Scope to...

Blogger pack

Change Someone's World – Scope Face 2 Face Befrienders

Scope's Face 2 Face befrienders scheme, matching parents with disabled children with trained befrienders, has changed lives – helping parents feel less isolated and letting them know that others have gone through the same experiences.

"It's a relief to know that there are other parents going through the same thing and that you can make contact and find out more", a Scope befriender.

Befriending parents of disabled children

Scope works with hundreds of families every day, but there are still many more that could benefit from a befriender. There are also many hundreds who could become befrienders themselves, but who still need to go through the ten weeks of intensive training that it takes to have the skills to support other parents. Find out more here: http://www.scope.org.uk/face2face

Scope is raising funds to get more parents through the face to face befriender training. The link to the donation page is: http://www.scope.org.uk/lifechangers

We are also aware that in these straitened times people may be unable to give money to causes but will want to be kept aware so they may help in other ways. In addition it is crucial to let parents of disabled children know that such services are available to them and we need to get the word out further. People can sign up to find out more about the service at: http://www.scope.org.uk/befrienders.

With your support we will be able to raise awareness about the service as well as raise vital funds for it. We have thought of some suggestions on how you can get involved later on.

Background information

Every ten minutes a family receives the news that their child is disabled. Having a child can be an isolating and anxious time, even without the added challenge of learning about your child's condition or impairment, so we are sure you can imagine the heightened stress and loneliness felt by the families of disabled children.

"Without this Face to Face service there would be nowhere for me to go for emotional support. I don't want to be a number in a medical waiting room. This is more heartfelt – it's not about 'fixing' it's about listening." **Charlene**

In the case of Charlene and Alison, both felt initially that they were going through a unique experience – and that their friends with non-disabled children struggled to relate. For Charlene, Alison's role as a befriender was not about 'fixing,' instead the focus was on listening – and drawing upon a shared experience.

"For me it's the kindness. Just having someone listen to me, and understand what I'm saying without judging me, is what makes this such a great service." **Charlene**

For Alison, becoming a befriender was an equally important experience, giving her more confidence and a larger support group of fellow befrienders. Having felt isolated being the mother of a child with Down's Syndrome she was keen to share her experience and help those having similar feelings. There was an intensive ten week course with 12 other parents with lessons every Friday made up of talks, speakers and sharing experiences.

"Isolation is such a common problem for parents of disabled children. Some people who contact Face to Face haven't got anybody. They really are alone." **Alison**

The Scope Face 2 Face training develops the skills that are so important in befriending: how to listen without judging, how to empathise, re-stating what the other person has told you to ensure you've correctly understood, offering and discussing solutions and acknowledging where formal counselling may be more beneficial.

The Face 2 Face service has had a big impact, with 87% of users saying that accessing the service had improved or significantly improved their confidence in and understanding of how to meet the needs of disabled child and the rest of their family.

About Scope

Scope is all about changing society for the better, so that disabled people and their families can have the same opportunities as everyone else.

It works with disabled people and their families, offering practical support – from information services to education and everyday care.

Scope challenges assumptions about disability, influencing decision makers and showing what can be possible. Everything it does is about creating real and lasting positive change in individual lives and in the world around us.

Ways to help

All parents know how difficult it can be straight after a baby is born but the challenges are multiplied with the added pressure of a diagnosed condition or impairment. The emotional support and shared experience that Alison offered to Charlene has made a life-changing difference – and we want to use this as inspiration for the wider campaign.

We want to hear about the people who made a huge difference to you when you had your first child or went through a similarly life-changing experience. We want to use the campaign as a time to stop and publicly say thank you to all those who have helped us; they might be family, partners, friends or even a stranger.

There are lots of different ways you can get involved:

Write a blog post

We would love for you to write a post on your memories of having your first child, or when you went through a similarly life-changing experience, and to whom you would like to say thank you for helping you through those challenging times.

