

INFORMATION SHEET

Parents Perspectives



making a difference
to the lives of people with
severe learning disabilities

Alison

I am a single parent of two boys. My youngest son, Steven, is severely autistic, (classical Autism) and also has severe learning difficulties (SLD). He has no speech at all, is in nappies most of the time and attends a SLD school where he is in the autistic unit. I am unable to work, as I have no one to look after Steven in the school holidays.

My husband left me several years ago, when Steven was 4. He has Steven to visit about twice a year if I am lucky! I think he would not be bothered if his son went into a home, but I couldn't do that to Steven so I struggle on. His teacher has said to me that he is very difficult, and she admires me for keeping him at home.

Let me describe my son's behaviour. He has no speech, but has begun to use Pecs symbols to request food, drink or the toilet. He will use the toilet for a wee but not to defecate, at the moment, but we are working on it! He will also try to eat odd things, paper clips, play dough, stuff on the floor and will nip threads from cushions etc, give them a good chewing and swallow them. I am told this is not uncommon in autistic children.

He is quite tall. I am only 5ft 2ins and he reaches my chin. He is very, very strong and very aggressive, especially when he doesn't get his own way, eg. if he has to leave somewhere he doesn't want to, or if he is made to stop doing an activity he enjoys. When he is having a tantrum he will kick, over and over, bite, punch and hit out. More often than not, he is doing all of these four things at once, and you can't always get out of his way if you are trying to stop him doing something, or touching something he shouldn't.

He is obsessed with things like TVs, video recorders, stereos and game stations, and is likely to break items like CDs or DVDs. Friends and family will not allow him into their homes because he is so destructive. This makes me very isolated. People will see me on my own, or have me in their house on my own, but will not have anything to do with me when I have Steven. It makes me very sad to say the least.

Outside of the house, Steven is obsessed with video shops, game or computer shops and fruit machines. You can never walk past a pub without him trying to run in. He is also obsessed with cash tills, buttons on buses and computer screens, often in shops and restaurants. He likes to play with cash machines, ticket machines and vending machines – any kind of machine that has buttons. He will press the button on a hot drinks machine and watch the drink spurt down the drain!

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need, when you need it. Please consider a donation to support our work. Thank you

He tries to turn off arcade machines by the mains switch, as he knows this will make the machine shut off, then start up again, which he likes to watch. Obviously this kind of behaviour doesn't go down too well when we are out! It makes the places I can take him very limited. I can no longer take him out by myself as you cannot turn your back on him for a second. He may run off and has no awareness of the dangers of traffic.

I was advised by my social worker and clinical psychologist not to take Steven out on my own because of his aggressive outbursts, so often Steven and I are prisoners in our own home. I am in the house with the front door and garden gate locked, not able to take him out. Steven wants to go out and indicates this by trying to open the front door, or by getting his buggy out from under the stairs. He is unhappy and frustrated, and so am I.

I am now on anti-depressant tablets from the doctor because the situation makes me so unhappy. But I found my own temporary solution to this situation by putting a job advert on the local university website, to find someone to accompany myself and Steven on outings. I offer £8 per hour and a young girl now comes with me on a regular basis. I did have a carers assessment but apparently there is no money left. So I use my credit card to pay her myself. I am going more and more into debt, but it saves my sanity so I pay it.

I will never abandon Steven as I love him too much, and I will keep him at home as long as I possibly can. If he ever does live away from home I would hope to see him at weekends, even if I was not able to take him out, and visit him during the week. Steven gets bigger and stronger every day, but despite all this he is still very loveable and affectionate. Maybe he would benefit from going to a specialist school, although I haven't received any help or advice about that.

January 2003

Judith

After an apparently normal start in life, Tom became ill at around five months, suffering from severe colic and mild fits. As he was my first child I relied on my Health Visitor and GP for advice. Their well-meant assurances delayed a diagnosis of his illness until he was nearly a year old. After consulting a paediatrician, I was told to try a milk-free diet. Tom's recovery was rapid, but he then failed all his development tests. For a further year I worried about him, having been told to carry on with whatever I thought best and wait and see. A year is a long time to know something is wrong.

When Tom was two and a half we were given a tentative diagnosis of autism, subsequently confirmed by a clinical psychologist with a particular interest in autistic children. Once we had the diagnosis, support was offered almost immediately in the form of a pre-school teacher-counsellor. A part-time nursery place followed in the local SEN school.

