

# Step by step support leads back to a rewarding life

I t had always been a sort of dream that I would open a small residential home with three little old ladies with dementia and give them, my staff and myself a good time, while providing them with truly person-centred care. I was to fulfil this dream, though it involved meeting the needs of not the 'little old ladies' I had envisaged but men with Korsakoff's syndrome (see box, overleaf).

Steven is one of my clients. His story goes back to autumn 1999 and charts two years. It is a tale of recovery and optimism and the day-to-day realities of person-centred care in action.

## A waste of time?

Steven was on a medical ward at the local hospital. The staff on the ward did not hold out much hope for him as he had what they called 'wet brain' - by which they meant that his brain had been damaged by alcohol. We had been described to them as a rehabilitation facility and they felt we would be wasting our time on him.

A CAT (computerised axial tomography) scan had shown atrophy, and the psychiatrist had diagnosed Korsakoff's syndrome. Steven needed prompting in all aspects of self care, had previously been incontinent, and was extremely repetitive in conversation. He did not understand where he was or why, but thought he was in the hospital to do some maintenance work as this had been his occupation.

The social worker had approached us as she was finding it difficult and distressing to find an appropriate placement for someone his age and with his diagnosis, and was hoping we might



Bryn Derw

have a place. Fortunately a bed had recently become vacant.

It was agreed between his social worker, his daughter and myself that it could be worth Steven coming to Bryn Derw for a trial period to see if we could meet his needs. The main concerns were whether we could ensure he had no access to alcohol, could supervise his taking of medication and vitamins, and make sure he had an appropriate diet.

When Steven was told he was to move he was shocked at the information that he was not returning to his flat but going to a residential home. However, when he arrived with us his daughter helped him to unpack his few belongings and he enjoyed lunch. He then spent the afternoon in his room.

## Early days - pointing the way

The next day Steven was confused but talkative. He was able to find his way round the house by means of the easy directional signs and arrows, 'Toilet', 'Bedroom', 'Bathroom', provided. When his ex-wife rang him up in the first month of his stay, he was distressed and confused as to why he was there and not

with her, despite the fact that they had been divorced for years. The distress quickly disappeared, however.

During the first few months, Steven needed to have a member of staff in the bathroom to ensure he washed himself. I find this difficult to remember or accept when I look at his independence now.

## Encouraging healthy habits

Following a visit to the psychiatrist, Steven was given thiamine supplements (see box, overleaf) and vitamins. As he became more aware of his problems, he became low in mood and therefore St John's Wort was added to treat his depression, with great success.

While he was in hospital, Steven had stopped smoking. At Bryn Derw he asked for a cigarette a couple of times, but staff explained to him that not smoking would aid the recovery of his brain. They also told him that nicotine would increase his stress levels which in turn could impede memory improvement, and Steven accepted that he no longer smoked.

A month after he came to us, Steven was able to make hot drinks for himself and another resident June, who he befriended and helped care for. He would lie in until late, then help with June. He would push her in a wheelchair wherever she wanted to go and without complaint, help her at meal-times, chat to her, and keep her interested and happy by watching videos and listening to music with her. Although he was still sometimes confused and disoriented, June did not notice this, and Steven appeared genuinely settled and at home.

He enjoyed taking part in quizzes and doing crosswords, and was especially likely to take part in activities where others' needs were paramount. Steven was even aware of this himself: he once told me that if I ever wanted him to do anything, the best approach to get him motivated would be to tell him that it would help someone else!

