

Summary of address given by Stephen Heaton

R.C.B.I.S. Conference for Family and Clients

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“Family Relationships: Dealing with Change.”

Stephen was the senior medical social worker over a period of almost 30 years at the Child Development Centre, Hotel Dieu Hospital, Kingston, before his retirement in 2002. For his final decade at the C.D.C. he was the social worker assigned to the pediatric acquired brain injury team. He now sees a few clients at Extend-A-Family, Kingston, without fee.

Stephen’s address was a combination of information presented to the audience, questions, interaction with the audience as the talk progressed, and finally stories from Stephen’s professional practice and private life, to illustrate the topic. All names were changed to protect client confidentiality. At Stephen’s request a full version of his talk is not presented here, since he feels one really needed to be present to understand in context much of what was presented. However Stephen offers the following summary in the hope that it will prove to be informative and stimulate further reading and discussion.

“The brain injured person can become more severely affected by the actions of others than they are by the results of the brain injury itself.”

This is a quote from a gentleman who was severely brain injured after being hit by a drunk driver over 25 years ago.

“The changes in the brain injured person’s thinking, personality and behaviour, pose the greatest burden and challenge for me.”

This is a quote from the wife of a man who sustained a severe brain injury, who was also struck by a vehicle several years ago.

My response to the first quote is, “handle with care,” which puts the onus on us to be compassionate and understanding, often a lot easier said than done. My response to the second quote addressed to family members and caregivers is, “take care of your own needs as well as those of your brain injured relative, and seek out as much support as you can muster.” Again, this is probably a lot easier said than done.

Brain injury unbalances the individual and their family, and their normal range of behaviours and responses. It also challenges, in spades, coping styles, strategies and efforts. Put more bluntly, if you don’t take care of your own needs, you are at huge risk for stress related physical, emotional and psychological burden.

The good news is that some studies show that even for the brain injured with very impaired memory function, it can be the coping style that determines successful adjustment.

I would like to say a few words about CHANGE. Change, rather than death and taxes, is the true constant in our lives. Change effects every part of our lives, particularly our family life. Change brings the promise of growth, but it always, and I emphasize ALWAYS, brings the reality of loss.

At this point in the presentation Stephen and Therese Conway read the children's story book by Eric Carle, entitled ("Slowly, slowly, slowly," said the Sloth). Copies of the book were available for the audience to view.

Both Stephen and the audience had some positive comments concerning the meaning of the story. Some of the audience could relate to the fact that the world is a busy fast paced place, and it is not always understanding of people with differences who can't go so fast. Stephen felt that the sloth gets bad press, and read the dictionary definition of slothful as meaning "full of laziness." However in the book the sloth copes by going sooooo slowly. It seems to serve them well. We assume that the sloth has only one coping style, but in the foreword to the book, Jane Goodall, a primate researcher tells us that when the sloth moves to a new tree, usually about once a week, it sometimes has to swim across a river, and in this situation, the sloth is a remarkably fast swimmer. So here we see two coping styles, the first very slow forward, or even, off, and the second, fast forward.

Presumably if we take 100 sloths, they all have these two coping styles. Humans of course, are far more complicated than sloths. Humans have different social histories, different personalities and different coping styles, some of which can vary over time for the same individual, depending on the situation. Humans are, of course, highly idiosyncratic, highly individual if you will. However, in my experience it is useful in working with people in therapy, to go slowly, or perhaps even better, to make haste slowly (*festina lente*) in Latin, which could be translated as "hurry slowly!" So that is what we will try to do today.

I have had the privilege over many years, of listening to peoples stories of how they try to cope with the challenges that life throws at them, and of witnessing their journey through some of these challenges. One of my coping strategies as a therapist is to counter my impulse to jump in and try to fix things. Instead I try to STOP, THINK, and PLAN to go slowly. There is a petroleum product called STP and this is a cute reminder to me. On the bottle it states, "Enhances performance!" Stopping, thinking and planning to go slowly, seems to enhance my performance too!

