

SHORT BREAK CASE STUDIES

Date: September 2010

The case studies provided in this paper are real examples that illustrate the different ways that short breaks can be taken. The recurrent theme in each story is that a personalised approach, where the needs and aspirations of all those concerned is central to planning, ultimately leads to better outcomes. To achieve this, however, people needing support sometimes have to take control, collect ideas and information, and 'push hard' to have their views heard. We hope these stories will provide some encouragement and inspiration.

The names of the people involved have been changed.

Our online Short Breaks Directory (www.sharedcarescotland.org.uk) provides information on many different services across Scotland that can provide breaks in a variety of settings, catering for different ages and abilities.

Case Study: Terry & Family

Background

Terry is a 19-year-old man with muscular dystrophy who lives with his parents. His parents are his main carers and external support is very limited. His younger sister also lives at home. Terry uses a powered wheelchair for mobility.

Terry's short break

Holiday respite / short breaks were offered annually at a predetermined time which was agreed with Terry's whole family. Terry's family appreciated this as it gave them all the opportunity to plan well ahead and achieve maximum benefits from the breaks. The break itself comprised of Terry enjoying a five-day break away with a group of friends who also had muscular dystrophy at an activity centre which had a dedicated respite unit and support staff who were able to cater for all of Terry and his friends' needs. During this time Terry was supported to engage in a range of activities that most 19 year olds enjoy such as going to the pub, listening to music, going out for meals and to the movies, playing DVDs and computer games as well as wheelchair skating!

SHORT BREAK CASE STUDIES

Date: September 2010

Case Study: John & Agnes

Background

Agnes is a 70-year-old lady who lives with her husband John who is several years her senior. Agnes uses a wheelchair and has had adaptations made to her home. She is in the first stages of Dementia. John provides all her support. John has recently been getting bad nights' sleep because Agnes now needs care during the night. John and Agnes have never been separated throughout their married life.

John and Agnes' short break

It was clear that a short break would need to be identified which could accommodate Agnes's care needs through the night to give John a necessary break. It was also vital that they could continue to spend as much time as possible together.

What was identified and offered proved to be very successful. Agnes went to stay in a nursing home in a scenic part of Scotland not too far from her home. The nursing home had a designated respite bed and was able to meet her needs. In addition John was able to stay in a bed and breakfast facility directly next door to the nursing home concerned.

As part of the agreed plan each morning John would leave his bed and breakfast accommodation and join his wife for breakfast in the nursing home next door. They would then spend the remainder of the day together exploring the area, visiting the usual tourist attractions. Each evening upon their return they would enjoy dinner together in the nursing home before John left Agnes for the evening in the capable hands of the nursing staff.

Case Study: Robert & Pat

Background

Robert is an elderly gentleman who has had Parkinson's disease for some time. He cannot now be left alone and his wife, Pat, does everything for him. This meant that she found it increasingly difficult to do essential things such as keep dentists' appointments (she had to take Robert with her) or to do the things she had enjoyed such as attend meetings at her church where she had always taken an active role.

SHORT BREAK CASE STUDIES

Date: September 2010

Robert and Pat's short break

Robert has had the support of a paid carer twice a week for three hours for almost ten years now. The paid carer takes Robert out to places that he continues to find of interest, and this gives Pat the breaks that she needs in order to continue to live a life of her own.

Case Study: Isobel

Background

Isobel is a 69 year old lady who worked all her life as a nurse. After having a stroke, she needs to use a wheelchair and cannot get out of the house on her own. Isobel is able to deal with her own medication but relies on paid carers who visit periodically throughout the day to meet her needs in all other respects. She has very little contact with her extended family and her mental state is suffering because she spends so much time alone. Isobel was not deemed eligible for financial support for a short break from her local social work department on the grounds that there was no unpaid carer involved who required a break from their caring role. However the Council ran a Short Breaks Bureau and the staff there were able to give advice and information to help Isobel look at alternative options.

Isobel's short break

Isobel decided that a break was essential to her well-being and that she could meet the costs of this herself. With information from the Short Breaks Bureau, she contacted a private sector agency to see what they could offer. What was agreed upon was an all inclusive person-centred support package. This was made up of a 4-day short break at a hotel in Pitlochry inclusive of half board, transport, theatre tickets, excursions and a care companion.

Case Study: Eric & Family

Background

Eric is a 22-year old man with cerebral palsy who needs help to transfer to and from his wheelchair. He lives at home with both his parents in suitable housing; his father also has cerebral palsy. His mother is the main carer with additional input from paid carers, a physiotherapist, an occupational therapist and social work. There is no extended family input into the household, which is very busy most of the time with numerous paid carers and professionals involved in supporting the family. This leaves Eric with little privacy.

SHORT BREAK CASE STUDIES

Date: September 2010

Eric's short break

It was identified that the family needed a break, in discussions with all concerned it was agreed that what best suited their needs was for Eric to have a break on his own thus relieving the pressure on all family members. It was recognised and understood however that it was essential to ensure whatever was offered was age appropriate to achieve maximum benefit for all concerned. In the end a 5-day break was arranged for Eric and a companion (one of his own friends) to attend a world championship pool competition in England. Accommodation plus all reasonable expenses were paid for by the local authority in the form of a Direct Payment.