Tom settled in quite well, the school was very supportive, and we became the subject of various research projects. I was given plentiful advice on how to deal with Tom at home. Unfortunately the advice did not take into account the difficulties of being the parent of a hyperactive three year old with a new baby and with a husband whose work took him away frequently. I lived on adrenalin; my husband withdrew into his work. Respite, when offered, was inadequate (one afternoon a month with a carer).

The next three years were a struggle for survival. We were offered more respite, this time in a purpose built hostel, but found that Tom was much more difficult when he came back home, though he continued to make progress at school. Music therapy (in which I shared) provided a welcome interlude and a unique opportunity for me to develop a close bond with my son that laid the foundations of our attempts to communicate.

The arrival of our third son, not long before Tom's fifth birthday, proved to be the straw that broke the camel's back. Tom became intensely jealous and tried to be a baby too. He refused to walk, monopolising the double buggy so that I had to carry my middle child while pushing the other two. If I insisted he walk, he lay down in the road so I had to drag him, provoking unpleasant comments from passers by. He insisted on sitting on my lap and being fed baby food. He then decided that he would no longer wear nappies at night. Well-meant advice on the use of urine alarms and two-hourly lifting proved disastrous. Tom became nocturnal, wailing and shouting all night for two or three nights in a row. A purpose built sound proofed extension did little to improve the situation, as I could still hear enough to keep me awake. Tom became terrified of anything to do with toileting.

I had struggled with the physical wear and tear - headaches, bronchitis all winter, chronic back pain and a torn arm tendon - but could not cope with lack of sleep. The day I threw Tom across the room because I could not stand his constant noise, I phoned my Social Worker and asked for help. Two vivid memories stay with me from that meeting; the Social Worker's astonishment that I, always a "coping, sensible parent", had cracked; and his comment to the other professionals that I "must be helped to learn to love and care for my child". My reply and consequent fit of hysterics is not printable. I felt like some kind of child-abusing monster, and a failure as a parent. Tom was put on the Child Protection Register, although it was made clear to me that this was a necessary precaution until residential care could be found for him.

Nine months later a place became available in a SEN children's home nearby. Tom was introduced gradually over a period of three months, initially accompanied by me, and settled in well. He continued to attend his original school, and came home at weekends. Unfortunately our new-found peace was shattered by my husband's redundancy. The stresses of the last few years had affected his work noticeably, and we felt that it was no accident that redundancy came when it did. After a prolonged job search we moved to the other end of the country, leaving Tom behind while I tried to find a school for him and settle into our new home. Six months later I was no further forward, struggling with an uncooperative local authority who persisted in viewing us as temporary residents, as my husband's new job had broken down and he was once again unemployed.

In the mean time, Tom, now aged nine, was suffering badly from the separation and my infrequent visits. He refused food, wouldn't wear clothes, became incontinent, started smearing and hitting himself. The staff tried their best to cope, but were really at a loss how to deal with such extreme behaviour. In desperation I flew him up to our new home, feeling that I had to choose between the likely break-up of my family and my son's slide into self destruction. He had lost a stone in weight, and the bruises on his face and hands had become deep open sores with repeated self injury. A further six months at home produced some improvement, but in Tom's present state no school was prepared to touch him.

Eventually, with considerable reservations on their part and mine, one school agreed to try. I felt that it was not the right place, but there seemed to be no alternative, and our family

was in serious difficulties. My husband had already sought help for his depression, deepened by continuing unemployment and Tom's problems. I had returned to work part time, but was becoming increasingly worried about our future.

My fears proved well founded. The school and staff were not equipped to cope with an intelligent, highly manipulative but also very distressed child with severe communication problems. The staff had expected the withdrawn, isolated, unreachable kind of classically autistic child they had encountered before. Within weeks of Tom's admission staff were refusing to work with him and other parents had complained of the effects on their children. We were told he had to go. We were told he was a write-off ; the only place left was the secure ward of a local mental hospital. At this stage I felt I had lost any hope for my son. There seemed to be only one way out, taking him with me. Fortunately I lacked the courage to do it, and sought counselling help which proved my life line.

The school agreed to keep Tom while we searched for another place, provided he was sedated to make him containable. Finally we were referred to another school which specialised in children with severe challenging behaviour. I met the staff who came to assess Tom, and was overwhelmed by the fact that they homed in on his good points when no one else could see anything but problems. Ten months later Tom was admitted. And after eighteen months of systematic, painstaking, patient work, we had a child who was off his sedatives, trying to communicate, joining in activities, smiling and apparently happy much of the time. In a few more months his self injury had virtually disappeared, and he was starting to use sign language for the first time.

