

*Bindi Gauntlett describes how a series of workshops for carers of dependent relatives helped them recognise and better meet their own, often neglected, needs.*

# The feeling of being cared for

**M**ARGARET yearned for the days when she went abroad on holiday with her husband Michael, staying in luxury hotels, soaking up the sun and the sights, and eating delicious meals cooked by someone else. But they had not been able to go away together on such a holiday in years.



Michael suffered from a range of chronic disabilities, including kidney disease, which obliged him to have dialysis three times a week, and they now struggled financially. Margaret felt sad and frustrated that she could never again share the kind of experiences with him that she so wanted. But when, in the carers group she was attending, she started to see the difference between wants and needs, she realised that what she wanted might have been the full trappings of a carefree holiday but what she actually *needed* was the feeling of being cared for and sharing carefree time with her husband. When she recognised that, she began to think about getting that need met in different sorts of ways, such as making an occasion of going to a lovely country hotel with Michael to enjoy one of their special teas. In such small ways, she could ensure that she too received the caring that she needed.

Learning to enjoy the present instead of regretting a lost past and lost future was one of many life-affirming moments for those who attended “Finding the Balance”, a set of six morning workshops based on the human givens and specially designed for people caring for chronically ill or disabled relatives. The workshops came about after the Wiltshire Human Givens Centre was contacted by a team from Bath and North East Somerset Council, who were running a project called “Give us a Break” – part of a government initiative to recognise the needs of carers and provide opportunities for them to learn new skills or enjoy relaxation activities, with respite care provided for their relative, if needed. The “Give us a Break” team knew of the human givens and had been impressed by the “Just What We Need” parent courses based on the approach;<sup>1</sup> they felt it would be useful to offer something similar to carers, so that carers could be more aware of and mindful of their own needs, as well as those of the relatives they were looking after. As I am an experienced human givens therapist who has also trained in the “Just What We Need” programme for parents, it seemed we had a match.

We arranged to run the workshops twice, once on a Monday in one venue and once on a Wednesday in another. At first, the proposal was that we would use one of the community resource centres

in the area – which were often rooms within residential homes. I felt very strongly, however, that, if carers were to be given a break, they should be made to feel special and looked after. So we ended up in a hotel for one group and a former stately home for the other – both of which were luxurious yet homely. The workshops ran for six weeks, from 10am till 2pm, with a coffee break for real coffee and home-made pastries mid-morning. Every session ended with a guided relaxation and a story and then we all enjoyed an extremely tasty lunch. Those who could not easily make their way to their venue were collected and returned in a taxi paid for by the project. All this was much appreciated by people whose circumstances dictated that they did not get out much and often did not have much money. They felt appreciated and pampered and that in itself lifted moods and made them more open to sharing and experiencing new perspectives.

“Finding the Balance” aims to enable carers to recognise the importance of their own needs and find healthy ways to meet them, in the process creating more ‘spare capacity’ to manage both their caring role and their lives outside. Many different life circumstances were represented among group members. Some were carers of spouses, some of parents or adult children, and some cared for more than one person. A few had been main carers for just a couple of years, most others for seven or eight years and one had been caring for her learning disabled son for over 40 years. Many people were well educated and had had professional careers, while others had been unskilled workers or had not had paid work at all. Sometimes caring roles had increased gradually, as a result of chronic illness; for others, the mantle of main carer had been assumed suddenly, after an event such as a traffic accident or a stroke. But the one trait everyone had in common, their caring, enabled them to connect with each other almost immediately.

It quickly emerged that most people had signed up for the workshop because they felt that, in the course of their caring role, they had started to lose their sense of themselves and wanted to create a healthier balance in their lives. They wouldn’t have wanted anyone else to be doing their caring and some came seeking reassurance, encouragement and hope but most, it seemed to me, were looking for a renewed sense of meaning, outside their caring role. We established at the outset a group agreement, which included confidentiality and respect for others’ opinions, and

this quite quickly enabled people to start relaxing and opening up.