I want to say a word about EMPATHY, defined as the act of trying to put oneself in someone else's shoes and to try to imagine what they are feeling. It is always only partially successful, but often informed if you have had a similar experience to the person you are trying to empathize with. Even then it can be a challenge, because we all have our unique life history of growing up in a family with it's own style of coping, we each have our own personalities, and we are each connected to a social world in varying degrees, between the two extremes of social isolation and social immersion. My challenge today is to try to put myself in YOUR shoes.

My experience with brain injury has been with children, and pediatric acquired brain injury is different to adult brain injury in that recovery takes place in the context of a developing brain and of child development itself. It also takes place in a culture and society which is supposed to nurture, care for, make allowances for, indulge, provide support to, etc, simply because children are children, not yet fully formed adults. I am not at all sure that for adults with brain injuries this understanding world exists, despite the valiant efforts of services such as R.C.B.I.S. This is where I will need your help and understanding, because you know far more about adult brain injury than I will every know.

Stephen then read very briefly from two books about severe brain injury, one by Abigail Thomas, entitled “A Three Dog Life,” and the other book, by Canadian, Alan J. Cooper, entitled “Brain Injury.” Both books are now in the R.C.B.I.S. collection. Stephen read these books in order to better understand adult brain injury, and both refer to very severe brain injury. All of you here live in the community and may not have such severe injuries, but the point did come across that the challenge which brain injury brings never goes away, and both the injured and their caregivers and families are heroic in that like the quote from the legendary cowboy actor John Wayne, they may be scared to death, but saddle up anyway. That is courage.

So let us look at coping. The notion of coping styles is itself controversial and some academic researchers challenge that such a thing exists, claiming it is impossible to disentangle a coping style from temperament, personality, family history, and the myriad of life situations that challenge us all everyday. However I am not going to get bogged down in this complex controversy, but rather will ask your permission to assume that coping styles exist, even if it is only to stimulate thought and discussion.

You have all heard of the term “dysfunctional families.” This concept has come under attack in recent years, and the noted children’s brain injury speech and language researcher, Dr. Roberta de Pompeii prefers to use the more neutral and compassionate term “reactive family patterns” when looking at how individuals and families cope with the challenge of the brain injury in their midst.

Stephen went on to illustrate his talk with some examples from his practice. He talked about “George” who described his coping style as “get the other guy before he gets you.” His wife Mary, described her coping style as “peace at any price.” Stephen discussed how these pervasive coping styles had very limited value in many situations and in fact actually left the individuals in constant internal distress. His work with this couple is aimed at helping them understand their styles and to learn to explore a wider range of options in approaching life’s challenges. He gave other examples of a fix it Mom who was in a hurry to speed things along in her son’s recovery. With support from the whole team, she was able to reframe her approach. However this was not a quick journey, but one which evolved over a long period time. Her husband Fred said that he thought his job was “to bring home the bacon.” That is how he coped. With less success, we tried to help him look at other ways he could support his wife. He would also cry whenever his brain injured son’s challenges were addressed. We never did get beyond the emotional response of crying, but we tried.

Stephen talked about two general styles people have when trying to cope, one being termed ACTIVE COPING, and the other PASSIVE COPING. He gave the example of Angela and

David. Their 12 year old daughter, Claudia, fell from a horse and sustained a severe brain injury. In the first couple of interviews with Stephen, Angela turned to David and said, “Well I attend all the appointments and do all the worrying, and all you do is work and jog!” On the surface it seems that Angela is clearly an active copier, and David a passive copier. However when we looked at things further it turned out that David thought a lot about Angela and her injury while he was jogging, and he had also gone on the internet for information and called his cousin, a nurse at a big Toronto hospital. Interestingly he hadn’t told Angela any of this, but you begin to see how difficult it can be to classify coping styles. However we will proceed.

The successful outcome of active coping is a restructuring of the problem or challenge, making appropriate plans and mobilizing support. The outcome of passive coping is generally avoiding facing up to the issue and compounding the challenge being faced. Changing your coping style is not easy. However it is preferable to avoidance. Also one needs to take into account not only yourself but also the other person, and the context, so that one arrives at a balanced response, what that wise professor of social work, Virginia Satir used to call, congruent coping. Balance is the key word here. The academics have other terms for passive and avoidant coping. Some refer to attentive coping, that is paying attention to the issues, or vigilant coping if you will, to cover active coping. Other researchers refer to problem-focused coping, clearly a variant of active coping whereas they refer to emotion-focused coping when attention is turned to the emotional reaction rather than the issue itself.