Tom progressed so well that he moved into a community house with two other children. He continued to expand his repertoire of signs, his self help and domestic skills, and social activities. In school he made exciting developments in communication skills, including starting pre-reading and computer activities. Tom came home for several visits, supported by a member of staff and for the first time for many years we felt that he was really part of the family. He played with his brothers, much to their delight, and enjoyed a variety of family outings.

However, Tom's progress and our pleasure in him proved all too fragile. Suddenly, for the first time in over two years he became self injurious and unpredictably aggressive. He was unable to communicate what was wrong, but became increasingly difficult and distressed. His behaviour deteriorated to the extent where he had to be admitted to hospital on several occasions. Hospital visits were traumatic for all concerned, and achieved very little. The hospital staff seemed to think that the problem was little more than "bad behaviour", and were reluctant to listen to school staff who accompanied Tom, treating them as "mere" carers. I had to intervene in person and in writing.

Eventually Tom was diagnosed as having a suspected stomach ulcer, and treated with antibiotics. His recovery was delayed by further illness, this time suspected kidney trouble. In each case only a partial examination was possible because of the need for sedation and general anaesthetic.

Once Tom's physical recovery seemed to be under way, it was necessary to return to the most basic calming and containment programmes, last used four years previously, to restore some stability to his behaviour. The onset of puberty in the middle of his illness was a further complication. Tom is now making a gradual return to his previous skills and

activities, with a much more hopeful future ahead of him than seemed possible a few months ago.

Tom's progress has been hard won by the vision and dedicated, systematic, consistent hard work of his present carers, and our determination as his parents never to lose sight of the fact that he is first and foremost our son. Giving him a future as an individual human being is at least as much of a challenge as his behaviour.

April 1998

Sue

Even as a young baby, Louise had what I can only call aggressive tendencies. I don't think she felt more aggressive than most other children, but aggressive acts played an unusually large part in her repertoire of behaviour. She would grab your face and dig her fingers in, which as she got bigger and stronger gradually became more and more painful until she could easily draw blood and often did. As you can imagine this fairly anti-social behaviour got in the way of her relationships with other people. Adults who knew her could accept that it was not personal, although it was sometimes very hard to do, but other children and strangers were not so understanding.

We tried to give her a "normal" upbringing and I took her to playgroup and Tumble-tots etc. but she was quite dangerous to other small children, despite the fact that she was still young and not very mobile due to her hemiplegia (lack of mobility down right side). I always had to stand between her and the other children (or hold her hand), a way of behaving which has since become a way of life to us. Louise is only now learning that she does not need to "be with" someone all the time, to restrain herself.

Fortunately she does have a sister and three cousins with whom she had closer contact although even this could not always be conducted in a natural manner. Luckily her sister was older than Louise and was strong enough to look after herself, although she was often brought to tears by hair pulling etc.. I concluded early on that another baby would definitely not be a good idea.

She would also sweep objects off surfaces, such as her dinner or sugar bowls (to this day we still tend to lay the table with all the crockery up the other end, away from Louise.) She would also empty her cups of drink onto the floor. With all this pouring and throwing I was forever wiping up and we decided not to replace the carpets until times were better. (We got a new dining room carpet last year)!

As Louise got bigger further behaviours joined her repertoire. Kicking appeared mainly as a reaction to impatience and stress. It was difficult to discipline her because she would become aggressive when reprovved or prevented from doing something and would then work herself up into a hysterical tantrum; consequently she was often spoilt. She was also very sensitive to atmosphere and would lash out if she sensed someone was miserable or angry, perhaps because she assumed it was something to do with her. By this time she had a massive guilt complex about her behaviour which unfortunately often resulted in yet more aggression. It was a bit of a vicious circle.

Despite this trauma (and drama) she was not a miserable child most of the time and we adapted our way of life to fit round her. It could be very wearing, but we managed to go on holidays abroad, to local fairs and fetes, on shopping expeditions and to the library and we even visited National Trust properties. All the normal things families do.

Then, just as we were beginning to think things were improving and reports from school were hopeful instead of being full of dire incidents, things changed. Her behaviour became very erratic and she developed extreme mood swings. Over the next 2 to 3 months her behaviour deteriorated rapidly and we had to be vigilant again at times when we'd begun to relax.

