

CFU Carers' Support Group



For carers and relatives of people with fronto-temporal dementia and semantic dementia

Newsletter

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www.cfucarers.org.uk

Welcome

Welcome to the October edition of the CFU Carers Support Group Newsletter! Thanks to all of you who came to our Carers' meeting on 27th September. Dr Russell Sheldrick, a Consultant Clinical Neuropsychologist, who specialises in the rehabilitation of people with traumatic brain injury, gave a very thorough and interesting talk on Coping with Challenging Behaviours. Based on the idea that behaviour is governed by basic universal principles, he explained how it is possible to identify the factors which trigger

and sustain difficult behaviours, and then find ways to change the environment in order to promote positive behaviour. We've provided a quick summary of his talk in this newsletter for those of you who weren't able to attend. Don't forget you can also log onto our carers' website at: www.cfucarers.org.uk to read previous newsletters and summaries of invited talks. We hope to see you at our next support meeting on 15th November!

Contents

Welcome	2
Handling Behavioural Problems	3
Carers' Questions	7

Handling Behavioural Problems

Russell Sheldrick, Consultant Clinical Neuropsychologist

Some Background and Terminology

Emerson, a psychologist working with children with learning disabilities, defined challenging behaviour as behaviour that:

- jeopardises the physical safety of the person and others.
- limits the ability to use ordinary community facilities.

This implies that challenging behaviours do not simply entail behaviours that are physically harmful but also behaviours that make normal daily activities (e.g. a trip to the supermarket or to the day centre) for the person and their carer difficult.

Rules of Human Behaviour

All behaviour is shaped by basic principles, which if understood, can help to understand why challenging behaviours occur. These behavioural rules were first discovered by psychologists in the 20th century.

Classical Conditioning – what comes before the behaviour

Pavlov (1849-1946) is famous for his experiments on classical conditioning in dogs. Based on his observation that dogs salivate more when they are presented with food, he trained dogs to associate food with the sound

of a bell by ringing a bell before each meal. Very soon, he found that dogs started to salivate every time they heard the bell, even if no food was presented. In this classic experiment, Pavlov uncovered one of the most important rules of animal and human behaviour: that behaviour is governed by association. The dogs learnt to associate the arrival of food with events that happened immediately before it, i.e. the ringing of the bell.



Similar examples can be observed in human behaviour. For example, staff on a hospital ward noticed that a patient was always aggressive to one of the nurses. When they started examining his behaviour, they realised that this nurse was responsible for administering the patient's daily injections. The patient had associated the pain of the injection with what happened

immediately before it, i.e. the arrival of the nurse, and so was aggressive to her every time he saw her, even if she wasn't about to administer the injection. These examples show that, in order to better understand behaviour, it is important to identify its triggers, by looking at what happened immediately before the behaviour.

Operant Conditioning – what comes after

Skinner (1904-1990) is famous for uncovering another important principle of behaviour: behaviour is reinforced by its consequences, or what happens immediately after it. If the consequences of a particular behaviour are pleasant, then this behaviour will increase; if they are unpleasant, then the behaviour will decrease. For example, in the case of the nurse, the fact that she ran away screaming rather than continuing to administer the injection meant that the patient's aggressive behaviour was positively reinforced and that he would be more likely to do it again to avoid another injection.

In order to understand specific behaviours, we need to understand what their function is by identifying the triggers and consequences that sustain them.

Assessment of Behaviour

When confronted with a challenging behaviour, it is important to think what function the behaviour plays for the person. Based on our

understanding of how triggers and consequences affect behaviour, we can perform a detailed assessment of the behaviour by asking the following questions:

- WHAT is the behaviour?
- What happened IMMEDIATELY BEFORE?
- WHERE did it happen?
- WHO with?
- How OFTEN?
- WHEN?
- What happened IMMEDIATELY AFTER?

