



**Shared Care Scotland**  
**Inspiring Breaks Programme**  
**Evaluation Report**

**Inspiring  
Breaks**



# Shared Care Scotland: Inspiring Breaks Evaluation

## Introduction

Our funding from the Long Term Conditions Alliance Scotland (LTCAS) enabled us to develop and deliver a Scotland wide programme of local **Inspiring Breaks** workshops to support individuals with long term conditions and unpaid carers to be **more actively involved in selecting and shaping** the short break and respite care services they receive, and to consider the outcomes they would wish such a break to have. The workshops took place between October 2010 and June 2011.

The workshops and follow-up activity were therefore designed to:

- Give service users and carers the **information, skills and confidence** to be the lead partner working with health and social care to determine the short break support they want;
- Provide **person centred planning** tools to help people to develop their individual outcomes and to plan how they can be more in control of achieving these;
- Explain alternative ways that people can be supported to have a break and how they can **mobilise wider community resources** for short break purposes;
- Empower service users and carers to create opportunities to contribute to local short break planning and commissioning will also be a key feature of the programme, giving them a **stronger say in the future direction of services** in their local area.



This report will describe the process of delivering the Inspiring Breaks programme, our learning from the programme, feedback from both participants and peer-facilitators, and ideas for the future.

## Peer Facilitators and Workshop Content

One of the key features of Inspiring Breaks was the involvement, from the very start, of Peer Facilitators who were themselves living with a long term condition, or caring for someone with one. We advertised widely through Shared Care Scotland (SCS) and LTCAS networks, and received 14 applications for the positions, from people throughout Scotland. The funding was initially for the involvement of five Peer Facilitators, but after interviewing short listed applicants, and finding the potential and enthusiasm amongst them to be so high, we decided to involve six throughout the national programme. Two of the six live in Highland, one in Aberdeenshire, one in Aberdeen and two in Fife. Three are carers, and three are individuals living with a long term condition.

Our first activity within Inspiring Breaks was to hold a two-day workshop with the Peer Facilitators. This served the following purposes:

- To develop, with them, the content of the Inspiring Breaks workshops
- To get to know them as individuals, and for them to get to know one another
- To develop their confidence in delivering the workshops

It was a very successful two days on all fronts – and together we developed the training programme and the core resource within the workshop, a Short Break Planner. We were very pleased to find we had recruited highly motivated, confident and creative people to work with us – and are confident that their continued involvement in the programme was a key to its success and impact.

The outline for the training day, which ran from 10:30-3:00, was as follows:

- An introduction to the programme, including setting the context of the Government’s funding being received through the LTCAS
- Icebreaker
- Defining ‘a short break’
- Modelling the use of the Short Break Planner
- Participants working with the Short Break Planner
- Input from the local authority – Q&A

In each workshop we distributed information to support participants, including hand-outs on:

- What is a Short Break?
- Accessing Short Breaks
- Planning for the Best Outcomes
- Alternative Short Break Case Studies

We did our best to ensure that we were able to offer a particularly nice lunch on each day, and that the venues were inviting – as we wanted to offer participants a ‘good day out’; being aware that such days were likely to be all too rare.

The role of the Peer Facilitator was key to the impact of the workshops – as they were people who had key experience in common with participants. This enabled an experience much different from working with ‘professionals’. These were people who had lived experience of the challenges faced by people in the workshop – as well as very motivating stories of overcoming or simply living positively despite some of these challenges.

### **Programme of Workshops**

Our intention was always to offer workshops throughout the length and breadth of Scotland – 20 in total. Some of the workshops we scheduled in the north failed to go ahead due to low numbers -Shetland, Moray and Inverness. These dates were re-allocated to other areas.

We were, however, successful in delivering 19 workshops, including one specifically for carers of people with mental health problems (in partnership with Glasgow Association for Mental Health), and one for young carers (in partnership with Edinburgh Young Carers). Peer Facilitators were present in every workshop.

In total, we reached 240 people living with long term conditions, or their carers.