### I want and I need

The format of the course was the same for both groups and, in keeping with the principles of human givens, identifying and discussing essential needs seemed a sensible place to start. Once we had got comfortable with each other, I asked people to form pairs and to complete some sentences beginning "I want" and some sentences beginning "I need". Distinguishing between wants and needs proved to be a tricky concept for many to get their heads around at first. Then Margaret had her breakthrough moment and others followed, if not immediately, then over the next few weeks. One woman, for instance, who was caring for her husband with dementia, had said, "Sometimes I want to slap Phil." Later on, she came to see that what she needed was to find a way to calm herself down at such times and distract herself instead. Another woman said she was supposed to have a knee operation but considered that just a want, as she had no one to look after her elderly mother, so had kept putting it off. She came to realise, with the support of the group, that she needed the surgery; it wasn't an optional extra and, if she didn't have it soon, she would be incapable of caring for her mother at all. Sharing such stories helped people to take different perspectives on matters that they might have had closed minds about.

It was helpful for people to look at the human givens list of essential needs and interpret what fulfilment – or lack of fulfilment – of them meant in their particular situations. The need for security, for instance, brought up many concerns. Some people felt less financially secure; some felt insecure because they didn't receive much help or respite and had to fight hard to get assistance, when they didn't have the energy left to do so. For others, their sense of security had been dealt a savage blow by the suddenness of the change in their lives – this was particularly the case for one woman whose husband had had a stroke; in a moment, all their plans for retirement had been wiped out entirely and she no longer felt 'safe' in any expectations. We looked at different ways in which people could increase their sense of security. For instance, Kerry wanted to be able to have a weekend away with her husband to build on their relationship after nine years of caring for their son, who needed physical care three hourly, day and night, whilst Jim had only recently become aware of an agency, which could help fund private care for his wife, and was able to plan the first step towards accessing this.

The need for emotional connection struck a lot of chords. Many people felt sadness about their gradual loss of connection with partners or parents who had dementia and, as with Margaret, the importance of valuing and enjoying the 'now' was brought to the fore. Aileen shared the fact that her husband, who had moderate dementia, had always used to dry the dinner dishes as she

washed them and would sing while he did so. Now, if he watched her doing the drying up, he would often sing one of those songs to her, almost as if he were serenading her. It was, she realised, a special moment to treasure when it happened.

With the increased burden of caring, a number of people had let friendships go and could recognise that they needed to pay more attention to staying in touch, even just with a phone call. One or two people, however, felt that spending time with friends without their spouse or when their spouse was unable to do the same would be disloyal. Sharing this in the group helped them to see that pursuing friendships didn't betray their emotional connection with their partner but would be more likely to enhance it, if they felt less trapped and resentful, as a result.

### Ruth's dilemma

Ruth had been married for 45 years to a man who, from her description, was clearly on the autistic spectrum and had been careless of her emotional needs over those years, so, for her, the emotional connection had not been strong to start with. She felt she had had to cope largely alone in bringing up her three sons and now she was spending her twilight years caring for a physically disabled man who had become even more selfish and sharp – a much harder ask when the love had not been strong to start with. She learned the benefits over the weeks of finding healthier ways to cope with unreasonable demands. For instance, he had a tendency to fall asleep in the afternoons and then want to watch late-night news programmes and discuss them with her, when she wanted to go to bed. By a few weeks into the course, she had started saying to him firmly, "That's a very interesting topic. I'd love to talk about it tomorrow", instead of silently fuming or feeling bullied. She also became more resolute about insisting on having some private time to visit her children and grandchildren, instead of giving in to misplaced guilt.

Unsurprisingly, most people felt they were giving much more attention to others than they received for themselves and came to recognise how this might be affecting them – becoming unreasonably angry with their loved one, for instance, or seeking attention in inappropriate places. One man felt, on reflection, that it was for this reason that he made so many calls to his siblings to tell them about the small details of their mother's day.

People who had given up careers or jobs or who were already retired when they became carers often felt a strong loss of status, especially if they did little outside their caring role. (Similarly, many felt that they weren't achieving anything of value and that their day was made up of just a collection of chores, which they would usually fail to get through. We were able to address this when we looked at the value of goal setting.) One man was a skilled artist and resolved to find the time to express this aspect of his sense of identity again. Others realised that they were still good gardeners or organisers and, indeed, carers – all



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of which gave them a specific status in the eyes of many others. Karen, the woman who had spent over 40 years caring for her learning disabled son, felt liberated, to use her word, by the realisation that, in all that time, she had been not “just a woman who had never had a paid job” but someone who had a distinct, important role.