For example, take the following incident:

A physiotherapist visited Mr X in hospital to help him with some physical exercises. She approached his bed from the left side and took his hand. Mr X retaliated by swearing at her and hitting out. The physiotherapist attempted to calm him but then left without carrying out the treatment.

Assessment of the behaviour involved keeping a record of other instances when Mr X had struck out at staff and trying to answer the questions listed above. The results showed that Mr X always struck out when he was approached from the left side and that he tended to be more aggressive with female members of staff. Incidents were also more likely to happen in the morning, as Mr X was waking up and still feeling a little disoriented. It turned out that Mr X

had a visual impairment on the left side so could not see members of staff approaching on that side. His behaviour could be understood in terms of a defensive reaction to being startled, which was exacerbated by feeling groggy and disoriented in the morning. It was decided that all treatment should be administered in the afternoon, preferably by a male member of staff. All staff were asked to approach Mr X on his right side (where he could see them) and talk to him so that he was not startled. Following these interventions, Mr X's behaviour improved and there were less incidents of aggressive behaviour.

Interventions

Once the specific behaviour has been assessed, one needs to think carefully about how to intervene. Interventions should always be based on a thorough assessment of the challenging behaviour. Interventions which prevent the behaviour from happening in the first place are always preferred. It is important to think what can be changed in the person's environment as well as their interaction with others in order to reduce the likelihood of challenging behaviours.

Stage 1: Changing triggers

a. Changing the environment

The first thing to think about is whether there is anything we can change in the person's social and physical environment. Different

people have different needs for stimulation in the environment.

Some people get overloaded and may need less stimulation in terms of:

- noise
- lighting
- number of people
- sudden approaches

For example, busy places like supermarkets may cause people to feel overstimulated.



Challenging behaviours can also occur because people are understimulated and are in need of:

- regular activities
- social interaction

Sometimes, getting the right balance can be a bit of juggling act as some people may be apathetic if understimulated but easily get agitated if they are stimulated. Some people have very rigid routines and may become agitated if their routines are interfered with. This is not necessarily a sign that they are bored or understimulated. Rather, it may be their way of achieving a sense of security and meaning in their life, and gaining some control over their

situation. If the routines are disruptive to other people, it may be an idea to gradually change the content of the routine so that they become more meaningful and are helpful to others (e.g. helping with domestic chores as part of routine).

b. Changing our communication

Aside from the immediate environment, it is important to think about how our communication can affect the person's behaviour. Confronting someone about their behaviour can often lead to rows, which lead to yet more challenging behaviour. One way to avoid this is to 'choose your battles' and only focus on those situations that are causing the most trouble. For example, Mrs Y is developing a weight problem because she has started eating a lot of sweet foods and doesn't do much exercise. Mr Y has tried confronting his wife about her eating habits and even withdrawing sweet foods altogether, but this only leads to more irritability and agitation on her part. As an alternative, he decides to avoid confrontation and give her low-fat biscuits instead, thus helping to keep her weight down.

Another alternative is called the '**de-escalation technique**', which can be used to avoid arguments when people are agitated or aggressive, as in the following example:

Mr Z has gone into respite care for the first time. He is very agitated and keeps shouting at the staff to let him go home. The staff want to give him

a chance to settle down and try to avoid entering into a confrontation. According to the de-escalation technique, the first thing to do is to acknowledge the person's emotion, and tell them you want to understand why they are angry, possibly drawing them away from the immediate situation (e.g. away from other people, into a quiet room). It is then important to try and engage the person's attention by initially agreeing with certain elements of their concern (e.g. that they feel trapped or don't know anyone) and siding with them. Once the person is engaged and talking, it is easier to shift the topic of conversation gradually away from their problem onto other things. Adopting a calm behaviour encourages the other person to mimic your body language and also remain calm.