Steven was always looking for purposeful activity and would also help in the kitchen if well supervised. However, if he was involved in something, carers would need a lot of patience. Everything would take much longer due to the prompts and reminders Steven required to tackle even the most simple task. ->

This story is set in a family-run home called Bryn Derw. Manager Lynda Boughey has expanded her services and now runs Carezza Care. This organisation combines direct services to individuals in their own homes with a small residential unit that is being developed, and a range of other training and consultation services connected to alcohol-related brain damage. Carezza Care has four independent flats in a supported community house which is used as part of a rehabilitation process to offer greater independence and control to individuals. The philosophy remains that which is captured in this article - that a positive care environment can tailor and design support to each person's unique needs and maximise the abilities of that individual. Lynda says, "It is our belief that the environment and care regime is paramount to the success of rehabilitation. We believe that people who have suffered from a brain trauma, whatever the cause, have the same right to an ordinary life as everyone else and that it is important to make every effort to establish the optimum level of ability of such individuals."

## Responding to changing moods

Steven's mood was changeable. This was particularly the case when family visited and on these occasions a carer needed to stay in his room as the normally placid, caring man could be angry, moody and verbally aggressive with his relatives.

Steven would have times when he was deep in thought but would not want to talk about these thoughts or feelings, and we quickly learned when to give him the time and space he needed. On admission we had completed a *Getting to know you* form. One of the key messages from this was that Steven was someone who liked people. He also stated that his biggest fear was being alone and lonely, which was probably why he was so settled at the home, as it is impossible to be alone there unless you want to be.

When a change was happening in his thought processes, we could always tell. Steven would bring his book downstairs for days but would rarely get past page six. He seemed to use the book as a reason not to get involved if asked to take part in a game, for example, but it actually meant he was deep in thought.

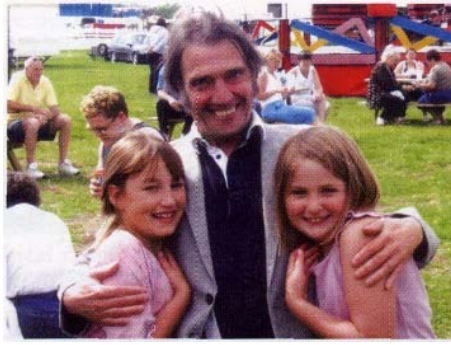
Twelve months after he arrived, we gained some insight as to why Steven said little. He explained to another resident that he was having difficulty distinguishing truth from fiction - his correct memories from his incorrect ones - and that rather than confront or upset people, he chose to keep his thoughts to himself.

Christmas was a difficult time for him and his family. Steven was distressed by his problems and his relatives felt guilty but unable to have him home over the festive period because they remembered the previous Christmas when Steven had had problems with alcohol. In the end, however, Steven passed Christmas quietly with our own family and did not show any concern about not being with his own. He enjoyed all the activities and outings we organised, including going to watch all the staff from the local hotels jump into the sea on Boxing Day.

At new year, he enjoyed the millennium fireworks and kept busy fussing over June all evening: was she warm enough, did she want a drink, and so on.

## The women in Steven's life

In addition to June, there were two other important women in Steven's life. They were aged five and six! One was my daughter and the other my granddaughter. Steven spent hours being taught by one - she is extremely bossy and does a great impression of her teacher! With the other little girl, he spent time drawing. Both children benefited from his time and attention over the two years he lived with us. He helped them with reading,



This friendship helped Steven to develop new qualities of patience and understanding, and both children benefited from his time and attention. He helped them with reading, writing and arithmetic, and taught them to tie their shoelaces.

writing and lots of sums. He also had the patience to teach them to fasten their shoelaces.

One of the wonderful things about this contact was that Steven was not only starting to recover some of his previous skills, he was also developing others, such as patience and understanding, which had not been part of his personality before Korsakoff's. It was clear that his intelligence and cognitive abilities were noticeably improving and he would increasingly answer questions on the TV programme, *Who wants to be a millionaire*.

Steven became increasingly able to take care of himself and to pay more attention to his personal hygiene. He was now shaving without as many prompts and would bring his washing to be laundered. Sometimes he would bring clothes down which had not been worn since the last wash, but this was easier to bear than his not washing or changing his clothes at all.

