

ARTICLE FROM REPORT

Life balance workshops at Douneside weekend for parent carers

Ross Stoker



Ross Stoker, Male Carers' Development Worker: Ross has worked with children and young people with disabilities, predominantly autistic spectrum disorders, and their families for over 15 years. He has held a variety of positions, e.g.

playscheme worker, one-to-one, supported living, outdoor activity holidays, supported work placements, Adult Basic Education tutor, Social Worker, etc. He qualified in post-graduate Social Work in 2005 and came to VSA Carers' Centre to launch the Male Carers' Project in August 2006. In his spare time Ross facilitates a weekly social group for young people with Asperger Syndrome. Ross is currently working across Aberdeenshire on a project funded by the Scottish Government to explore the needs of men with a caring role.

Note: This article is compiled from the report of a two-day respite and training event held in North East Scotland in February 2008 to discuss the issues facing parent carers of school-age children with disabilities. The weekend was organised by VSA and the material is reproduced here with their permission.

Summary

Seven couples from across Aberdeen and Aberdeenshire, all unpaid carers for at least one child of school-age with a disability, attended a two-day residential event at Douneside House, Tarland, Aberdeenshire. The weekend, organised by VSA (a major social care charity in the North East of Scotland) began at 11am on Friday and ended at 4 pm the following day. The couples all stayed overnight within the main house and had exclusive use of the luxury facilities (gym, swimming pool and beautiful grounds) throughout their two-day stay. All meals were provided to a very high standard and all places were fully funded by VSA Male Carers' Projects. The three consecutive workshops featured in this article took place on the second day and began with men and women in separate groups discussing aspects of life balance. Parents valued this opportunity to reflect on their situations and emotions and couples felt that thinking about the similarities and differences between men and women had been highly productive.

The full report is available for free download from www.vsa.org.uk/carers-info.html

Introduction

'I have enjoyed everything about this weekend. The setting and the house are outstanding. A breath of fresh air! Thank you to everyone involved, greatly appreciated. It needs to reach a far wider audience for other parents to be able to gain better knowledge.'

- A parent.

This residential weekend in February 2008 at Douneside House, Tarland, Aberdeenshire, was attended by seven couples who were all unpaid carers for at least one school-age child with a disability. The weekend, organised by VSA (a major social care charity in the North East of Scotland) began at 11am on Friday and ended at 4 pm the following day. The couples all stayed overnight within the main house and had exclusive use of the luxury facilities (gym, swimming pool and beautiful grounds) throughout their two-day stay. All meals were provided to a very high standard and all places were fully funded by VSA Male Carers' Projects. The programme for the weekend consisted of a mix of training workshops and relaxation opportunities.

This article features content from the Life Balance Workshops that took place on the second day.

The workshop facilitators were:

- Sue Barnard, Development Officer for Families of Children with Disabilities, VSA.
- Gwen Currie, Freelance Life Coach and Consultant.
- Chris Sojka, Male Carers' Support Worker, VSA.
- Ross Stoker, Male Carers' Development Worker, VSA.

Life balance workshop one

After morning coffee, the group was asked to form two discussion groups, male and female.

The men went with Ross and Chris to the lounge and the women stayed with Gwen and Sue in the conservatory. Both groups were asked the

same question and the subsequent discussions (ninety minutes) were recorded on flipcharts and digital voice recorders. The next few pages will highlight and compare the key points that the men and women chose to speak about in each group. The following symbols are used to show whether the quote is from a woman or man:



The simple question for both groups was, ***What is different since you became a carer?***

There were many similarities in perspectives and shared views across both groups, but also differences in how these were expressed, how they coped with changes and how issues were prioritised. As it turned out, ninety minutes of continuous discussion barely scratched the

surface of what could have been talked about. Overall, there were more similarities than differences and someone remarked that perhaps Venus and Mars weren't so far apart after all.

Both groups felt that the caring role had changed their lives to different extents. The initial response to the question from the men's workshop, after a moment's collective silence, was... 'Everything!'



It's almost like every decision you're going to make, the first thing you have to do is consider how it will impact on the caring situation...your whole life is conditioned by that need.

This was echoed in the women's group but particular focus was attached to the impact on other members of the family, especially siblings.




I think my youngest has a terrible time because he has had to grow up very quickly.




I do feel guilty that I haven't given her the time she requires, she had a terrible childhood really.


Feelings of guilt featured prominently throughout the women's discussion. The men chose to speak more about stress. There was a consensus across both groups that becoming a carer went hand in hand with elevated levels of


stress. Where differences emerged between the groups, they were about the methods people chose to cope with stress.

