HEAD INJURY: A FAMILY AFFAIR

Stresses on the family

It is frequently said that there are not just head injured individuals, but rather head injured families, because the whole family is affected.

Some would say that families are the real victims and often suffer more than the head injured person because they are more likely to have accurate insight into the problem. No family is ever prepared and ready for a head injury; most families already have a full agenda of problems to cope with before clearing the decks to cope with the problems of head injury. Research into the effects of severe head injury on the other family members gives some indication of the extent of their difficulties. The following points are worth noting:

1. Close family members are likely to experience high levels of anxiety and depression during the years following a head injury. As time elapses, there is often a decrease in relatives' capacity for coping, particularly with emotional and behavioural problems.
2. Spouses often feel isolated and trapped with a marriage where their emotional needs are not being met. Some describe this as being neither married nor single. Relationships are put under enormous strain and it is estimated that between 20 and 50 per cent of all marriages in which one spouse has had a severe head injury end in divorce.
3. Children often experience emotional problems as, alongside coping with the initial trauma, and the subsequent difficult behaviour of a parent with a head injury, their own needs are often neglected and this can impair their performance at school.

Families need attention, education, guidance and support if they are to survive, regroup and rebuild their lives. Some families cope better than others, but all have difficulties. There is no normal way of responding to a head injury. The saying that 'people act abnormally in abnormal circumstances' is undoubtedly appropriate.

The people in families and relationships who seem to cope best are those that have two special qualities: first, the ability to be flexible, not being rigidly tied to how things ought to be, but being able to embrace change and view it as a challenge; and second, the ability to communicate openly and honestly, directly expressing emotions both positive and negative and recognising the needs of themselves and others within the family. If a family has these characteristics of flexibility and open communication, then it is possible that, out of the crisis of head injury, a family can grow in strength through its way of dealing with it. The fragility of life can give a whole new perspective and intensity to the love that existed prior to the head injury. Having a person with disability in the family often brings a new sensitivity and awareness to other members of the family. It is often said that the experience of head injury tends to make strong marriages and relationships stronger, and troubled relationships more troubled.

HEAD INJURY: A FAMILY AFFAIR

The family's stages of emotional reaction

The family close to the person who has had a severe head injury embarks on an emotional roller-coaster, where emotions rise and fall as expectations soar and plummet.

Coping with a head injured relative is not as straightforward as coping either with illnesses where there is a cure or with death, where there is a final resolution.

In death the enormous loss is final and very obvious. The loved one has gone and relatives then have time to grieve and mourn. Rituals such as funerals help that grieving process.

Family members go through a well recognised range of emotions, from shock, denial and anger to sadness and acceptance.

However, with head injury, because of the long-drawn-out process of recovery and rehabilitation the emotions associated with loss come and go in recurring cycles.

One day a relative may feel grief at all the losses, and the next day expectations may dramatically rise because the person has made a step forward, and the emotion of grief is temporarily shelved.

It often takes a very long time for individuals to accept that their loved one is not going to 'get back to normal'. The familiar body is there, but there are many changes, most of which are losses.

At the same time as the members of the family are trying desperately to cope with feelings of loss, they also have to react to the everyday events and difficulties associated with head injury. These include coping with the cognitive, behavioural and social problems, lack of information and services, uncertainty about the future, possible financial difficulties and role changes.

Just as the person with the head injury goes through various stages of recovery and acceptance, so does the family. It is helpful to map out the different stages of emotional reaction families are likely to go through.

Stage one lasts from the time of injury to medical stabilisation. The family's initial emotional reaction is usually a mixture of shock, panic, disbelief and denial. Their main concern is with the survival of their loved one: 'Please God, let him live'.

Stage two occurs when the patient regains consciousness. At this time the family experience relief, elation and often massive denial about future realities.

There is a tendency to focus on minor improvements in order to justify often unrealistic beliefs about recovery. In these early days the family often do not want to know anything about head injury or head injury support groups.

Stage three typically coincides with the period of rehabilitation, and family members may maintain a hopeful attitude. However, during the latter part of this stage they may begin to become discouraged and concerned by slow progress. At this point the family member may experience a mixture of anxiety, anger, guilt and depression, which may be expressed in anger towards professionals.

Stage four is often precipitated by a return to the community and discharge from rehabilitation services. Awareness of the probable permanence of impairments and the realisation that there will be little further change, produce feelings of depression, anger and grief.

Stage five can be said to be the relative's emotional acceptance and realistic recognition of the person with the injury's limitations.

This is perhaps a point on the horizon that people work towards and never quite reach – a long journey, rather than a destination.