### Loss of control

Most people felt that they had lost control (of their own lives), while being given – or taking – too much control over someone else’s and responded readily to the idea of becoming conscious of choice, both to recover and give back a degree of control. For instance, carers could still make many choices – about what they ate, what they wore, how they spent any free time, etc – and could ensure their loved ones exercised simple choices too. Before leaving to come to the group, Celia had used to prepare her husband’s lunch and leave it ready for him on a plate. She had realised that, out of what, in this case, was a misplaced sense of caring, she had been mollycoddling him unnecessarily. “Now I say to him, ‘There are rolls in the fridge and there is ham or cheese to put on them.’ He has lost control over so much but he can make a sandwich and he can choose ham or cheese, and then he can make his choice when he feels hungry, not hours in advance, when I would have prepared it.”

A few people were able to see the need for control reflected in the behaviour of members of their families, such as siblings or adult children, who, while not themselves bearing the daily burden of caring, were very ready to criticise or give advice. Recognising this as an expression, albeit sometimes inappropriate, of an essential need enabled carers not to become so emotionally aroused by it.

This whole process of looking at needs also helped people realise that they were already meeting some of them sufficiently, and that was reassuring to them. One woman lived in a small flat, where she cared for her disabled father and her young autistic son, with whom she shared a bedroom. She felt she had very little privacy but then mentioned that she had a dresser drawer in her bedroom, in which she kept her most precious things. Her son knew that this was ‘her’ place and he must never open the drawer. That gave her a small sense of privacy, even in her crowded, often hectic surroundings. Neil, on the other hand, who cared for his wife and rarely saw family or friends, felt that home could often seem empty rather than private and that he would feel more of a sense of privacy if he went to the café in the local library centre and just sat with his thoughts as he watched people passing by. Later, organising such an outing became one of his goals.

Discussion of the need for meaning and purpose led to some poignant moments. Everyone had a very clear purpose in terms of their caring role but most felt that they had also lost meaning, through abandoned hopes and plans and inability to look far into the future. For a few, sense of meaning still came through part-time paid work

or through their faith, but others realised that they very much needed to find ways to re-establish a sense of who they were in the wider world.

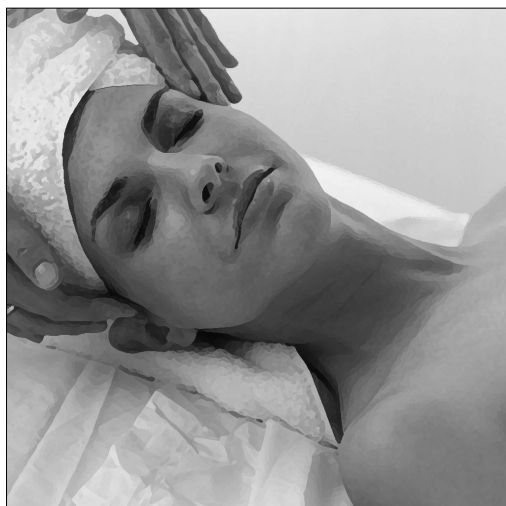
We spent quite a lot of time discussing the differences between typical male and female responses and behaviours. For instance, women, who are more naturally multitaskers, might have too great expectations of ‘mono-tasking’ male partners or parents with memory loss. A woman might, for instance, give her father or her husband two or three instructions at once, instead of one at a time, which would be easier for him to process, or a list of three items to buy from the local shop, causing anxiety and memory failure, when asking just for one would have led to a successful outcome. It was revelatory for some women to learn that, in certain important respects, men’s brains work in different ways from their own, and vice versa. One man asked, to the hilarity of the female members of the group, “What is multi-tasking?” Appreciating that men and women very often communicate differently (with the male’s emphasis on facts and the female’s emphasis on feelings) helps any couple handle differences and conflict better – and so is especially valuable knowledge in the confines of carer relationships, where emotional arousal is common. Feedback, at the end of this first session, showed that people were clearly connecting with all the new information we were discussing.

