

CHAPTER 8

Social and leisure activities



When you have to make time for endless appointments, phone calls or therapy sessions it takes a great juggler to find any time to do ordinary things, especially if you have other children. Many of us found it difficult at first to bring a sense of normality to everyday life. But quite early on, most of us realised how important it was to try to do some things as a family.

You have to realise that this is just one child in your family, and you are a family and you all count, each one of you counts. You focus so much on your special needs child that everyone else goes out of the window, and it's getting a sense of proportion again...

Being a family means different things to different people - not everybody fits the nuclear family stereotype. Many of us struggle with feelings of isolation as a single parent. Being the parent of a child with additional needs can reinforce those feelings, especially if your child's condition is one that makes it difficult to 'fit in' with ordinary family activities. Often other parents who have children with similar conditions are easier to be with and a good source of ideas on safe places to go and enjoyable things to do.

We know that getting out and about can sometimes seem hardly worth the effort. 'How will I get there?', 'Will she embarrass everyone?', 'Will they be accepted?', 'How will I deal with problems in public?', and 'What will access be like?'

However, finding social activities and things that you can enjoy together can go some way towards restoring normality. Most of us have found places to go where everyone can join in - and Amaze has done some work to help venues in Brighton and Hove become more accessible and welcoming.

In this chapter we'll talk about some of the things to think about when choosing leisure opportunities and where you can find out about fun things to do in Brighton and Hove. We'll also introduce you to the Compass Card, a free leisure incentive card that can make leisure in the city more affordable and more welcoming.

CHOOSING LEISURE ACTIVITIES

Like everyone else, children and young people with disabilities or special educational needs want to have a social life and take part in activities they enjoy. But as a parent you want to know that they will be welcome, safe and supported. And if you have other children it's important to make sure they're enjoying their leisure time too! Here are a few pointers:

A bit of research goes a long way

When you're considering new activities you may have lots of questions. But if you try to answer them all at the same time, it may feel like your child is too hard to include. Sometimes it's useful just to sit and see how a session runs. Written policies are fine, but what happens in practice is more important. Also, ask other children, young people and parents what they think. Their views might offer different perspectives that enrich your impressions.

When parents need to stay

Don't dismiss a club because parents are required to stay. Some of the best activities are organised by other parents and volunteers who cannot take responsibility for supervising children who need the toilet or want to sit out for a bit. Sometimes you have to balance the value of a free or inexpensive opportunity for your child against the chance to have a break yourself. Also, these are often the places to meet other parents and exchange advice and support.

Inclusive or exclusive?

Sometimes disabled children and young people want to be like their non-disabled peers and to distance themselves as much as possible from their differences or disabilities. So they may want to join an activity that includes all kids, including those with additional needs (we describe these as 'inclusive'). At other times the same children may only feel confident in more exclusive activities alongside their disabled peers. Be aware how your child feels.

What matters to your child?

Remember, children just want to make friends and have fun. It's easy to get too hooked up on rules and protocols, structure and learning outcomes, although these are all important. Encourage

your child to think about what's important – often things that might seem insignificant to us make a big difference to them. Once they've joined an activity ask your child how things are going and listen to them on all channels – if not in words, they may tell you through their behaviour or gestures what they do and don't enjoy.

Your other children matter

Obviously there'll be times when you want to do things as a family, but sometimes brothers and sisters who don't have disabilities or special educational needs will want the chance to do things on their own. If you have other children in your family, don't forget the Young Carers Project, run by the Carers Centre. It offers them opportunities for social activities with other young people who share the experience of living with someone who is ill or disabled. Autism Sussex not only runs activities for children and young people on the Autistic Spectrum, but organises separate activities for siblings too. And you may find that inclusive activities are suitable for children with and without additional needs.

And you matter too!

It can seem like the hardest thing of all, but you need to look after your own health and wellbeing too. The Carers' Card is a free leisure incentive card in Brighton and Hove that's designed especially for carers, and parent carers of Compass Card holders automatically qualify. If your child is under 18, call 01273 295153 (and have your child's Compass Card number to hand – it's on the back of the card); if your child is over 18, call 01273 295555.

FINDING OUT WHAT'S OUT THERE

All children are different, but there's something out there for almost everyone. So whether you're looking for something to

do as a family, searching for a suitable sport, planning a holiday or looking out for opportunities for your child to socialise – it's often just a question of knowing where to look.

Fun Things fact sheet

Start with the Amaze fact sheet, 'Fun Things to do for All Ages'. It's packed with stuff – from parent groups like Brighton Pebbles, to drama classes, youth clubs and sports clubs – and it's updated annually. Call the Amaze helpline for a copy, or print it off from our website. If you can't find what you want there, call the helpline and we can look into more options for you. Our website's also a rich source of information: have a look at our events listings.

