

'BRIDGE' bringing generations together: Knowledge exchange programme for families and individuals living with Tourette syndrome (TS)

The monthly BRIDGE (Bringing together Different Generations) events were tailored to suit local needs; in Inverness, Fort William and Stonehaven they have happened on a Saturday afternoon as many of the participants have to travel over 20 miles on narrow roads; but in Glasgow, Stirling and Dundee events happened in the evening too. Most notably, Fife area group held a number of activities that included the older and younger people in such as water sports and barbecues, outings and meetings.

In all cases, the BRIDGE meetings were set out for the older people to explain their past situations to the younger Tourette syndrome members group, who in turn supported the older members to become more resilient in going out in public and dealing with unwarranted attention, as many of them had spent years in semi isolation.

The monthly events included training, peer support and mentoring, which meant that the older cohort gave support to the younger ones about dealing with the life-long manifestation of their TS, and both age groups shared experiences, whilst the youngsters are able to report on research, coping mechanisms such as Habit Reversal Therapy, and demonstrate the benefits of self management which had been elusive in the lives of older people with TS.

200 young people worked together with 87 older people, to develop the project further with introductions to management techniques, and for the cohorts of 5 groupings to meet one another formally.

A 'Gathering in Perth' brought together our cohorts, to celebrate healthy approaches, discuss management, offer training in management (Habit Reversal Therapy, relaxation, Having Your Say) and raise awareness with our roster of professionals and practitioners.

The funding also supported a wider ranging Outreach and Training programme and resulted in 24 bespoke visits to our groups, for delivering specialist support, awareness training, self help courses, and materials were developed during the BRIDGE project, that supported intergenerational work.

A new fact sheet was written by collaboration with the cohorts and a new training programme was also designed using this material, resource materials for GP's demonstrating the expertise gained from our members working together. It is clear that there is a difference between the treatment (both social and other) of adult people with TS, but the other side of the coin is that older members now are unable to compete in the employment market, or in social settings – whereas for younger people there is a modern emphasis on fitting in, being part of a crowd – and also there is the additional problems from social media which doesn't reflect conditions such as TS in a good way. BRIDGE has taken heed of this and the responses of the public, both age groupings helped one another cope with the prejudice and isolation that sometimes comes with the condition.

The programme also 30 new older volunteers to our cohorts, and have attracted older members to our meetings where it was previously perceived as being too family centric, or for individuals who were younger.

The team at Tourette Scotland have continued to deliver the project, and financially manage the budget: Project Co-ordinator, Outreach Worker (part time), Trustees: Treasurer, Line Manager (Chair).

Our new material includes how to cope with TS and what to do in difficult situations, contributed to and developed by our older/younger cohorts, collaborating.

It's evident that the generations can help one another. Without the funding of the Generations Together programme Tourette Scotland would not have been able to develop on the outcomes for the benefit of future generations of older people with TS.

Example of work written due to the work of the BRIDGE cohorts:

Information sheets

Rage attacks
Bullying
Tourette syndrome and employers
Tourette syndrome and college
Tourette syndrome and school
Tourette syndrome and neighbours
TS and sleeplessness
Parents coping, Grandparents coping
The GP appointment
Understanding and dealing with coprolalia
TS and school
What are tics
TS and Holidays
Police and TS
Dealing with difficult situations
Sensory processing and TS
Post Diagnosis – what next?
Do you think you have TS?
TS and bereavement
Teacher's pack
Professionals Pack
Our awareness training programme
Our Outreach programme
Our website, Facebook and forum

Case Study:

B has been struggling for four decades due to her TS, and spends much time indoors; she was pilloried at school, treated for mental illness despite the fact that TS is neurological in origin; and has never fulfilled her potential, or married, or became integrated in her community. As part of the Tourette Scotland support group in her area she did come to a few meetings, but found it hard to fit in as much of the group were 'boisterous youngsters, bitter parents' and she needed a lot of boosting to keep attending. When BRIDGE began, B was given a special support programme whereby we worked with her to build confidence and hear about the impacts of TS on her life, on a one to one basis. It was apparent that she wished to help others not live the life that she had. Our worker and B went to events, befriended a family with three TS youngsters; B became a supporter to two of the younger children (girls) whom she taught to knit, which calmed her tics and she thought would help them. They all went to support groups and outings together. The experience of B when at school, and then in trying to find love and work, had marked her for the rest of her life and she gave encouragement and support to the girls so that they would be able to self manage, ask for support in school, speak out about their condition in public, and become more confident to know about their condition and what it was really about, rather than the gothic experiences that beset B when she was small. B in turn, reflected on her condition, became challenging in her family circle when asked not to attend family gatherings and was stronger in her approach to how she was being regarded by others – and became more confident in self-management herself; joining a local craft circle. This has been a rewarding outcome for both an isolated older lady and a family needing experienced support through our team and from someone with a willingness to be engaged with them.