<b>Location</b>	<b>Number of Participants</b>	<b>Date</b>
Renfrewshire (pilot)	11	26 October
Edinburgh (pilot)	15	9 November
Falkirk (pilot)	16	22 November
Aberdeen	12	2 February
Glasgow (with GAMH)	16	16 February
Dunfermline	17	21 February
Inverclyde	14	4 April
Dundee	10	26 April
Scottish Borders	8	27 April
Glasgow	16	4 May
Perth and Kinross	16	9 May
Dumfries and Galloway	12	12 May
East Ayrshire	19	12 May
Aberdeenshire	12	7 June
Argyll and Bute	12	14 June
Argyll and Bute (Short Break Bureau volunteer training)	4	15 June
East Lothian	17	15 June
Edinburgh (Young Carers)	8	16 June
Perth and Kinross (PR Carer's Centre)	5	27 June
<b>Total</b>	<b>240</b>	
69 had a long term condition, 158 were unpaid carers, and 13 were support workers.		

## **Pilot Phase**

We began offering the workshops in late October 2010. As it was a new initiative, we planned to pilot the first four events and then review the experience and adjust the workshop accordingly, prior to rolling the full programme out in 2011.

Our early experiences were varied – but gave us important learning for the rest of the programme.

We were surprised at the high number of professionals who put themselves forward for the workshop – at one event they were the majority of participants. This was despite the publicity being clearly targeted at people with long-term conditions and their carers.

Generally speaking, we heard that staff were keen to improve their own understanding of alternative short breaks, due to the emerging policies around *Personalisation* (offering more choice to those who receive support services) and an increasing number of local authorities seeking to offer more choice in the types of breaks people might access generally, including through the establishment of Short Break Bureaux.

While staff took up their roles in workshops in a various ways – some offering useful information to participants, and even practical support – we also had the experience of staff, due to their numbers, monopolising the workshop with their own issues as providers of short break services. As a result of this we established a policy that staff could only attend if they did so with someone with an LTC or carer, and that their numbers would be limited to 2-3 per workshop.

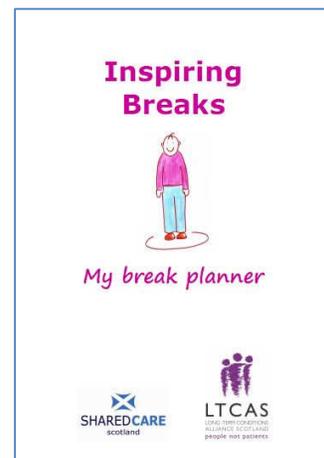
We also learned how important giving sufficient advance notice of the workshop dates was, as one of the four pilot workshops was unable to go ahead due to small numbers. The amount of time and effort required to promote workshops would also need to be increased.

In addition to the need for these changes, we were affirmed that the structure of the workshop, and the materials offered were appropriate and useful.

### **General Experience of Workshop Delivery**

While feedback on the workshops was overwhelmingly positive, we are well aware that the role of peer support, and the opportunity to share often distressing stories with people who genuinely can identify and empathise, was of equal value to all of the information and resources which we offered to participants.

Offering workshops during early 2011, in the context of drastic government cuts, we encountered many stories of services being withdrawn, reduced or simply not being made available. Some of the stories were truly heart-breaking – a kinship carer (grandparent) looking after a severely disabled child without any support, and in utterly inappropriate accommodation; a mother with three autistic sons who gets incredibly minimal respite; a young man with a learning disability who has had fantastic breaks while using children’s services, but who (with his parents) is now left with very little information or support to access breaks through adult services. We heard many stories from elderly people who are looking after partners with dementia or physical disabilities, who don’t take breaks because



they were previously unaware that it was possible to take them *with* their partner, rather than put this person in a care home in order to have a break.

We heard – consistently – that people are not given information by professionals, but find it ‘by accident’, if at all. We heard people sing the praises of local carers’ centres, but also their anger that they found these resources on their own; they were almost never directed to them by professionals.

Participants were very grateful for the written and verbal information we gave to them – and verbal information they received from one another. Again, we continuously heard their frustration at the fact that this information was not given to them by the many professionals (medical as well as social work) with whom they are in contact.