Coping styles are further classified into 5, 12, or even 28 groups, but today we will focus on the five grouping. Remember that each of us uses a combination of effective and ineffective coping styles, but we are arguing that people tend to have characteristic styles. Whatever ones coping style, it needs to be said that the existence of resources in any given situation, can have a huge impact on outcome. With pediatric acquired brain injury the presence of a supportive family played a bigger role in adjustment than did the extent of the brain injury. Also, the pre injury strengths in terms of intelligence, personality and problem solving abilities also bade well for successful adjustment. As far as adult brain injury is concerned, a paper by Dr. Daniel Gardner, a California based psychiatrist working with this patient group, does make the point that pre injury functioning in adults is a significant factor in adjustment. Dr. Gardner notes that unresolved issues from before the injury are compounded by the injury. As he puts it, “It is not only the kind of brain injury that matters, but also the kind of head.”

Any list of coping styles is arbitrary. Roberta de Pompeii identifies five main coping styles, namely COGNITIVE COPING, EMOTIONAL COPING, PHYSICAL COPING, SPIRITUAL COPING, and SOCIAL SUPPORT BASED COPING. Let us arbitrarily follow the list as printed and begin with cognitive coping styles.

COGNITIVE COPERS

With cognitive coping, thoughts and perceptions rule. On the positive side, cognitive copers often come up with such statements as the following,

1. “let me think about my strengths here.”
2. “let me look at how I have handled challenges in the past.”
3. “let’s break the problem down into smaller more manageable bits, and so forth.”
4. Stephen’s strategy of stop, think and plan is an example of cognitive coping.

The novelist Sue Townsend, who wrote the best seller, "The Diary of Adrian Mole," was talking on the radio about the recent onset of her blindness. She said that she had to learn to shut down the part of her brain that was preoccupied with her blindness and concentrate on what she did have, what she had left. She said that everyone in her family, and her friends, were so depressed for her, but she couldn't bear to have them all be so miserable. This must surely be courageous cognitive coping at its best. She was able to recognize her problems but also see beyond them.

EMOTIONAL COPERS

For many people emotions rule in terms of their reaction to stress, loss, threat or challenge. We all, of course, have emotional reactions, but it is the ability to respond to these emotions appropriately that is key. Intense emotions, like sadness, anxiety, guilt and anger are likely to fuel very negative reactions, and such intense emotions are often familiar to those with a brain injury, and those who love and care for them. Very negative reactions to these emotions end up increasing stress, of course, and compounding problems, leaving us stuck, depressed or out of control. Arriving at a balanced and appropriate response to challenge is, of course, a process, or journey, which can involve many steps, although the number of steps and amount of time involved varies dramatically between individuals. The big thing with emotions is that they are not something to be rid of in a hurry, but rather they need to be processed or worked through. However wallowing in them can lead to "drowning."

Stephen illustrated the difference between cognitive coping and emotional coping with the example of a couple who were faced with their old dog's very declining health. The cognitive coper announced that it was time to book an appointment at the vet's for euthanasia and arranged it for 2 days hence. The emotional coper agreed, but cried all weekend, decided he couldn't face going to the vet's and left for work leaving his partner to follow through with the decision. To the surprise of everyone the emotional coper having sat in his car outside the vets (unbeknown to his partner) for 10 minutes in anguish of indecision, suddenly decided to face the challenge and jointed his partner for the procedure. He even had the dog sit on his lap, when the needle was given. The cognitive coper felt better to have the support of his partner, the emotional coper felt better for having been there for both his dog and his partner, and clearly showed that he could overcome his emotional response of avoidance and switch to a more balanced coping response.