Fortunately for us, on one of her visits the school doctor noticed Louise's shoulder twitching and what she called "an absent look" and recommended she have an epilepsy test. Although nothing showed up on the EEG. or CT scan, Louise was diagnosed as epileptic and put on Carbamazepine and gradually her mood swings subsided. It was a great relief to be able to do something as one of the worst aspects of having a child with these sorts of problems is the sheer helplessness you feel most of the time when faced with behaviours which you have been given no training or even advice, on how to handle.

Although Louise had regular physical check-ups we had very little help with psychological problems. No one seemed to be able to suggest the best ways of reacting to Louise's behaviour, in fact most of them seemed as much in the dark as we were. A little good advice early on would, I think, have gone a long way towards helping us reduce the behaviours and preventing new ones appearing.

By this time Louise's behaviour at school had become too difficult for the staff to deal with and Louise herself resolved the problem by refusing to get out of the buggy they used at the school to help control her. She stopped eating lunch and hardly even got out to go to the toilet. The school finally said she was not suited to a local SLD and needed a special place. Luckily we'd seen a programme about a specialist school and how it positively tackled behaviour problems, which was an attitude we didn't find in the other schools we visited. Despite the fact that it was 224 miles away we decided we wanted her to go there.

May 1998

Iris

I got to a stage when I couldn't cope any more. After coping for a number of years with Gary's behaviour and trying to protect his two younger sisters, trying to keep the household in a calm mood and living on my nerves, I got to a stage where I just couldn't cope. I was constantly getting hurt by Gary. At his special school they had three staff looking after him, but were going to have to exclude him. It was only at this stage that help was there. Gary went in respite Monday to Friday and we were given a list of residential schools to go and visit.

The schools were all in the north of England. At the time, we couldn't face the fact that Gary had to go away, and the thought of him being hundreds of miles away - we were heartbroken. But we decided to give it a go because we felt that if we didn't Gary could end up drugged up so that people could cope with him.

Over the next two years Gary improved 100% and we were overjoyed when plans were made for him to return home, with the help of respite care, and for him to return to his old school and have a classroom to himself and a teacher plus a classroom assistant.

At first when Gary returned home we had lots of support. But as time went on, instead of building up respite so that we could have a break, staff at the respite centre felt they didn't feel confident to work with Gary.

Then Gary's Nan became ill and died. My Dad was dying of cancer. Gary had two helpers which was meant to be for most of the summer holiday, but they only lasted two weeks, and then said the agency had more work for them. I had to take Gary with me to care for my Dad. I wasn't getting any help with Gary. My Mum was disabled I was trying to cope with everyone. After two years without any respite, we decided that we couldn't go on.

So once again we started to look around for residential schools, hoping that things had got better and that there would be one down south, but it was the same story - everything was in the north of England.

I feel annoyed that children/young adults with challenging behaviour are sent hundreds of miles away from their families, causing upset to their families and to them. And it costs between £80,000 - £90,000 per child to send them! I feel as if a large part of my life has been taken away from me at the moment with Gary not living at home.

June 1997

Last updated: October 2004

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need, when you need it.

Our work is funded by donations, fundraising & grants; WE HAVE NO REGULAR GUARANTEED INCOME

Please support the Challenging Behaviour Foundation

*If you are a UK tax payer, through Gift Aid we can claim back 25p for every £1 you give – at no extra cost to you. Please sign the declaration below**

NAME: _____

ADDRESS: _____

POSTCODE _____

Please tick as appropriate:

I would like to support the CBF regularly. Please send me a standing order form

I enclose a donation I would like to Gift Aid my donation*

** Declaration: I am a UK tax payer – please claim back the tax on my gift and all future donations until further notice.*

Signed: _____ Date: _____

OR DONATE ONLINE:

www.challengingbehaviour.org.uk

**Please return to: The CBF, Freepost RRRH-GCJS-BRZJ,
The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 6BE
Tel. 01634 838739 Email: info@thecbf.org.uk**

ARE WE MAKING A DIFFERENCE?

If our resources or support lead to improved lives for individuals with severe learning disabilities

PLEASE LET US KNOW.

We are constantly needing to provide evidence to our funders and potential funders that our work does make a difference...

YOU CAN HELP US

by providing stories, anecdotes, or examples.

Please email, write or telephone:

THANK YOU FOR YOUR SUPPORT