We attempted to have a manager from the local authority, who is involved in Short Breaks, present at each workshop to hear about the types of breaks that people were wanting, and to share information about local provision and developments in this area. In the end, we had involvement in 12 of the 19 workshops (we didn’t request that anyone attend the final workshop, with young carers). When people did attend, it was greatly appreciated by participants. However in some instances participants were frustrated with the information shared, or what they experienced as defensiveness. When managers failed to show, it reinforced the sense that the local authority didn’t actually want to know what people want, and did not aspire to work together with people who use services.

It was our experience that the programme of workshops really brought several of our resources – namely our on-line directory of short break opportunities, our alternative short breaks DVD, and the Short Break Planning Tool – to life, by showing them at use in a practical context. The online Short Break Planner has received 418 additional ‘unique visits’ since January 2011 and this is likely to be a result of the workshops.



As our Communications Development Worker came into post in the spring, he attended several of the later workshops to demonstrate how to use the on-line directory, as well as making it clear that the service can be accessed over the phone with the support of Shared Care Scotland staff.

People had a range of reactions to the Short Break Planning Tool. Many carers found it challenging to be asked to think about *themselves* – as they were so used to thinking principally about the person they care for. We often heard from people with long term conditions, and their carers, that it was difficult to find appropriate accommodation or opportunities which would enable them to have their ‘dream’ respite. We almost always heard carers describe how impossible it would be to have a quality break without feeling certain that the person they care for is happy, well cared for and having a break of *their*

choice. We also heard from many – particularly elderly carers – of the guilt they felt about having a break, despite knowing they really need one.

The workshop in partnership with Glasgow Association for Mental Health (GAMH) was possibly the most challenging session as - generally speaking - people with mental health problems and their carers are often not recognised as needing respite. We heard a great deal of frustration with the system, and also *very serious* need for respite.

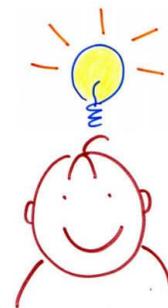
The most common reoccurring themes across the 19 workshops included:

- Poor access to information and resources
- Poor, and sometimes non-existent, communication with professionals (we regularly heard of phone calls not being returned)
- A sense that those who shout the loudest get the most (and that those who don't shout are often ignored completely)
- A lack of suitable opportunities for those with complex support needs, particularly children, and those with mental health problems
- Too little flexibility in the type of breaks offered, and the timing of them. We heard many people describe wanting more frequent breaks of a shorter length, rather than 1-2 weeks
- How restorative it is to come together with other people who face similar challenges – to share information, support and acknowledge the efforts that one another make.

## Participant Feedback

We asked participants to fill in a pre-evaluation at the start of each session, to tell us how confident they were in relation to the topics we would be discussing. We asked them to rank their knowledge (1-5) of the following programme aims:

- I have a good understanding of the range of ways that short breaks can be provided in different settings
- I know how to access and arrange a short break
- I am clear about the outcomes I want from a short break service, and have a plan to achieve these
- I am confident about assessing my needs and working with care managers, service providers and others to co-plan and meet these needs
- I am aware of ways in which I might share the future direction of short break services locally
- I am connected with other people in my area who require and are using short break services



*My Interests*

At the end of the session, we asked them to rank themselves again, to see if there was any increase in their knowledge. While we did not collect evaluations from all participants (in each session there were some people who had to leave early, or could only stay for part of the day, and left without filling them in at the end) we did collect them back from the majority of participants.

Of the total number of fully completed evaluation sheets returned to us (184), 97% showed an increase in at least one area of their knowledge – with the majority of those showing an increase in at least three areas.

The area that showed the least increase was awareness of how they might shape the future direction of short break services *locally*. When we designed the programme, our expectation was that representatives from local authorities would be able to let people in their area know how they might be involved, or consulted, particularly in light of the personalisation agenda which Council's are now seeking to implement. As several workshops were without a representative, and the quality of their input varied significantly, we believe that this reduced the potential for participants to leave feeling confident of how they might influence local services. We hope that by making them aware of Shared Care Scotland, and signing many of them up as members, we will be able to facilitate their influence nationally – as well as link them in with local opportunities we are aware of.