### The brain box

In our second week, we started to look at innate human resources. For this, I brought out my ‘brain box’, a cardboard box filled with appropriate items to represent the different resources of the brain. (This is an idea borrowed from the toolbox used in the “Just What We Need” programme for parents.) People were quick to recognise how they might use their imaginations, represented by a toy butterfly, which can be made to gently flap her wings or to collapse completely if pushed too far – What if I don’t hear when he calls? What if she falls when I’ve popped out to the shop? What if I don’t get the medication right? – and were very interested to learn how allowing their anxieties to run away with them was a prime cause of difficulty in falling sleep, staying asleep and waking unrefreshed, which almost everyone suffered a lot. The expectation fulfilment theory of dreaming made a lot of sense to them (and they enjoyed the toy toilet I produced, as a concrete representation of dreaming as the flushing away of emotionally arousing ‘waste’ that hasn’t been discharged during the day). We spent some considerable time on discussing ways to improve sleep – for instance, practising 7/11 breathing or, if people were awakened in the night by some concern, writing it down to help them ‘park’ it and let them fall back to sleep. Just sharing ideas and techniques, tried and tested or novel ones, seemed to help everyone. As Margaret said, “Talking about this in the group makes me realise that we all have the same sort of sleep problems. It isn’t just me lying awake at night.”

## Lighter memories

Memory is represented in my brain box by a jewellery casket containing toy bracelets and snakes, and pattern matching by a disparate set of plastic birds. People recognised that they often thought regretfully of the past when confronted by reminders and that they could make much more positive use of their memories to lift themselves and to bring them closer to partners or parents. For instance, saying, "Do you remember how we used to do such and such together?" could bring a smile to the face and a chance to enjoy the occasion again in imagination – creating a different pattern pathway in the brain. They also realised that they could take control of how they responded to unhelpful pattern matches. For instance, it might always have been a bone of contention that someone's



husband left the top off the toothpaste or someone's wife didn't turn the tap off fully, and thus finding the toothpaste in the wrong place altogether or the tap flowing freely, as a result of that person's memory loss, could lead to excessive irritation or anger, if the arousal was not recognised for what it was and checked.

The realisation that a negative thought is sufficient to create negative emotion resonated with many people and they were extremely receptive to the idea of reframing negative thoughts. In small groups, people explored more positive ways to express critical thoughts such as "Why can't I be more like so-and-so?" (for instance, "How can I be more like so-and-so?") and re-wording sentences featuring that turn-off trio 'ought', 'should' and 'must'. We explored how different the feeling was when we focused on desired outcomes instead of doing a duty – for instance, "I'd like to make Martha/Mike a cup of tea now, as I know she/he will really enjoy one", rather than "I ought to make a cup of tea now"; "I'd like to have the ironing done by 6pm, so that I can relax" rather than "I should be doing the ironing". For people whose lives are taken up more than most by chores, the impact of this simple change of emphasis was perceived as very helpful. It was also useful to think how valuable the same tactic might be, when employed in communication with the relatives being cared for. Rather than, "You must take your pills", "We'll be able to go out for a stroll, once you've taken your pills" and so forth.

I was keen to get people setting goals for themselves and this was explored through the medium of a picture showing a climber progressing in small steps up a mountain path, negotiating obstacles on the way. Carers often feel

that they limp through their days, aware of all the tasks that need doing and never experiencing a sense of achievement because it is impossible to do them all. Having a goal changes the emphasis. Small tasks, such as making a phone call to the pharmacy or changing the sheets, become perceived as small triumphs when completed, if identified beforehand as goals.

People also found their days had more of a framework when they set such goals and there was less sense of guilt when other tasks were not completed, if those tasks weren't on the goal list for the day.

Equally important, however, was to set goals that reflected what individuals might like to do for themselves – such as go for a relaxing massage, phone a friend, take a walk alone, visit a café with a friend – and to break even these down into smaller

steps, such as first making the appointment to have a massage or phoning to arrange the meeting with the friend or arranging for someone to sit with the parent/child/spouse while they themselves went out. This latter threw up some interesting responses when people realised that sometimes they themselves put obstacles in the way of setting such goals – "I couldn't leave Patrick with my sister. They don't get on" or "No one else can do such-and-such like I can".