## Increasing Steven's confidence

Steven's repetitive conversations were always apparent. However, the content was often very appropriate and became increasingly knowledgeable and informative. His short-term memory was still very poor, but with patchy moments of clarity. As his confidence increased, his witty sense of humour also started to appear. His long-term memory was still very much intact and when we tried to interest him in an activity we kept to his existing hobbies or occupations to ensure success and to increase his self-esteem and sense of self-worth. Steven also completed forms for Community Voluntary Service, though he did not hold much hope of being accepted.

During an Alzheimer's Awareness Week, Steven attended activities with other residents and staff and was due to attend a pub quiz on the Wednesday evening. At teatime, he explained to me that he would not be able to attend as he

was unsure he would be able to go into a pub and not drink alcohol. I felt so proud of him recognising this possibility and feeling strong enough to tell me, rather than risk embarrassing himself in the pub.

By this time, family visits had become a very cheerful affair and Steven would make drinks for everyone - very much as if he were receiving visitors in his own home. Steven started to visit his daughter in her home and soon began to build a relationship with his grandsons. When a new one was born, Steven was thrilled!

Our voluntary worker started to play chess with Steven who was out of practice and had to face losing most of the games. However, Steven's chess game improved to the point where he was beating the volunteer. He was unwilling to join the local chess group, however, as the meetings were held in a local club and he felt unable to go anywhere near alcohol. Steven appeared to retain the knowledge that alcohol caused his problem and that he must never drink again, although in other ways his memory had not improved at all.

A new male resident was admitted who enjoyed snooker and chess, and the two men would start a game without prompting. They enjoyed each other's company, laughing, joking and chatting together, not noticing that they were repeating their conversations and jokes.

Steven continued to be attentive at all times to June despite deterioration in her health and her growing inability to respond to his attempts to cheer her up. We recognised that Steven would need new activities built around him, given the worsening in June's condition and the prospect of her needing to move on. We did talk openly to Steven about the difficulty of meeting June's changing needs, as we realised how important it was to involve him and keep him fully in the picture.

## Voluntary work

Despite his fears that he would not be accepted for voluntary work, Steven got an appointment with Living Prospects which supports people with learning difficulties and received an acceptance letter soon afterwards. This came at just the right time as June now needed to be moved into a nursing home, a change that would have undoubtedly created a big gap in Steven's life.

The fact that Steven felt able to volunteer showed he was gaining independence and confidence. However, it was still important to recognise Steven's continuing vulnerability and how easy it would have been to upset his recovery and make him retreat back into himself.

We discussed as a staff team how we could support Steven at a regular, slow

pace to keep him on the recovery road. There were additional factors to take into consideration - including the fact there were now two other men with Korsakoff's syndrome living in the home, each with their own personalities and particular needs.

We assisted Steven's entry into the world of voluntary work by means of a step by step plan.

Step one: A member of staff attended all sessions with Steven. Step two: The staff member left him for 10 minutes.

Step three: The staff member left him for an hour.

Step four: The staff member dropped him off, but stayed in the area in case he was needed.

Step five: Steven was dropped off at 10 and picked up at noon. Step six: Steven was picked up after lunch.

### Noticeable difference

The staff at Living Prospects commented on the noticeable difference in Steven in terms of his confidence and improvements in memory. A couple of months later, Steven felt able to increase his voluntary work to two days a week. In addition he also started to volunteer for Riding for the Disabled. He had always had a passion for horses, so this activity was again building on his strengths.

Steven was invited to attend a Christmas outing for the Living Prospects initiative as a thank you for his work, and he asked me to attend. The venue was a local hotel, but after discussion with me, Steven felt he would cope with the fact that alcohol would be available, and really wanted to go. Everything went well and Steven found he was able to go to the bar and order lemonade for us both. I don't know which of us was most proud of his achievement!

Throughout these months, Steven was supported by us to continue to visit June in her nursing home. Relationships with other residents were varied. However he coped well with one who was paranoid and constantly complained about having to take medication. Steven responded with a creative answer, explaining that given the cost of the tablets, they would not be prescribed if they weren't needed!