In addition to ranking their knowledge, we asked three questions at the end, in order to get some qualitative data about the workshops. A selection of their answers are given below:

***What worked well?***

*"To be able to talk about things with other people – the group was very supportive"*

*"Sharing experiences with other carers, and the clear information given by the facilitators"*

*"The chance to share views and opinions with other people and learn how they cope with situations"*



*"Finding out about what types of respite are available and speaking to the other carers about their experiences"*

*"Facilitators, the booklet, clear information – it was all very useful and practical"*

*"Learning about my right to have choice"*

*"The short breaks planning tool – simple and effective"*

*"To learn that both the carer and the cared for person can have a break together"*

*"Opportunity to give feedback to the Council"*

*"Breaking things down to their component parts"*

*"Discussion between us was unhurried and allowed information to be shared. Really appreciated facilitator's honesty and frankness in sharing his story...personal experience always makes a lesson more valuable"*

*"Being informed that there are people and organisations who can help"*

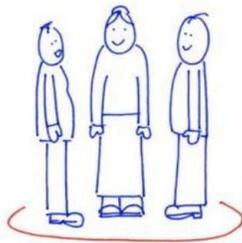
*"Thought the whole day was well structured – seeing the planning tool used first was really helpful"*

*"Very good day – worth the trip from Comrie!!"*

**What could have been better?**

*"Local Authority person was very evasive – could have been more up-front"*

*"Not so much 'paperwork'...maybe could have been sent out as pre-packs to read before, or have 'talking' versions"*



*"Sometimes delegates straying into personal experiences meant we did not get planner completed"*

*"More information about funding and an input from the Council would have helped"*

*"Not a thing!"*

*"More time – a longer session"*

*"Need more of these events, so that more people can attend and gain what I did"*

*"Needs to reach more people – maybe through carers' centres, or carers' week?"*

*"We don't all use the internet – please remember that"*

*"Maybe other people such as OT, Physiotherapists and social workers could have been present so they have all this information too"*

**What one message would you like to convey to people as a result of what you learned today?**

*"Come to one of these – you will go away with something and meet some great people"*

*"That there will be a respite sub-group formed from the carers forum, which will be somewhere to go for answers on how to make breaks happen"*

*"I am going to speak with my husband's social worker to make a better arrangement for my husband/family's break"*

*"I will contact Julie at the Carer's Centre to enquire what type of holiday is available or whether anything could be arranged to suit my needs"*

*"There is help, assistance, available – we need to work together"*

*"Carers need more support - local authorities need to be forced to fulfil their obligations to care for people and their carers!"*

*"We could do with more days like this – it was very informal, but very informative"*

*"Get help – don't suffer in silence"*

*"Plan our respite more carefully to make sure it is meeting the whole family's needs"*

*"I will stand up at my son's review and have our voices heard!"*

*"I am going to plan a break for myself and a friend. This course has opened my eyes to thinking about meeting my own needs and the importance of taking care of myself as well as my daughters. I have been given permission to put myself 1<sup>st</sup>...thank you!"*

*"Find out more about respite and go on Shared Care Scotland's website"*

*"I will be telling other families about what I have learned"*

*"Don't feel guilty about having a break"*

*"Contact my social worker and as for a re-assessment for respite"*

*"Keep smiling – there are worse problems out there!"*

## **Follow-up Evaluation**

When participants registered for the workshops, we asked if they would mind being contacted 4-6 weeks after attending, so that we could hear about anything they had taken forward from the day. We found, however, when trying to phone, that it was difficult to catch someone at a convenient time – so decided to send an email out to those who indicated they were happy to be contacted, and invite them to schedule a call at a convenient time or to send their thoughts in a reply. We did not receive many replies, as one might expect, but those which we did are below:

*"Through the Carers' Centre in Kilmarnock I recently received a 5 day respite break in Brighton. My father has had to be taken into care, as I could no longer cope. I enjoyed the workshop and gained a lot from it."*