 You develop different coping mechanisms...I take off to the hills and I feel like a right selfish person but sometimes all I really want to do is escape from that immediate pressure.


 That's why I go for a run after work, it de-stresses me. If I don't, I know I'll walk through the door like a coiled spring.

The men spoke about coping with stress through such activities as jogging, making music, playing football, working on cars, golfing, going for a drive. Most of these were solitary pursuits without other family members but some also involved the child with disabilities and/or their siblings. The women's group spoke about escapes too but on a smaller scale and more often whilst performing some other essential task, e.g. walking the dog, going round the supermarket, having a bath. Some felt that their caring role had significantly restricted any, even all, opportunities for escape.


 As a carer you are always bottom of the list, you always have to get everyone else sorted out first.

 I think when you become a carer the guilt thing hits you, it's a big one...I'm still learning how to deal with that.


Again, guilt seemed to provide a barrier to the women finding time for themselves. There were also lots of practicalities that got in the way too, e.g. one child received a support worker for one day a week to allow the carer to have time to herself but she referred to this day as her 'cleaning day', which was not to be considered an 'escape'. However, the need for breaks from caring was clearly acknowledged.


 ...you need to get away from caring because you are actually a better carer when you come back in. The way I do it now is to always have something planned...so that, if I can just get


through this, I have something to look forward to.

 It's like sawing through a big bit of wood. You can saw away, you stop for a second, your arm recovers and you can saw away. You've still got the big bit of wood to get through. Small breaks make it manageable for the overall journey, you know?


Work and employment was only mentioned towards the end of the women's session and did not feature significantly in the main discussion. Some female carers spoke about giving up paid work, reducing hours or providing unpaid, work-like tasks for neighbours, outwith their main caring role. Various opinions about work emerged.


 I like to get to my work to escape.

 I go to work for a break – it is still easier to do this job than do the work at home.

 I don't want to work, I want to *escape!*

For the men's group, paid work featured strongly in the discussion. All of the men were in employment except for one man who had given up work to become a carer for his wife and son. The men felt strongly that, for them, going to work was not an escape.

 It's [*the caring role*] always in the back of your mind.

 You can go to work but you're still thinking about it...there's an awful lot of pressure you feel on you, you're like a split person.



You're trying to hold down a job and you've obviously got to try and give everything you've got to your work and be seen to be doing your job as well 'cos you need your job to support your family. But sometimes you go to your job and it's difficult to concentrate on whatever you may be doing because you're thinking what's going to happen with this and what's going to happen at home... What does it affect? You can't categorise it because it is everything.

This discussion also raised a common issue across both groups of sleep deprivation.



Any job on 2 hours sleep is going to be a nightmare, that can impact on moods, diet, all sorts of things.



It's a constant battle with sleep deprivation... that's the biggest single thing that hits you.



The sleep issue is a big, big thing. The lack of sleep if you're constantly woken up. I don't think people realise if your sleep is broken every night for months, I do believe your body adjusts to it but then it becomes slept from whenever we went to our beds until 6am and I couldn't get back to sleep again.

The women spoke about this too but focussed more on sleep deprivation as one of many factors that contribute to an overall decline in mental health.



Exhaustion is caused by a lot of things – lack of sleep, not letting your mind rest. I don't get physically exhausted but I don't know why... It is mental exhaustion because of the fighting you have to do.

This group explored the impact of a caring role on their mental and emotional health, resulting

in periods of feeling low and a diagnosis of depression for some.



...you have to get on with it, it is your child and as long as a child is happy, loved and cared for that's all that matters. But it impacts on your health as well, you don't have choices, you just have to get on with it, nobody is going to say, 'Well, what do you want to do?' You don't have a choice – you just get on with it.

The women talked about loss of identity to varying extents, how it affected them and also how they felt other people did not always realise this.



[I feel] invisible as a person – well, your needs come last. Your own needs come last and everyone else's come above you, and people ask how is the person you are caring for and not how are you.



Some people ask how is your wee girl, how *[are they]* but what about me? They don't think that you just say yes she is fine everything is fine. I never thought of that before, I am always *[my child's]* mother...

Both groups spoke about how caring had affected them in terms of their social opportunities and relationships with their partner, family and friends.



We both had a large circle of friends but we just don't have time for them any more.

We're just down to a handful now. We've lost touch with really quite a lot of people.

Just haven't got time...



Losing your friends, the social activities so I have had to rely on my immediate

family to be my friends, to be my best friends...



You've so much to organise before you go out...when you're shattered and you're both shattered, going out for a meal, getting a taxi into town, taxi back...it's too much like hard work!



What most people deem to be such a normal easy-to-do thing, just for you and your wife to go for a meal is so difficult because you then think 'who are we going to get to look after them?'