ANXIETY AND PANIC

Understanding anxiety and panic

The first reaction is often panic, followed by disorientation, inability to concentrate and an extreme feeling of loss of control.

This usually occurs until the patient is declared medically stable. Often relatives say to themselves, "If only he lives, that's all that matters." However, the closer the patient gets to safety, the greater are the family's requirements.

Once it is evident that the patient will live, relatives focus on his progressing ability to eat, to walk, to talk, to care for himself and finally to return to work.

Anxiety levels constantly fluctuate around the achievement of these different stages.

Coping with anxiety and panic

1. Ask questions about what is going on in the hospital. What is that machine doing? Asking for explanations is important, as knowing something about what is happening helps the family feel involved and less anxious.
2. Acknowledge the fact that, in the early medical stages, the situation is out of your hands.
3. Do not try to take control; this will only lead to more frustration and panic.
4. Redirect your energies to those areas where you can have an impact, such as support of other family members, or care of dependent children.
5. Do not set arbitrary goals or expectations during the stage of medical stabilisation.
6. Keep communicating and expressing yourself. Don't bottle it up.
7. Learn some relaxation techniques from a counsellor or psychologist. Alternatively buy a book or tape about relaxation.
8. Deliberately take time for yourself. Give yourself permission to take part in a relaxing or pleasurable activity.
9. Don't try to be everything to everybody. Delegate responsibility to others. People often want to help but do not know how.
10. Prioritise – there are some things that just are not that important.
11. Stay clear of people who provoke anxiety.

DENIAL AND OVER-OPTIMISM

Understanding denial and over-optimism

Denial is a natural defence mechanism which helps us to cope with intense, painful emotions. It allows bad news to seep in a little at a time.

Similarly there is nothing wrong with optimism for keeping the spirits up, but there does come a point where denial and over-optimism can adversely affect the patient's rehabilitation and progress.

Denial by family members, combined with lack of insight in the patient, can produce an unwillingness to face up to the negative affects of the trauma. If problems are not recognised they cannot be helped or overcome.

A symptom of denial is 'doctor shopping' or deciding that the opinions of the rehabilitation team are inaccurate and looking for a different opinion.

Coping with denial and over-optimism

1. Take it one day at a time. Deal with today's problems without letting your expectations about the future affect immediate needs.
2. Deal with the way the patient actually is. Look for small signs of progress.
3. Ask professionals to share information. Sit in on rehabilitation or assessment sessions; ask for and read assessment reports. Professionals should be more than happy to include as many members of the family as possible.
4. Recognise that you need to work through a series of emotions, including anger, guilt and grief, but cannot if you pretend that everything will be all right.
5. Acceptance of reality takes time. It is only when the family have come to terms with reality that they can help the person the head injury to accept their new life ahead.

ANGER AND FRUSTRATION

Understanding anger and frustration

Anger is a natural emotion to feel in the circumstances. However, anger about what has happened is often directed at a variety of individuals, including doctors, nurses, family members, God and patients themselves.

A second aspect of anger is to do with frustration. If you are a person who is used to 'being in control', the occurrence of a head injury in a family can be the most frustrating event of your life.

Recovery does not follow a smooth pattern and definite answers are difficult to find. It is difficult to plan anything and now life is riddled with uncertainty.

What makes the situation worse is that often people outside the immediate family do not understand the deeper problem and sometimes can be insensitive with their comments.

Coping with anger and frustration

1. Recognise that you are primarily angry about what has happened. Apologise ahead of time.
2. Identify the triggers for anger, for example a particular nurse, a friend of the patient's, a critical relative. Avoid if possible.
3. Express your anger. Ventilate it with someone you trust. Don't let it eat you away. Seek counselling if necessary.
4. Discharge some of the anger in a vigorous, productive, physical activity (sport, house cleaning, walking or starting a self-help group).

GUILT

Understanding guilt

If you are the type of person who has taken on guilt before, you will be easily trapped into taking on mountains of it if a member of your family has a head injury.

The circumstances of a head injury provide multiple opportunities for feeling that you have not done your best for yourself, the patient, other family members and other concerned.

Beware of the little voice in your head saying things like: "I should have", "I ought to", "I must", because these statements will make you feel worse, and will not help the situation.

When you notice yourself using the words 'should', 'ought' and 'must', try challenging those statements by asking yourself the question, "Why should I?" or "How could I?"

Guilt is the result of an individual feeling overly responsible for somebody else.