*"I really enjoyed my day at the Port Glasgow Town Hall i found the day very informative but haven't put the information to use yet, but am sure I will."*

*"I took the information collected at the Inspiring Breaks Workshop to our regular meeting of Fife Action on Autism and some people were interested in what was happening re this."*

*"I think the most important thing I got out of the workshop was the "permission" to take care of my own needs. I now have a social worker for my daughter who now gets direct payments. I have employed a one to one worker to take her out at the weekends allowing me quality time for myself."*

In truth, the four replies we got back are probably fairly representative of the range of ways participants have taken their experience forward – no time to do anything yet with what they learned, shared information with interested others, made strong requests and secured additional services; and, sadly, found themselves no longer able to cope in their situation, with the inadequate support they were receiving.

### **Peer Facilitator Feedback**

As well as knowing we wanted to involve people living with long term conditions and carers in co-facilitating with us, and for them to have a positive experience of being part of Inspiring Breaks, we didn't give too much further thought to the success indicators for this aspect of the project.

As stated earlier, we were incredibly fortunate in the Peer Facilitators we attracted and engaged in this programme. The diversity of their own stories and experience was complemented by their shared commitment to this programme of workshops and desire to make a positive contribution to the lives of others who use short break services.

Working with peer-facilitators has been very exciting for Shared Care Scotland, and we are clear that they significantly increased the impact of the Inspiring Breaks programme. As an organisation, we will definitely seek to develop this way of working in the future. In fact, one of the peer facilitators is now sitting on the Scottish Government's Carers Strategy Reference Group!

They gave some important and useful feedback on their experience as part of this evaluation, as detailed below.

#### ***How was the experience of being a Peer Facilitator for you?***

*'I very much enjoyed the whole experience, from initial training and meeting the other peer facilitators to the workshops themselves. I felt well prepared and capable of fulfilling the role'*

*'Interesting – people have more difficult lives than me. I was touched by how people opened up – I thought it was very special how people shared their lives'*

*'The experience of being a peer facilitator was great – I enjoyed interacting with the other participants and also showing them how to use the planning tool'*

*'I found the whole experience of being a peer facilitator a very rewarding and humbling experience...I was amazed and disconcerted stories of so many unpaid carers and service users who experienced difficulties getting funding from local authorities to arrange even the shortest respite. In fact, it made me realise that my own long term health condition and respite needs were minor to what so many of the people who attended the workshops needed or experienced'*

**What did you enjoy most?**

*'Meeting other carers at the workshops, especially other parents with children with autism, and giving them hope that there is something that can make their children's, and their own lives, better'*

*'Having a new experience, and trying something different. Having something to put on my CV – I don't know where my life will take me, so good to do different things. The people I met were nice...actually, everything about it was enjoyable'*

*'The wide diversity of people of all ages I met and the respect they showed each other, immaterial of their individual situation and especially how no one was judgemental'*

*'I learned you could have a dream, and work out how to achieve this'*

**What could have been better?**

Each respondent replied to this question in relation to the workshop, rather than their personal experience...so answers are included below.

**What do you think worked well in the workshops, and what could have been better?**

*'The mix of people worked well but it may have been good to group people together with shared problems'*

*'I felt that just planting the seed of Inspiring Breaks idea was not enough to kick-start some people into action and that many of them might not have the skills to develop the concept further. Offering more support in the process would have been more satisfying for me personally and to see actual outcomes would have been most fulfilling. A professional from the local authority did not attend either of my workshops, and this lack of commitment was disappointing for everyone'*

*'I was very disappointed with the quality of the local authority representatives who attended my workshops, who with few exceptions were – I felt- very much on the defensive and in one case totally unprepared.'*

*'In my first workshop I worked closely with 4 ladies in completing the several pages of the booklet (planning tool) and this felt very successful. However in the second workshop this was less easy as there were fewer carers in attendance and it was more of an informal chat.'*

*This felt right in both cases and good that the workshop could be flexible in this way. The 'after lunch' sessions in both workshops were not structured as well (no one from local authority came, as planned) and it felt as though the day just 'fizzled out' rather than ending with punch, motivational material'*