As part of the post, you might want to include:

- A link to the campaign landing page: http://www.scope.org.uk/befrienders
- The stories of Alison and Charlene (see Appendix I below)
- Some of the image content attached

Use Twitter, Facebook and other social media

There will be a large social media push from Scope on the campaign and it would be great to have your support here. You can help us promote the campaign on social media through a number of ways:

- Talk about your blog content
- RT and share campaign content and what others are saying
- Use the campaign hashtags #lifechanger and #scopebefrienders
- Share the campaign on Facebook - https://www.facebook.com/Scope
- Encourage your readers to go to the landing page, fundraise or sign up for further information

Produce a vlog (video blog)

Alternatively, you can share the campaign via a video blog. A brief 3-4 minute video is an interesting extra piece of content for your site. This is another great way to say thank you and tell the story of how someone, or many, helped you through having your first child or a similarly life-changing moment. Similarly to the blog post idea, you might want to include the following:

- Talk about Alison and Charlene’s stories (see Appendix I below)
- Link to the landing page: http://www.scope.org.uk/befrienders
- Push on social media

Putting us in touch with other people

If you know other bloggers that might be interested in the campaign, please tell them about it and ask them for their support. We are always happy to talk to them and provide them with more details.

Appendix I: Case Studies – Charlene and Alison

Full Interviews with Alison and Charlene

Alison: I work as a cover teacher at my daughter’s special school for children with severe learning difficulties. My daughter has Down’s Syndrome. I also founded a parent and carer support group. It was at that group that I first heard about Face to Face, the headteacher had a leaflet and I thought I might sign up for this. I rang Anne but she had already filled the next training course with the maximum number of 12 people. But she was quite keen so she helped me get on the course, I was the lucky 13.

It was a ten week intensive course, once every Friday. The course helps you learn about other parents’ stories. All 13 of us had a child with a disability. Each week we had talks and speakers. Each week, a parent told a story. There were a lot of sessions sponsored by Kleenex! You shared confidential sensitive information in a really safe place. We made friendships, which I found one of the best bits.

It’s quite isolating being the mother of a child with special needs. My daughter doesn’t have many friends; nobody comes for sleepovers, so it’s only if I’m taking her to a club that I meet other disabled parents. Sometimes, you can feel like the only one going through a difficult time. But listening to everyone’s experiences and emotions was an eye opener. You are only living your own life and dealing with your own emotions.

Isolation is such a common problem for parents of disabled children. Some people who contact Face to Face haven’t got anybody. They really are alone. They might put their child on the bus to school and find it difficult to go out, walk into a support group on their own, meet new people. But a Face to Face befriender can come to your house.

We also had exercises and role play. You’d be talking and then you’d have a befriender and an observer. Once we’d all shared our stories, it was easier to do. It taught us how to listen properly and be very non-judgemental. It helped us give good eye contact and summarise what the person we were befriending was telling us. Whatever the befriender is telling you, you're there to listen. You can make some suggestions or signpost people to different services.

I lack confidence myself. When it was my turn to put my story across, I thought where do I start? I'd never shared any personal information about myself. It was such a release for me. I met some lovely people who listened to my personal story and felt the emotions I did. For me, as the weeks went by I was getting to know these people personally. They understood. I gained an awful lot and I've made some lovely friends. The befrienders meet regularly and give each other support.

The course has changed me as a person. I feel more confident now. I think it's helped me grow and find my voice.

If Charlene and a friend want to board a bus, there's only one space for a wheelchair. Even on the trains it's restricted.

Charlene: My son, Jacob, has got cerebral palsy. A good friend of his also uses a wheelchair. But when we all go out together, both mums and both kids, we can't get the same bus because there's only room for one wheelchair. Aren't disabled people allowed to have disabled friends?

It can be nerve-wracking to go to new places with my son, particularly if he's the only disabled child there. I don't like the feeling of walking through the doors and everybody turning in their chair to look at us. It makes me feel like we stick out. Also, as he gets older I'm finding it harder and harder to lift him.

I've been so grateful to Alison because she offers to come with me to after school clubs and that sort of thing. She helps me lift Jacob and she helps me deal with my nerves in new situations. Having her by my side has given me strength.

On Saturdays, when town is busy, I used to hate taking Jacob out. Not because I'm ashamed of him - far from it - but because people knock into his chair and stare at us. I get really anxious when people look. I don't want his disability to be an issue - I want people to see my fabulous boy, not his chair. I want Jacob to feel like he can do anything. So I wasn't dealing very well with the outside world, I suppose. I was too protective and defensive and when I got angry, Jacob got upset.