You just don't have time for friends, because your child with disabilities has become the focus, they go away with all your energy and attention you have got left and you just want some 'me' time...some times you just want to chill.



You need a bit of 'me' time. My wife is in with [our child] all day. I come home and she'll be in a bad mood 'cos he's been at her all day. She needs to get out sometimes. I don't always appreciate that enough...

The potential for the caring role to put strain on the relationship with their partner was a common theme in both groups.



...when you have the child all day and your husband is coming in and you want him to take over and you want to take a back seat but he has actually been working all day, that doesn't happen and you say 'right I've had it!' You forget because you have had her all day but he has been working and you haven't been working. I work in a school so I am off all the holidays, so I am on holiday but I am not on holiday because I can't do what I want to do, I am doing what has to be done.



...you're getting irritable, your partner's irritable. Without a break you know, and it's usually when they're in hospital and it's got a bit intense and you don't get the break and suddenly you discover

your allowances you make with respect to each other...now she's 'crabbit' at the wrong...you're out of phase with your 'crabbitness'. You're not in sync with each other. That allowance, having to check yourself and make that mental correction where you say almost, 'Right, this is her turn'. We do have, like any couple, to stop and say 'it's her turn' or 'it's his turn' and I think that's actually quite an important part of managing it.



Yes, it does put a strain on the relationship, I have met quite a few mums who are all on their own.

Having spoken about coping mechanisms, escapes, the effects of having a caring role and how to cope, the groups also looked at support needs. Are support groups or internet forums helpful?



I think an [internet] forum would be a good idea. I don't think a meeting week in/week out would work because what would eventually happen with a meeting would become just another meeting, what with the situation we've got with our kids, yet another meeting.



I am not speaking about a meeting as such, I am talking about let's go there and talk about us and have a cup of coffee and a laugh and a chat and maybe once every so often go out and have a meal together. That is what we do in [our local town].



I think it depends a lot on the individual because there is a [condition-specific support group] and [my wife] goes to it and I think I heard the other wives talking about coffee mornings and that, and [my wife] does go along and does glean a lot out of it, she enjoys the company, she enjoys that sort of...but we then go to functions where...children's parties and other dads go and...I absolutely hate it, I really do, from the time I arrive to the time I leave because I have nothing in common with these people apart from having a child with [specific disability]. If

I'd hit it off with somebody and become friendly with somebody it'd be fine but because I have not, I just feel awkward and unhappy that I'd rather be spending time with my friends at that point. Also my little girl's got blonde hair but we don't have other meetings for blonde haired children so...I can understand the thinking behind it is a good idea, that's just me, I find it painful. I've really enjoyed this weekend because I've gotten on with people.



I find that speaking to other mums who have kids in [*my daughter's*] class, we can stand and talk for hours and comfort each other. I have a friend, she is a neighbour but she is a friend. Her son has ADHD and she says I have given her the support because I have more problems and I have been there longer, my nephew has ADHD so I give her support. I do find that meeting someone weekly/monthly would help but then it is different for women.



I think having the support [*is important*]. If you imagine having the opportunity to come together once a year and swap your stories over the year or whatever the development is, has got a value because it's 'Let's have a right good session, let's see how well the support's working'. If the frequency's too regular you sometimes feel you have to generate something to go with (*firm agreement from rest of group*) that's a bit false. Knowing that exists. To be able to underline it with this kind of meeting [*Douneside weekend*], now and then, face-to-face with like-minded people...it's just great, it's super, it's a way of reinforcing how we feel and how it's going and I think it's just excellent. Personally, I wouldn't like to see it much more than that. If we needed it, we'd go to the centre and get some help and support and knowing how to do that, but now and again I think this is great.

In addition to the above sample of comments, one mother was in the process of setting up a new support group in the city. These discussions would suggest that the two groups on this

weekend appeared to have quite different views regarding the usefulness of regular support groups to them.

Both groups felt that the Douneside weekend was meaningful for them and were keen to repeat the experience.

Life balance workshop two – feedback

After lunch the groups met separately again to spend half an hour briefly looking over the flipchart comments made by the other group in the morning workshop.

There was a significant air of anticipation in both groups prior to finding out what their partners had spoken about. Inevitably, with only seven couples, there were also attempts to identify 'who had said what' but, overall, anonymity was maintained and two highly productive discussion sessions took place.