Coping with guilt

1. Accept guilt as a normal feeling over which we have minimal control.
2. Don't expect yourself to be perfect. You can be angry, tearful, blaming, sad and critical. Accept how you feel. After months of caring for a difficult, unrewarding patient it is natural at times to 'wish he was dead'.
3. Accept that you are not responsible. Sometimes these things happen. No amount of taking the blame will alter what has happened.
4. Schedule your guilt session. For example, agree to worry only between 8 o'clock and 9 o'clock, and then make an effort to forget it for the rest of the day.
5. Try to distract yourself with some engrossing activity, such as gardening or sport.
6. Accept that there may be little you can do to change your loved one, so there is no need to feel guilty when you see no improvement. Allow yourself to let go, take care of yourself and rejoin the human race.

GRIEF AND DEPRESSION

Understanding grief and depression

After a certain point in the process of rehabilitation, progress will slow down; a plateau will be reached. It is often at this point that members of the family realise that life will never return to the way it was, expectations have to alter and plans have to be changed. It is a time to recognise the enormous losses that have occurred.

Families need to grieve for those losses: the injury has taken so many things away, even though they have not physically lost the family member. This grief and sadness is often delayed, because the family has been so busy they have not had the opportunity to grieve.

It is important to recognise that this sadness is a stage that everybody needs to go through before reaching a point of acceptance. Feeling sad or depressed, although painful, is a sign of progress, rather than something to worry about and try to avoid. Most family members will experience grief at some point, particularly if they have been very close to the patient, or if they now feel hopelessly trapped.

Symptoms may include anxiety attacks, disturbed sleep and eating habits, obsessive thought, lethargy and agitation.

The overriding feeling is that of helplessness and hopelessness. This reaction is just as natural and predictable as it is for the bereaved to mourn.

Coping with grief and depression

1. Allow yourself to cry. Allow yourself to remember and talk about the past. Have a good cry over old photographs.
2. Accept that the past is behind you and that the future will be different.
3. Modify your goals and expectations. Very few people who have had severe head injury return to their former level of functioning, but that does not mean that they cannot be happy at another level.
4. Make the most of what the person with the head injury can do, and try to forget the things that they can't.
5. If you feel that you are 'emotionally stuck', seek professional help. It may be that you are feeling so numb you cannot feel sadness or grief. Perhaps you are feeling suicidal. If you are using alcohol and drugs to dull your misery, you may need to deal with the feelings directly so that you can move on.

TIREDNESS

Understanding tiredness

Having a relative involved in a head injury creates a long standing trauma. The emotional upheavals and physical tension are in themselves tiring.

Loss of sleep through worry, and being incredibly busy travelling to and from hospital, means that the relative is usually experiencing debilitating tiredness and fatigue.

Often the idea of looking after yourself, through food, diet or exercise, is rarely considered. In some ways it is analogous to having a new-born baby, but it is much worse.

Coping with tiredness

1. Look after yourself. Eat well and try to get as much sleep as possible. You are no good to your loved ones if you are ill.
2. Put off until tomorrow what is not absolutely necessary.
3. Delegate responsibility. Ask friends and family to do things. Others are often only too pleased to help.
4. Do not feel that you have to be constantly by the patient's side.
5. Learn relaxation exercises if you have difficulty sleeping.

LOSS OF LOVE

Understanding loss of love

A head injury can affect a person's emotional responding, libido, sensitivity, ability to empathise, and also encourage a tendency towards self-centredness.

This will invariably mean that the spouse, parent or child with a person with a head injury will notice a change in the fabric of their relationship; it means they will get less love. This is often more difficult for a spouse than for a parent or child.

We all choose our partners because of their personalities; we do not choose our parents or children. Often it is easier for a mother to look after her adult son because he is returning to a childlike dependent state; she has her son back. It is often recorded that a wife will say that she still loves her husband, but feels that their love has changed, and is no longer the romantic love that first attracted her to him, but more akin to the love between sister and brother.

Coping with loss of love

1. Talk to the loved one the way you used to.

2. Let the loved one make as many decisions as possible or ask their opinion, even if it is not necessarily needed.

3. Approach the situation as you would a new relationship.

LACK OF TIME FOR SELF

Understanding Lack of Time for Self

It is understandable that, initially, when the person with the head injury returns home, the family is supportive and inward looking. It is only natural that at first they are busy adjusting and have less time for outside interests and friends.

However, the danger is that this habit becomes longstanding and difficult to break. It is a mistake to isolate oneself from old contacts.

It is possible that many old friendships may dwindle because the family feels that these old friends do not understand, cannot accept the problems, or feel uncomfortable. If this happens make every effort to form new acquaintances.

Be firm with yourself and recognise that you have needs too; set boundaries and learn to say 'no' to the person with the head injury. Make time for yourself.