He is a quieter, calmer man than many of the others and so chose to distance himself at times from some of the activities involving groups of residents, although he continued to enjoy games of Scrabble, which he was pretty good at, and chess, reading the newspaper and discussing the news. He also enjoyed helping the girls play on the computer, but only if there was no other resident in the room.

Alcohol-Related Brain Damage (ARBD) The term ARBD covers a range of conditions which merge and overlap

- Prolonged misuse of alcohol can lead to brain damage. How much of this damage is irreversible depends very much on the individual, and is the subject of much debate among health professionals.
- If the person stops drinking alcohol, there is a chance of improvement.
- The parts of the brain most often affected by alcohol are those used for memory, planning, organising, judgement and social skills.
- Thiamine is essential for the metabolism of carbohydrates. The body can only store small amounts. It is present in many foods but severe alcoholics may eat almost nothing which leads to a thiamine deficiency. Taking supplements appears to help prevent a worsening of Korsakoff's syndrome and even improve the condition.

Some common difficulties are:

- memory loss - particularly for events arising after the onset of the condition
- difficulty acquiring new information or learning new skills
- lack of insight into the condition (even when people have great gaps in their memory, they may still believe are functioning normally)
- inventing events to fill in the gaps, most common in the early stages (known as confabulation)
- some people are very quiet; others are talkative and repetitive in speech. *Taken from Carenza Care website: [www.carenzacare.co.uk](http://www.carenzacare.co.uk)*

In March 2001, Riding for the Disabled was cancelled due to the foot and mouth outbreak. Steven seemed to retain this information, though he occasionally muddled it with a previous outbreak, but nonetheless took a great interest in the subject. When the riding resumed in the summer months, the stables asked us if Steven could attend, because if not they might have to cancel some of the rides. This message was important for Steven. It helped him realise the significance of his contribution and that he was needed. Thereafter, he never missed a session and it was amazing to watch him running around the field alongside the horse, smiling and full of life.

Steven gradually became more and more independent and needed less and less prompting to get up, shave and do all aspects of his self-care, including tidying his own room and ironing his

clothes. One day, I walked into the kitchen and found Steven was making his own lunch, something he had never previously done without encouragement. From then on he made his lunch every day.

By August 2001, two years after Steven's arrival at the home, Steven had undoubtedly made huge steps in his recovery. He continued to need the clues, cues and prompts provided by staff he trusted, but he had developed a greater repertoire of tactics to cope with his memory which was still very poor. To compensate for this, his intellect, humour and inner resourcefulness had increased.

### Steven today

Steven now lives in one of Carenza Care's new developments. He has his own independent living flat, in a house that has four flats and a communal space. This arrangement means he can be in company when he wants but that he can also be alone should he wish. He has his own tenancy and in the main he is able to care for himself. His memory is still poor but he has excellent coping mechanisms and it would be difficult for anybody who meets him to know he has a problem.

In the past few years, both Steven and I have been on a massive learning curve. We have continued to work together for his recovery and although we have strayed sometimes from the path we started on, we both feel we are reaching our goals.

The Carenza Care team helps him to remain active and he has many interests, including bird watching and horse riding. This love of nature and the countryside means he is outdoors, and happy, much of the time. His companions throughout this journey, my daughter and granddaughter, remain his friends. They constantly push him to experience new activities and challenges, the latest being to join the local amateur dramatic society so they can go with him.

Steven used to be a compere and still enjoys a good singalong with the karaoke machine. One day, maybe, we will see him and his co-tenants on the TV programme, *Stars in their Eyes*. But, to me they are stars every day, and Steven the brightest.

To come back from where he was has taken buckets full of strength, determination and courage. I hope he will lead the way for many others with Korsakoff's syndrome to return from the depths of despair they all reach, to the normal life Steven looks forward to. I hope that his story might give hope for a new and brighter future for many people with his diagnosis.