Stage 2: Changing the consequences

Changing the consequences of a particular behaviour may help a person understand what is socially acceptable and what is not. This means providing feedback on positive as well as negative behaviours. Consequences of unacceptable behaviours do not necessarily have to entail an unpleasant reaction or confrontation but could just consist of walking away from the person or ignoring them.

Rewards

Rewards for positive behaviour should be given immediately after, so that

the person can learn to associate the reward with their behaviour. Rewards can be more effective if they are implemented as part of a contract (e.g. if you go for a walk today, you can have your favourite dish for dinner). It may help to record positive behaviour in a chart so that the person can see the benefits of their good behaviour. Rewards can take any form, such as a gift, a card or simply positive feedback, depending on what the person responds to best.

Negative feedback

As with rewards, negative feedback should be given immediately following the behaviour. Negative feedback is more effective if it is used in

conjunction with a system of reward, otherwise it may trigger more behavioural problems. Examples of negative feedback are turning away, using simple gestures such as thumbs down, or strong verbal reprimands to let the person know their behaviour is not socially appropriate.

Monitoring Behavioural Problems

As with all interventions, it is important to monitor how effective strategies are and to modify them if appropriate. An easy way to check if strategies are working is to note down how often behaviours occur and track whether they have decreased since the start of an intervention.

Carers' Questions

Q. I took my husband to the dentist and he simply refused to get in the chair. He has never had a problem doing this before so it came as quite a surprise. What could I do next time?

A. If he says 'no' to everything, it could be down to poor understanding of the situation. One way to try and avoid refusal is simply to take away the element of choice (i.e. rather than asking him to sit in the dentists' chair, lead him straight to it and sit him down). Another suggestion is to make the situation as calm and 'normal' as possible. One example of this working is of an inpatient who refused to wash. Washing became an increasingly frenzied activity, with more and more nurses becoming involved, who in turn provided more and more physical and verbal encouragement. One day they tried the opposite action, leaving him alone with his washbag and a basin. After a few attempts, he did eventually wash on his own, suggesting that it was the overstimulation and bombardment of people encouraging him that meant that washing became a negative activity.

Carers' Questions

Q. Can a lack of stimulation (work, leisure activities, driving etc) cause obsessive and rigid behaviour?

A. It's unlikely to be a direct cause, but the increasing amount of spare time can make more room for it and provides more opportunity for such behaviours to develop and become detectable. To deal with such a situation, one suggestion would be to use the obsessive tendencies and rigidity to your advantage – you could build new routines and/or tasks that are meaningful in order to replace the difficult habits and behaviours that they have become prone to.

Q. My husband's behaviour is frequently embarrassing and irritating. What is the best way to cope?

A. Living with and caring for someone with behavioural problems is undoubtedly extremely difficult. Telling someone 'no' all the time can be exhausting and frustrating and can have detrimental effects on your own self-esteem and well-being. The key is to choose your battles. Sometimes, you have to accept that you have no choice in the matter and that however much you try, you cannot physically stop someone from doing something. If you were to argue against everything, you may just end up feeling constantly upset and frustrated. However it can be equally upsetting for some people to care for a person who gets their own way 100% of the time. In some circumstances you might feel that it is essential that you make a stand, simply for your own self confidence and feeling of self-worth. Yet again, it's all about balancing the costs and benefits and making a choice about what to do in each situation.

Q. My husband refuses to go to a day centre. This is a constant battle and I always end up giving in. By giving in all the time, will I make it harder for myself in the long run?

A. Dealing with problems like this is always difficult. In a situation such as this one, you may just have to accept that he will never agree to the day centre and you could start to look at other options in order to give yourself a break. Are there other members of the family that he is happy to spend time with, for example, or might it be better to try and get involved in a care scheme such as Crossroads (www.crossroads.org.uk)? If the day centre is your only option, you could possibly try and motivate him by building it into a reward scheme. Of course, this doesn't always work – logical reasoning is not always possible. Overall, everyone is different and the most important thing is to weigh up all the options and work out the benefits and costs.