People's reactions are blunt, and I'm going to have to start handling that. Because Jacob doesn't look physically disabled, people think he's broken his legs. When I explain that he has cerebral palsy, I get reactions like: 'oh what a shame.' It's not a shame – it's not fair, that's what it is.

I wish I wasn't so explosive but Alison helps me deal with my anger and face the world with a calmer view. I used to hate the fact that Jacob needs a wheelchair. Now I can't wait for him to get his flashy new wheelchair – he's designed the colours himself!

Alison: Charlene is a wonderful mum, you can see how much she loves Jacob from the minute you see them together. We talked about Charlene's anxiety to get to the bottom of what was bothering her. I give her coping strategies, for example, if people are looking to say to them: 'hello, do you have any questions you would like to ask?' Face to Face is about the small things that make big differences.

Charlene: For me it's the kindness. Just having someone listen to me, and understand what I'm saying without judging me, is what makes this such a great service.

Alison: On the first day we met, I went to Charlene's house and we talked for more than four hours. From there we saw each other once a fortnight. Now it's only when Charlene feels she need to talk. At the end of the first visit, she said to me: 'was I alright'! Like it was some kind of interview!

Charlene: I had wanted to contact Face to Face for a long time, it took me years to build up the courage. Honestly, it's hard for me to speak about my son having a disability because I'm still coming to terms with it. I get very emotional when I talk about Jacob – I would describe it as a fierce mother's love. I wanted to wrap him up in cotton wool.

But I know in my heart that I can't, that being over-protective is not good for him. So eventually, my mum persuaded me to call. I took a deep breath and picked up the phone. I wanted to speak to someone who was outside our family and who could keep a calm head. Anne got back to me very quickly. She came to my house and we had a chat. She told me that she had two children with cerebral palsy. We bonded.

From that very first visit, I got support. I told Anne that I was struggling to keep my son at his school because it's private and the funding had run out. Anne mentioned a charity who might be able to help me and today, they are funding his fees – it's £154 a day! Without meeting Anne, who knows what might have happened? I would probably have had to move Jacob to a new school. (BACKGROUND: Jacob was in a mainstream school but was being taught on his own and there were no after school activities. Now he's been in a specialist school for 2.5 years. The school just presumed Jacob could stay, but the local authority wanted him to go to the local school. I put up a big fight and won! It was very stressful but all I ask is that Jacob is happy).

The biggest change for me is the freedom I have gained. I enjoy my son more. We go out and about and I feel less anxious about what people might think. Alison has helped me see the brighter side of things. I've stopped caring about what people think, and started celebrating Jacob's quirks and how special and imaginative he is. Jacob wants to be a priest when he's older. He can't tell the time yet, but he knows exactly when mass is!

Without this Face to Face service there would be nowhere for me to go for emotional support. I don't want to be a number in a medical waiting room. This is more heartfelt – it's not about 'fixing' it's about listening. I feel like a weight has been lifted. Sometimes my mind is so overcrowded with thoughts: 'Have I given Jacob his medication? When's the next appointment?' It can be completely overwhelming. This is a time to clear my head and think about me. I'm not just Jacob's mum, I'm Charlene.

Alison's daughter does not have the same disability as my son. But she's got the experience of going through life as the mother of a disabled child and that's what counts. My friends don't understand. Their experiences are so different to mine. For them, mealtime is simple, you sit round the table and everyone eats. But I have to sit with Jacob and sometimes I have to feed him. It takes twice, three times as long. This is the sort of reality that my friends don't understand what being a 24/7 parent is – but Alison does.

When Jacob was first diagnosed at three, I felt like landmark moments like walking had been taken away from me. But they haven't – it's just different. We celebrate different successes together and Alison has helped me realise that it's important to set different goals.

Alison: It's so rewarding to know that I'm making a difference. We've had a few tears together and shared intimate emotions. I feel honoured that she's shared her innermost thoughts with me. I've been there and I've felt alone. I know what it's like and I think that helps.

ENDS