Case Study: Jane & Family

Background

Jane, a 19-year-old with a significant physical and learning disability, lives with her parents and two younger siblings. Both her parents provide full time care for her and her sisters with some additional support from social services. The family decided they wanted to enjoy a break away from the pressures of their normal caring routine as a family. In particular they wanted to be able to do something 'different' together that they might all enjoy.

Jane and her family's short break

A 7-day family break was provided on a canal boat, which cruised the Forth and Clyde canal. The boat was fully adapted and wheelchair accessible throughout. A voluntary skipper was also available to the family as required.

Case Study: Amy & Family

Background

Amy is a 23-year-old lady with Downs Syndrome who lives with her parents who are her main carers. Amy also has a younger sister who also had Downs Syndrome and a brother at university. Amy's brother is able to offer his parents assistance when he is back from university. Some minimal day care is offered by way of respite to the parents with some informal support also being offered by neighbours.

SHORT BREAK CASE STUDIES

Date: September 2010

Amy & her family's short break

Both parents were in need of regular breaks from caring for their daughters. It was important therefore that breaks for both siblings were coordinated to coincide with each other and were age appropriate as well as being acceptable to the parents who were anxious as to what might be available. What was identified in the end were regular breaks (approximately 5 days every 2 months) at an activity centre, which could accommodate both sisters at the same time. The facility concerned had a dedicated respite unit and staff, which were more than capable of catering for both their needs. Hence both sisters were able to enjoy a break together and engage in a range of activities which took their interest such as canoeing, cycling, rambling etc.

Case Study: Jack

Background

Jack has dementia. He had been able to have two short breaks each year staying in a guest house with a support worker, in an area of his choice. He could plan activities taking advantage of the support worker's car. This arrangement ended abruptly when he turned 65. After much lobbying, he was offered up to 8 weeks in a care home each year by his local authority but Jack was not happy with this arrangement and declined the offer.

Jack's short break

Jack was only able to arrange a suitable break when he discovered by chance that a care provider had a contract with his authority to offer a break in a bed and breakfast setting, but with full support from the hosts who were experienced and qualified carers. This was not a cheap option – the cost of food and care was covered but Jack had to pay his own fares to the destination, the travel costs incurred by his hosts, and the cost of excursions. Because it was a good experience he felt it was money well spent.

Case Study: Daniel and his Mum

Background

Daniel is a 12 year old boy who looks after his mother, Anne, who has severe arthritis and needs help with bathing, getting dressed and household chores. She also has mobility problems. Although Daniel attends school regularly and is doing well there, he spends a lot of time with his mum and misses out on doing the normal kinds of things for a boy of his age. He doesn't really have a lot of friends, but

SHORT BREAK CASE STUDIES

Date: September 2010

attends the local young carers group. An opportunity arose for Daniel to have a trip to London to see some of the sights, and go to a show.

Daniel's short break

Although Daniel had won the prize of a London trip, he really wanted his mum along as well. He knew that with help, Anne would manage to go to see 'The Lion King' with him, but also wanted to get out on his own to see some of the sights. With this in mind, his local young carers worker contacted the nearest young carers project in London, and arranged for the worker there, together with two young carers, to meet up with Daniel and show him around for one of the days. This gave Daniel a bit of independence and some company of his own.

Case Study: Alistair

Alistair who is 17, is severely disabled and profoundly deaf. He has complex health care needs including gastrostomy tube feeding, regular medication and occasional suction and oxygen. Because of his needs, any form of short term break must be well organised and requires carers to have skills and training on his health needs and his communication system. The difficulty of finding groups of people who have these specific skills, and that are working within an establishment that Alistair can visit, has led to his family using direct payments. They consider that whilst there are positives and negatives to Direct Payments, they do enable the provision of tailor-make breaks that are not only effective for the family, but also enhance Alistair's life. This far outweighs the negatives.

Alistair's family consider that Direct Payments work so well because they don't limit what Alistair can do, and because they can choose who to employ, Alistair's carers share the family's commitment to giving him a better life. They work together to think of ways to adapt what normal teenagers do, and give Alistair and his various disabled friends the opportunity to do the same.

Examples include:

- carers of the local children and young people who use direct payments, organize group outings, to the cinema, bowling, having a meal out or going shopping, so that they have peer activities and time away from parents;
- Alistair, supported by his carer, has had a friend to stay over for the weekend with her carer;
- Alistair was supported by two carers, to visit a friend who has recently gone away to college.

SHORT BREAK CASE STUDIES

Date: September 2010

About Shared Care Scotland

Shared Care Scotland is a national charity which exists to support the development and improvement of short break services for carers and the people they care. Our services include:

- An online and telephone enquiry service to help put carers and service users in touch with short break services that best match their needs
- General information and advice on all matters relating to short break services
- Events, networks, publications and learning resources to share knowledge, experience and successful practice.
- www.sharedcarescotland.org.uk
- 01383 622462