Contact FIS

Brighton & Hove City Council's Family Information Service (FIS) has lots of information on childcare and play schemes and on children's services across the city. They offer an extended childcare finding service to families who have additional support needs and run something called the 'At Home Childcare Service' that links experienced childcare workers to families whose children might be best cared for in their home environment. FIS also publishes details about school summer holiday activities in its 'Summer Fun' booklet, which is published in June and distributed via schools. The booklet can be downloaded from the council website.

As simple as ABC

ABC Magazine covers Sussex and includes lots of information on things to do and places to visit for parents of babies and young children. It's free and you can find it in places like libraries, children's centres and doctors' surgeries.

Sports and physical activities

If you're looking for a local sports club, the council's Sports Development Team has a website, Active for Life, which lists more than 400 local clubs and groups. Visit www.activeforlife.org.uk. There's also an Active for Life directory that's published once a year. Look out for a copy in your local library or leisure centre.

Your accessible city

If your child needs to use a wheelchair, you'll need to know whether places are accessible. The Fed's online 'Accessible City Guide' is a good place to start. It covers a wide range of attractions, public buildings, local transport, parks, restaurants, sports facilities and more. You'll find it at www.thefedonline.org.uk. Accessibility in the city has improved a lot in recent years and even the beach, for years a no-go for wheelchairs, is more accessible. There's an accessible walkway for wheelchairs in front of the lifeguard station near King Alfred Leisure Centre car park and you can book beach wheelchairs from the Seafront Office on 01273 292716. The council's web site also has loads of information on accessibility in public facilities like parks – visit www.brighton-hove.gov.uk and click on the relevant links.

Google it!

If you're web-savvy, it's worth searching online for what you're looking for. Visit www.childfriendlybrighton.co.uk and www.kidsinbrighton.co.uk for some ideas – but be aware that content can go out of date quickly, so make sure you check details before you start making firm plans.

Try the library

Your local library has lots of information on things to do in Brighton and Hove, as well as a full programme of regular

children's activities. You'll find sensory books called 'bag books' in Jubilee Library; audio books and children's CDs and DVDs in most libraries; and a toy library in Whitehawk Library. There are some signed story times at Jubilee Library and many libraries have regular storytelling and Baby Boogie sessions for young children. There are also lots of events in libraries and you should find that children with additional needs are welcome. Pop into your local library to find out more.

THE COMPASS CARD

The Compass Card is a leisure incentive card specially developed for children with significant additional needs or disabilities. Launched by Amaze in 2003, it provides dozens of free or discounted leisure opportunities across the city. It makes leisure across the city more affordable, contributes to helping children and carers feel more welcome in local venues, and means you don't have to explain your child's additional needs in a public place.

But let's start at the beginning – The Compass database. All local authorities in the UK have a legal obligation to keep a 'disability register' of children from 0 to 19 who have special educational needs or disabilities that affect their daily life. In Brighton and Hove, the register is called 'The Compass' and Amaze manages it on behalf of the council's Children and Families Service. Individual details are kept confidential, but Amaze collates the data and the council uses the overall findings to improve local services. Children who are registered on The Compass automatically get a free Compass Card.

To see the full range of Compass offers, you'll need to get your hands on a copy of 'Your Compass Card', our Compass Card guide and our Compass Card Activities guide. Call the Amaze helpline for a copy, or download one from our website. Offers and activities change, so if you've got an email address, we can

keep you up to date via our weekly e-bulletin, 'Compass Team News'.

Offers include: free swimming at the city's public pools; free gym sessions for 16-19 year olds at eight local gyms; free fitness sessions for 12-15 year olds at five gyms; free carers' tickets at The Duke's and Odeon cinemas; special offers at Komedia, Brighton Dome, Theatre Royal Brighton and The Old Market (TOM); free CD, DVD and audio book hire at city libraries; free travel on the Big Lemon bus route; soft play and farm discounts; and discounts at Sea Life, Bowlplex, Brighton Wheel, Forest View Holiday Home, High Sports climbing wall and Paradise Park. We're adding to these benefits all the time so read the Amaze e-bulletin, or call the helpline for the latest offers.

Please note: there's a big change on its way for the Compass Card. From February 2015, we'll be extending the upper age limit for card membership from 19 to 24 – great news for young people!

Compass Card Activities (CCAs)

Amaze has developed a range of activities for Compass Card holders called 'Compass Card Activities' or CCAs. They offer teachers or coaches with additional needs experience, discounts and incentives for Compass Card holders, an opportunity to feedback on activities and information on other stuff your child might be interested in.

At the time of writing, our CCAs included adventurous and sporting activities like archery, climbing, kayaking, trampolining and multi sports, as well as more creative pursuits such as art workshops, cookery, cinema screenings and Otherworld immersive theatre shows. We are also running pilot street dance courses with Marina Studios.

To get the full list of the latest CCAs and find out which ones might be suitable for your child, read the Compass e-bulletin, call us, or look at the latest Compass Card Activities guide on our website.