Coping with Lack of Time for Self

1. Try to avoid setting up a pattern of decreased social contact.
2. Do not give up your job unless this is absolutely necessary.
3. Do not convince yourself that your care is indispensable. You must recognise and give time to your own needs. If you do not you will wear yourself out and be no good to anybody.
4. Plan social activities, giving them priority. Try to talk about things other than the person with the head injury.
5. Both carer and cared for need to have some time on their own. This may mean altering the layout of your house, or letting a friend look after the person with the injury for part of the day, or letting them go away for respite care for a week or two. Learn to let go!

ROLE CHANGES

Understanding Role Changes

We all play a variety of different roles or have well established habits within our family, our work and our social life. These might include being breadwinner, decision maker, joker, helper, trouble maker, dependent and problem solver.

Changes produced by head injury often mean that our roles have to change: the breadwinner becomes unemployed; the leader and organiser now needs to be led and organised; the father figure may take on a role closer to dependent child; the life and soul of the party becomes withdrawn and lacking in confidence.

However, because the roles of the person with a head injury change, so do the roles of other family members. In a marriage, if the husband with a head injury can no longer deal with the family's finances and bill paying, the wife has to do it herself; her role changes as well. In some cases she may have to pay bills for the first time, become better organised and make important decisions on her own for the first time in her life.

This requires the ability to change. Inevitably, initially this 'having to change' produces many feelings of fear, anger, resentment and frustration. The family member may say, "Why should I?, "Why me? This is a normal reaction. However, if these negative feelings can be overcome, the relative or spouse of the head-injured person has an opportunity to change and grow into a stronger, more fully rounded, capable person.

Coping with Role Changes

1. Discuss changes openly with family and friends. Identify areas where there may be difficulties and ask for help.
2. Recognise that you may have to take responsibility in implementing these changes, as the person with the head injury will probably see himself as he was before the accident.
3. Try to express your feelings about these changes. Don't store up resentment.
4. Try to view change as a challenge and an opportunity rather than a problem.

OVER-PROTECTIVENESS

Understanding Over-protectiveness

Over-protectiveness is particularly common when patients are discharged to parents' homes. This is understandable initially, as the person may be very fragile, dependent and needy at first.

However, with encouragement, the person with the head injury becomes more independent and as this happens the family needs to withdraw. Rather than doing things for him, family members need to help him do things for himself.

The more families do for the person with the injury, the less will be the improvement. Often this over-protectiveness happens because the family members feel sorry, guilty or worried about a possible second injury. Family members need to ask themselves, "Is this the best thing to do for him in the long run?" The person with the head injury needs the opportunity to test his skills and either succeed or fail in as normal a way as possible. If family members are continually over-protective, the message that they are subtly conveying to their loved one is, "You are incompetent, inadequate and untrustworthy." This can easily undermine already fragile self-esteem and confidence.
Also, as time goes by, the person with the injury feels resentful and angry at the relative who is "always doing things for me". The family should try to recognise the need to be firm and to take some calculated risks. After all, risk is inherent in everything we do. We all need the dignity and opportunity of risk to be fully human. This applies equally to people with a head injury.

Coping with Over-protectiveness

1. Recognise your over-protectiveness tendencies. Ask yourself what else the person with the head injury could possibly do without help. Ask for an outside opinion if you feel that you are too close to the subject.
2. Understand and recognise the feelings behind your over-protectiveness. Especially consider the possibility of guilt. Talk it over with someone – a friend, social worker, counsellor or psychologist.
3. Acknowledge the individual's limitations but focus on his strengths. Monitor gradual step-by-step progress.
4. Accept that, in order to make progress, you need to take some risks. This may involve letting the person travel alone, cook a meal or be left alone in the house. There is always a chance that he will get lost, or burn a saucepan, but these risks need to be taken if real progress is to be made.

UNDER-PROTECTIVENESS

Understanding Under-protectiveness

In situations where there is under-protectiveness, family and relatives are often still at the level of denial of the disability, expecting the person with the head injury to be as absolutely capable as before.

There has been no redefining of roles, and the husband, wife, mother, father or school child is expected to carry on as before. This often creates anger and resentment because the person cannot do it, and fails to live up to false expectations.

The family and friends have not moved to the level of realistic acceptance. It is very difficult to accept that all family members' lives have got to change.

Coping with Under-protectiveness

1. There is an enormous need to communicate and exchange information concerning changed roles.
2. The person with the head injury needs to be assertive and learn to say, 'No', or 'I have difficulty doing that. Could you help me?"
3. Seek professional help. A third party with experience of head injury can provide information which allows everybody to be realistic. Encourage family and friends to look at professional reports and assessments.
4. Recognise your feelings of reluctance to accept the changed role.

Source: Powell, T. (1994) *Head Injury A Practical Guide* (pp.132-155). United Kingdom: Winslow Press