fancied him. Not what I intended. Oh dear. Although I have done this type of thing more than once, I had not identified it as 'sib' behaviour until I read about the other sib's experience.

Making connections with other siblings has made me more positive about who I am. Instead of fighting against being a sibling, I've come to

'Ever since I can remember, I have strongly identified with my brother and wanted to take away his pain.'

focus on what I have in common with my brother – shared history, values and some common hobbies from childhood. We have begun cycling together regularly as we used to do as kids. I wish we could cycle off into the sunset and live happily ever after. I know that is not to be. I want a life of my own, too. But I am more optimistic about the future than I was.

I am encouraged by the changes in society since my brother and I were growing up. There is much more acknowledgement of and help for those with disabilities and for those who care for them. Sibs is part of this change. I have found it really useful being able to ask for advice on particular problems from those who understand and have experience of similar situations.

My youngest niece is also a sib, as well as being the daughter of a father with learning disabilities. I am glad there is now much more support on offer for her. She has not yet taken up the opportunity to join Sibkids but she knows it is there and I hope she will take the plunge soon.

I am excited about the future of Sibs with its potential to pool adult siblings' experiences through workshops and newsletters. I have already learnt so much through my contact with adult siblings worldwide and I look forward to increasing opportunities to make UK contact.

Margaret, adult sibling

*Not to be reproduced without permission from Sibs
Views expressed by adult sibling contributors do not necessarily reflect those of Sibs*

'Making connections with other siblings has made me more positive about who I am.'

Sibnet

SibNet is a bulletin board for adult siblings run by the US Sibling Support Project. We know this project well and it is a really good resource for siblings who want to share their experiences with siblings worldwide. To join Sibnet visit their website

www.siblingsupport.org

Support for bereaved siblings

Sibling bereavement support is available from The Compassionate Friends (TCT). Visit www.tcfsiblingsupport.org.uk. This website is for any bereaved adult siblings. You can also get bereavement support through their Helpline Tel 08451 23 23 04. The helpline is answered by a bereaved parent who will refer you to one of the TCT Sibling Contacts, who are all bereaved adult siblings themselves.

Resources and information

National Strategy for Carers

The National Strategy for Carers was published on 10th June 2008, signed by seven Government departments. The Strategy says that by 2018:

Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role

Carers will be able to have a life of their own alongside their caring role

Carers will be supported so that they are not forced into financial hardship by their caring role

Carers will be supported to stay mentally and physically well and treated with dignity

Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

Increased funding for breaks and employment support for carers has been made available in England. Funding will be made available over the next 3 years for the voluntary sector at local and national level to support their work with carers. Sibs will be looking at how this funding can be used for supporting adult siblings.

Download the strategy summary at www.sibs.org.uk/Help_for_carers/

Cinema cards

If you and your brother or sister enjoys films then get a Cinema Exhibitors Association Card. This entitles the holder to one free ticket for a person accompanying them to the cinema. It is valid in many of the main cinemas across the UK. To apply for the card, your brother or sister will need to meet one or more of the following criteria: a) Be in receipt of the disability living allowance or attendance allowance. b) Be a registered blind person. Visit www.ceacard.co.uk or call 0845 123 1292 for details of

how to apply and a list of participating cinemas.

Watch a great DVD

The Guardian newspaper has sent us some copies of What's Eating Gilbert Grape (Cert 12) to send out to adult siblings. If you have not seen this film I recommend that you do. Johnny Depp plays a young adult sibling who has a younger brother with a learning disability, played by a very young Leonardo DiCaprio. The film portrays the conflicting emotions often experienced by siblings, the practical aspects of being a carer, and how siblings

need permission to lead their own life. It is quirky and slow moving as it builds up an intimate portrait of the characters lives and is definitely one of my favourite films. If you would like a free copy just contact us with your name and postal address

Sibs website

Make sure to visit the adult sibling pages of our website.

www.sibs.org.uk/adults