As might be expected, the emphasis was on goals being positive, achievable, related to needs, time limited and specific (PANTS, illustrated by a cartoon of same, courtesy of the "Just What We Need" course). One man initially said his goal was to find peace of mind and that he didn't know how to set about getting it. He wanted not to be worrying about doing things wrong or not doing enough for his wife. I suggested instead that he might try to become aware of anything that already gave him peace of mind, even just for a limited period. As the weeks went by, he realised that pottering in his garden gave him peace of mind and he chose to set goals around making sufficient time to do so.

## Taking time

For carers, it is especially important not always to be rushing to complete the next task or focusing on what else is waiting to be done but to take five (on the mountain) and enjoy the view so far. Appreciating the now meant a lot to people, when they allowed themselves the space to do so – the aroma and taste of a savoured cup of coffee, rather than one swallowed in haste, the joy of looking at or walking in the garden. One day, at one of our venues, the trees in the extensive grounds were covered with frost and looked still and beautiful. We took a few moments simply to

appreciate the view and to recognise how important it is for all of us to stay in touch with nature. Research has shown how confinement in concrete urban spaces can increase anger levels, while looking at nature calms us. That reminded people of how beneficial it was, both for themselves and for their loved ones, to get out into countryside (even if it seemed such a chore to organise) or, at the very least, to sit somewhere with a view. Such seemingly small things had huge value, they could see, because, when they themselves felt contentment, that communicated itself to their loved one.

Focusing on the now had another important benefit. No one at either group ever chose to look into a future in which their loved one would no longer be with them. What they wanted was to make more of each day, for their loved one and for themselves. They responded cautiously, at first, to the suggestion of sharing in the group each week three good things that had happened in the previous week. As they readily admitted, the demands of caring often led them to focus on what didn't go right rather than on recognising what had brought pleasure. But they quickly got the hang of noticing small pleasures, such as an unseasonably warm day, an enjoyable conversation or a minor accomplishment that had brought them satisfaction. Aileen, who had had one particularly worrying week when her husband was extremely unwell, still managed to come up with her positives, and found that helped her.

### The power of positive

Keeping emotional arousal levels down was something we returned to a great deal over the weeks. People began to experience for themselves how changing a negative thought into a positive thought or action changed not only their own mood but also that of their relative. They practised more strategies for averting or cutting short irritable reactions by doing something positive for themselves (such as painting, embroidering, putting on a refreshing face mask or listening to music) and particularly popular was the suggestion that, when the person they were caring for took a nap, they could choose to take a nap themselves, if that was what they most needed, rather than running on empty, frantically trying to seize the break to complete some chores. (This is the exactly the advice that is given to frazzled new mothers.) Anxiety-management techniques, such as stopping catastrophising, not trying to cram too much into a day, and relaxation, breathing and mindfulness exercises



were eagerly received, as everyone admitted that they worried inordinately. Also welcome was the idea that people didn't have to invite more anxiety into their lives in the form of reading the news or watching it on television. Most news is negative and, although it somehow feels that 'grown-ups' ought to keep abreast of the news, it

may be much wiser not to when spare capacity is in preciously short supply.

Just as learning how reframing a thought could change a feeling was significant to people, so was the understanding that our reality is what we perceive, and that perceptions can change. We looked at some of the classic pictures that show this vividly – a duck

that, viewed differently, can also be a rabbit; an ugly old crone who, viewed differently, can also be perceived as a beautiful young woman, and so forth. Looking at an Escher picture helped further embed the idea that what might appear impossible perhaps is not – Escher had to create his 'impossible' pictures, after all. That day's session ended with the marvellous story of the cracked pot (see page 35), which does much to illustrate the importance of going beyond face value – particularly meaningful when caring for loved ones who are no longer their old selves.

When, in another session, we looked at the power of sayings to convey wisdom succinctly, one group member instantly offered up the line from Shakespeare, "There is nothing either good or bad but thinking makes it so", and the following week gave us, "Fear knocked on the door; Faith opened it; there was no one there".

### Our many selves

In our last session, we explored feelings further and how difficult it could be sometimes to identify them absolutely.