Applying for a Compass Card

You'll need to fill in a Compass Registration Form, which asks for information about your child and the local services you need and/or use. The form's available on the Amaze website, or you can call the helpline and get one sent to you.

To be eligible for a Compass Card, your child will need to be under 20 (under 25 from February 2015), have a significant disability or special educational need and live or go to school in Brighton and Hove, or be looked after by the city. Most children on The Compass are eligible for Disability Living Allowance or Personal Independence Payment (PIP), or have a Statement of special educational needs or an Education, Health and Care Plan (EHCP).

If you want to check whether your child is eligible for a card, or if you need help completing the form, call the Amaze helpline or email compass@amazebrighton.org.uk.

EXTRA HELP AND SUPPORT

Leisure Buddies

There's extra help available for some young people who want to do particular Compass Card Activities. Local charity Extratime can provide specially trained staff called Leisure Buddies to help your child get the most out of their activity and to make sure coaches understand their needs during their first few sessions.

A bit like a short term leisure befriender, Leisure Buddies can also help your child get to and from an activity and can really help if your child feels anxious about trying something new. Buddies need to be booked in advance. For more info, call the Amaze helpline or Lisa Nash on 01273 420580, or email lisa.nash@extratimebrighton.org.uk.

Access 2 Youth

This is a new project from Extratime that provides young volunteer befrienders to support 13 to 19 year olds with additional needs to access youth clubs across the city. Call Zoe Anstey or Lisa Nash on 01273 420580 or email zoe.anstey@extratimebrighton.org.uk for more information.

Travel training

Parents of young people may feel anxious about their teenage son or daughter travelling around the city independently. Amaze has teamed up with the Grace Eyre Travel Buddy Project to provide a training programme for parents to give you the tools you need to help them learn to travel safely and get you feeling happier about them doing it. Call our helpline for more information.

Over 18s with learning disabilities may also find Grace Eyre's Travel Buddy Project useful. They run a 12 week Travel Training Course that includes road safety, using buses, staying safe and dealing with the unexpected. And, once the training is complete, some trainees can be paired up with a volunteer travel buddy who may be able to help with a specific journey. For more info, call David Matthews on 01273 222049, Ben Gardiner on 01273 222053, or Active Lives on 01273 201909. Or you can email travelbuddy@grace-eyre.org.

HOLIDAYS

We all feel like a break every so often, but sometimes the thought of all the planning makes it seem too much of an effort. Just like other forms of leisure though, there's plenty on offer. There are holiday companies that specialise in providing breaks for people with specific disabilities or access requirements and mainstream travel agents are getting better at providing information about facilities for disabled people. There are plenty of sources of useful information that will help you plan a holiday. There are also grants and subsidies that can help keep the cost down if money is very tight.

Be clear what's on offer

If you're planning to book a holiday, double check your child's needs will be catered for and consider asking the company to confirm arrangements in writing. It's remarkable how many people still think that an entrance up half a dozen steps is accessible for a wheelchair user!

Insurance

Are you properly covered? Make sure holiday insurance is appropriate; in the small print you'll probably find, for example, that 'pre-existing conditions or illnesses' aren't covered. If this affects you, look for a policy that suits you better.

It has taken me quite a bit of time to adjust to the need to do all this preparation, but then it's been worth it because it's made our holidays easier and I'm less stressed.

Help with holiday costs

If you're really struggling to afford a break, there are subsidised holidays around, or grants that may help you pay for them. Locally, Brighton & Hove's Children's Services has a specially

adapted caravan in the New Forest for families who have children with additional needs and the cost is subsidised. And there's a 10% discount on the prices for Compass Card families. Call 01273 295530 for details.

The 3H fund runs subsidised group holidays for physically disabled children and provides grants for holidays in the UK when funds are available. The Family Fund can provide grants towards family holidays and the charity Happy Days funds and organises holidays and days out for families with children with additional needs aged 3-17. The Family Holiday Association is another charitable organisation that can help to fund breaks for disadvantaged families. Find the contact details for these organisations at the back of this book.

Finding information

The national charity Tourism for All (TFA) is a good place to begin when you're starting to think about taking a break. TFA's website has travel advice, transport information, a useful directory that lists places to visit and accommodation to stay in. You'll also find some really useful web links to other organisations that can help. Visit www.tourismforall.co.uk.

The Rough Guide to Accessible Britain is a huge online publication that's packed with ideas and practical advice for planning days out and holidays. All the locations mentioned have been reviewed by disabled people. You can view it for free at www.accessibleguide.co.uk. Disability Now Magazine has a travel section with lots of holiday information. Visit www.disabilitynow.org.uk or you can call to subscribe. Contact a Family publishes a booklet, 'Holidays, play and leisure'. It lists organisations that provide holidays and holiday accommodation for families with disabled children. You can print it off their website (www.cafamily.org.uk) or call them and ask them to send you a copy on 0808 808 3555.