SPIRITUAL COPERS

Whether religious or not, spiritual copers tend to define the reality of loss in a positive light, seeing it as an opportunity for growth or change, or as a challenge they feel they are up to tackling. Spiritual copers actually tend to be more active copers than passive copers. The religious often gain strength or direction by trusting and even collaborating with their God. In my pediatric experience, many parents of infants born with physical disabilities or with medical fragility had the view that they had been chosen by God to be given the responsibility to raise and care for their child with special needs. By focusing on the positive, spiritual copers often do in fact respond to a challenge as a test of strength and an opportunity to learn some valuable life lessons. For them, trusting in God, or in their own ability to get through a situation, is a much less overwhelming and less threatening perspective. I saw many parents of children with special

needs take up causes on behalf of other disabled children, tackling bureaucracy, and advocating for enhanced support programs for children.

PHYSICAL COPERS.

Physical copers are active types. They keep busy, they laugh and cry and exercise, and eat well and listen to music, and run, jog, or cycle. They maintain their normal routines and also spend personal time. Obviously this is a caricature. Most of us, of course, do some of these things, but with physical copers it is a pervasive style. On the downside, sometimes physical copers are in a hurry to try to fix things, or they may fail to explore other aspects such as their emotions, or may fail to see that this style can be misunderstood by people close to them, emotionally, as in the earlier example of the couple whose child fell from the horse.

SOCIAL SUPPORT BASED COPERS

Some people seem almost naturally able to turn to others in times of crisis or challenge, and share their thoughts and feelings and concerns. They can ask for help, seek out information and support, join groups and connect with like-minded people. Most of us with time can do some of this. However, introverted people, or people who have a very defined independent streak, often find it difficult to seek out support. However, there are many shades of grey here, and again seeking social support can be a long journey for some. Stephen shared the experience of running a fathers' group with a colleague, for dads of children with special needs. We had never had any trouble getting moms' groups together, but some colleagues thought we would have an uphill struggle to get fathers to participate in a group discussion. Some said 'They won't come' or "they won't talk", or "it wouldn't be their thing." However, they did come, they did talk, although we always had to listen to "guy stuff" for 20 minutes before they would really start talking about their children and families and feelings and thoughts. By inviting these men to come to our group, we challenged the stereotype or myth that men's coping style is not to share emotions. The most revealing comment was when one father said he enjoyed the group because his wife was not present. He said if she was present he would just naturally let her do all the talking!

CONCLUSION

My goal today has been to try to stimulate thought. I have not given any advice, and I have not told you how to cope.

After a brain injury, everyone struggles to understand what its presence means. The needs of family and caregivers are equally important as the needs of the individuals with the brain injury. The process of adapting to an adult who in some ways is not the same person that they knew, is a huge task. Families need guidance in terms of what to expect, where to locate information and resources and how to find support. They also need client-centred, community-based services.

We have learned that family members whose approach to problem solving is negative or avoidant, are more likely themselves to become depressed and burdened. We also know that if a caregiver's approach is primarily emotion focused, they too are at great risk for depression. A shocking study reported in the Journal of Head Trauma Rehabilitation in 2006 showed that 50% of the study sample of key family members had clinical levels of anxiety or depression. There have been few controlled studies which really look at effective interventions for caregivers and family members of the brain injured. Key factors do appear to be the amount of behavioural control the family has in this situation, and secondly the amount of social support they are able to access.

An active, problem-focused approach is obviously preferable to a negative or avoidant approach. The latter, may however, reflect apathy and clinical depression, and these clinical states will need to be tackled before one can realistically expect more adaptive coping styles to be considered.

My final conclusion is about changes and when we are faced with threat, loss and challenge, it is possible that our reactions can be a choice, and not automatic, based on our characteristic ways of dealing with issues. By learning to adapt our coping strategies and styles, we not only survive or get by, but we also review our priorities and our values. This takes hard work and courage, and yes, patience and time. The ultimate balancing perspective comes from the eminent Swiss student of psychology, Carl Jung, who reminded us that when things are going well it is wise to remember the shadows, but also when things appear to be going badly that light follows darkness, just as surely as darkness follows light. THANK YOU.

Stephen Heaton