Some of this discussion has been integrated into the summary of the previous session, above. Both sets of carers were reassured that many of the things discussed were from a similar viewpoint. The topics of health, sleep, stress and social opportunities were all very similar. The men acknowledged that they had barely spoken about guilt but could identify with feeling 'guilt at not doing enough'. There certainly was an aspect of guilt attached to the fact that the men discussed the impact of caring more on family pets than on siblings but it was felt that the discussion had just not headed in that direction and would have been covered at some point. The women's group were surprised by the amount of topics the men had spoken about (seven flipchart pages), especially regarding relationships. In response to the men talking about how they could not 'switch off' whilst at work:



I often thought that he is away to work, he has escaped. That is a key point for me.

The men had spoken about how important a sense of humour was in coping but this had not been mentioned in the women's session. However, they agreed it was a key coping mechanism, for them too.



You have to laugh or else you'd cry.



Sometimes there is humour and sometimes there is not, depends what kind of day you are having. Sometimes you laugh at an incident, it is not that you want to laugh but if you don't laugh you will lose the plot.

One aspect of the women's group which the men found particularly powerful was concerning how some of the women felt about their identity and mental health. The women's group had written 'I am invisible – I am a shadow'



...strong...thought provoking.



...there's another thing we touched on earlier in people not recognising what they're doing. If a person's self-worth has come down to feeling invisible and you've not noticed that, it's a terrible sort of admission to say 'gosh, I didn't even realise you're now at the point where you're feeling that your own personality has been absorbed by being a carer.



That 'I am invisible' rings of a feel of undervalue. 'I don't expect myself to be recognised, it's just something I have to do' it's along those lines...that's strong that is. I still can't get over how strong that is.

The men went on to speak about how aspects of depression and anger affect them but, for a number of reasons and to different extents, cope with them in a different way.



Just deal with it. It's that wee talk with yourself...it's almost like a realisation that I don't like where I am at right now but I've accepted I'm there and shake myself out of it a wee bit...

There was much agreement about how the caring role is a teamwork exercise but that each person's roles are essentially different and an 'equal share' is not necessarily what is needed or expected in every situation.

The purpose of this feedback session was not to analyse what had been said in depth, but rather to let people consider what had been talked about in the groups and for each person to draw out their own themes from it.

Life balance workshop three

Having considered the ways in which caring impacts on their lives and hearing the different ways in which other carers deal with their own situations, both groups came back together as one large group again to share their thoughts about their own life balance.

It had been the original intention for Gwen to introduce the couples to a selection of tools which can help identify and explore aspects of life balance. However, a short discussion about the earlier workshops revealed that there was potentially a lot to talk about within the couples. The carers felt that they had been able to consider their caring role in new ways and that, for some, this was the first time they had taken an opportunity to think this way and share their thoughts with their partner. In response to this, the group was given the option of collectively discussing the tools (which were also included in the info packs) or to use the time available to speak with their partners about what changes they could make to improve their future situation as carers and partners.

The group were very much in favour of taking this opportunity to spend time as couples and discuss what emerged from earlier discussions. Some chose to find some confidential space within the building and some took a walk around the grounds. Upon returning to the group, the couples were not asked to share what they had spoken about but all agreed that the time together had been highly productive. Feedback sheets completed later on made specific reference to how useful this session had been and urged the facilitators to consider repeating the exercise in future respite weekends.



You should do that exercise when you talk as a couple every year.



For me, finding out how the female carers views differ and also the similarity of how they feel.



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In conclusion

One aim of this Douneside weekend was to bring couples together to discuss issues surrounding caring for a child or children with disabilities. The concept of training for carers is not a new one and we are aware of several examples of good practice. The Douneside weekend aimed to find an innovative way of delivering training, entirely built around the needs of the carers.

Whilst there was a pre-prepared programme for the weekend, the approach was informal and flexible so that the schedule could be adjusted in line with the needs of the carers. Part of the focus was on providing training in different aspects of caring (i.e. different approaches to meetings, what is person-centred planning, life balance, etc.), but in such a way that the experiences of the carers in the room could be shared and incorporated into the collective learning experience.

A further aim of the weekend was to provide a respite opportunity for the couples to enjoy time together away from their caring responsibilities. This has been highlighted as something that rarely happens for most couples and tends to fall to the bottom of the priority list where the needs of the cared-for come first. For many of the carers, the 'respite and relaxation' opportunity was their first priority when choosing whether to come or not.

Carers and facilitators alike considered the weekend to be a great success on several levels. Here are a few of the feedback comments on what worked:

* Sharing ideas and thoughts.
Feeling that you could say anything and others understood.

* It really helps to put things into perspective and also to know you're not alone.

* The house was just a treat!

* I have enjoyed everything about this weekend. The setting and the house are outstanding. A breath of fresh air! Thank you to everyone involved, greatly appreciated. It needs to reach a far wider audience for other parents to be able to gain better knowledge.

The author can be contacted through IQJ's editor.