*'Keep professionals and people who use services separate – what they need is too different, it didn't work'*

***Has being a peer facilitator had any impact on your plans for the future?***

*'I appreciate what Shared Care Scotland are doing and want to be involved in more work like this. I would like to see a workshop like this specifically for parent-carers and those in Highland (Inverness was cancelled due to low numbers) sometime if possible. Personally, it has made me think even more creatively about how I use my son's SDS package'*

*'Being a peer facilitator has made me want to do more work in training'*

*'The experience I learnt and gained was how to plan, organise and facilitate a workshop especially designed for a certain group/community of people. I believe my self-confidence has improved from my participation and observations...'*

*'I really liked being a co-facilitator – I would like to do it more. I really like working with people, and helping them through sharing my experience.'*

***Do you have any ideas about how we might develop Inspiring Breaks?***

*'More in-depth workshops with more practical help, rather than just giving 'theory''*

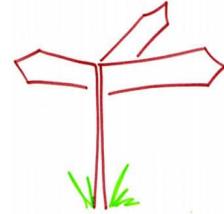
*'In an effort to increase attendance at workshops in future, I advocate considering contacting the relevant support organisations directly to ascertain the best day for the most people to attend. Possibly involve peer facilitators in following up the invitation to the workshop by telephone to encourage support organisations to be aware of the benefits that people would gain from attending'*

*'It might be good to train staff in other areas so that they can deliver the training to carers in their areas'*

*'Give staff a better idea about what should be possible for people who use services – their rights, what they want.'*

## Future Possibilities

We were approached by two local authorities about the possibility of delivering training in their area to local peer facilitators. We did go ahead with this training in Argyll and Bute, who are currently piloting – in partnership with The Red Cross – offering a short break bureau in their large, rural area. Training was delivered to three volunteers from The Red Cross, and the bureau Co-ordinator – with an emphasis on facilitating use of the Short Break Planner on a 1:1 basis.



Shared Care Scotland is keen to develop this approach further, and plans to seek further funding from LTCAS for this purpose. Training individuals – those with long term conditions and carers - for the purpose of supporting others in their networks to use the planning tool is an obvious next step, as it improves the likelihood that this funding will have a more sustained, and broader impact. A similar type of workshop could also be useful for staff who providing short breaks, as it would help them develop a new way of thinking about breaks, and offering people a break that suits them...their interests, their aspirations and their needs.

The key messages from the workshops will help to focus our efforts on improving provision and access to information and advice. In fact, this is already happening, as we have just initiated a piece of research into carer's experience of short breaks, and we have framed some of the questions around the issues that were raised through Inspiring Breaks to see if these are more widespread.

The 'Time to Live' fund which Shared Care Scotland is administering on behalf of the Scottish Government and National Carer Organisations, will give carers and service users the opportunity to apply for funding locally to support the short breaks they want.

## Conclusion

In summary, we are very pleased with what we have been able to offer through the Inspiring Breaks programme, and excited to think about how we take it forward. We have put the Short Break Planning Tool onto our website, so that it is widely available, and have begun conversations about what the next phase of this work might be.



The feedback from participants, and peer-facilitators, tells us that it was – on the whole – a valuable experience for those involved; and helped us learn about how we might make the next phase stronger still.

Involving local authorities in the programme has strengthened our relationships with them, and encouraged them to think more broadly about how they can open up more flexible short break opportunities. From our experience in the pilot workshops, we believe that

staff *do* indeed need some support, and training, to develop their confidence in providing breaks in new and different ways.

We wish to acknowledge the very important role of the two principal facilitators of Inspiring Breaks, who were key to each stage of its development and delivery – Jo Kennedy and Joette Thomas. It is also important to acknowledge the role of our Shared Care Scotland team member Lesley Gudgeon – who administered the programme, which was an enormous and constantly changing responsibility. And finally thanks to Helen Wilson at Envision for her Inspiring Break illustrations.

We are very grateful to the Long Term Conditions Alliance Scotland for the opportunity to develop the Inspiring Breaks programme, and the legacy which we will work to ensure that it leaves.



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