We also explored our many sub-personalities, using Pat Williams's powerful idea of seeing ourselves as the directors of our own operas, deciding which of our cast of personalities should, at any point, be taking centre stage.<sup>2</sup> I illustrated this with an unusual puppet of Red Riding Hood that I once came across in a curiosity shop; turning Little Red Riding Hood upside down, so that her skirt falls over her head reveals Granny, while the Wolf emerges from underneath Granny's bonnet. Characters that group members identified for themselves included Margaret Thatcher, Rescuer, Mummy Mum, Sister Theresa, Tantruming Two Year Old, Life Saver, Bossy Boots, Dora Do-As-I Say, Machiavelli, Comforting Clara, Old Bag,



## The cracked pot

AN elderly Chinese woman had two large pots, each hung on the ends of a pole which she carried across her neck. One of the pots had a crack in it while the other pot was perfect and always delivered a full portion of water. At the end of the long walks from the stream to the house, the cracked pot arrived only half full. For a full two years this went on daily, with the woman bringing home only one and a half pots of water.

Of course, the perfect pot was proud of its accomplishments. But the poor cracked pot was ashamed of its own imperfection and miserable that it could only do half of what it had been made to do. After two years of what it perceived to be bitter failure, it

spoke to the woman one day by the stream. "I am ashamed of myself, because this crack in my side causes water to leak out all the way back to your house."

The old woman smiled. "Did you notice that there are flowers on your side of the path, but not on the other pot's side? That's because I have always known about your flaw, so I planted flower seeds on your side of the path, and every day while we walk back, you water them. For two years I have been able to pick these beautiful flowers to decorate the table. Without you being just the way you are, there would not be this beauty to grace the house." ●



Grumpy Old Woman, Cup Half Empty, Sue the Secretary, Ted the Technician, Ginger Rogers, Claude the Clown, Cowardy Custard, Struggling Adventurer, Moaning Minnie, Strict Teacher, Financial Adviser, Nora Nurse, Dutiful Daughter, Brave Soldier and Danni Depressed.

We put the concept into practice by imagining ourselves embarking on an event such as a difficult discussion with a hospital doctor or a worrying appointment and deciding who it was most sensible to take to the occasion and who should be left out of the action.

### Scaling wellbeing

Towards the end of the final session, everyone completed a wellbeing scale. In pairs, people discussed where they would site themselves on a 10-point scale, where 0 represented feeling really quite low and 10 feeling about the best they could feel, and what they would need to do to rise one point higher or maintain their position. Afterwards, Ruth said that she was on a 10 right at that moment – having a pleasant time with others she could be herself with, enjoying being 'off duty' and anticipating a delicious lunch – but that she knew she would be down at 1 at some point later.

"It isn't desirable to stay at either end all the time but, if you are always in the middle, you aren't really living," she said. For her, having highs and lows and accepting that both would pass made her feel more alive than coasting. Others, however, felt that they were in the low to middle most of the time and that it was important to keep doing something, however small, to give themselves a lift. One did so by always having fresh flowers in the house, another by going into the garden, another by reading poetry.

People could see that periodically scaling how we are feeling serves to make us *conscious* of how we are feeling and how we can, if necessary, act to alter our mood. Every one also recognised that they cycled throughout the scale at least once each month, each week or even each day - and it was comforting to have evidence that even the worst times always passed. Scaling could also be a helpful tool to use with loved ones. If scaling

itself was not appropriate, the same effect could be achieved by asking them questions that brought them into the moment and made them aware of good times at the very moment that they were experiencing them: "You look really happy today"; "You are enjoying this film a lot, aren't you?"

### What helped most

At this point, we too looked at what had been enjoyed, or most valued, over the six weeks of our course. The pluses were plentiful and varied, from im-

portant basics such as the pastries and lunch, getting out, getting pampered and the luxury of being brought by taxi, through to meeting new people, sharing ideas, learning practical coping skills and strategies, feeling safe, listening to others, differentiating between thoughts and feelings, recognising the possibility of change and learning that carers could give themselves a break.

I felt privileged to run these groups and I hope to persuade other councils of the value of running something similar. As a society, we are indebted to those who so willingly shoulder the burdens of caring and we owe it to them to help them make their lives as fulfilling as possible, within the constraints of caring. The human givens approach is the perfect vehicle for conveying the know-how to do so. ■



### REFERENCES

- 1 Hoggan, L and Kane, C (2008). "Just what we need". *Human Givens*, 15, 2, 30-5.
- 2 Williams, P (2008). *Our many minds and the opera of life*. *Human Givens*, 15, 2, 12-18.