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Coping with head injury: introduction and overview

➔ Key points

- ◆ According to Headway (the UK's national brain injury association) every year around 1.4 million people in England and Wales will attend A & E as a result of head injury:
 - ◆ Each year over a million people attend hospital A and E in the UK following head injury.
 - ◆ Around 135,000 of these will be admitted because of the severity of their injury.
 - ◆ It is estimated that across the UK there are around 500,000 adults living with long term disabilities as a result of head injury.
- ◆ Head injury is one of the most serious challenges a family can face. How families cope with head injury varies enormously. A wide range of coping strategies can be used.
- ◆ *Active coping* strategies (such as seeking information and seeking support) are more effective than strategies that involve *avoidance* (e.g. trying not to think about the problems).
- ◆ Families require help and support to cope at all stages of their relative's injury, especially in the longer term when they are likely to be the main (or only) source of support to the injured person.

Coping with stressful and traumatic life events is something that almost all families will have to deal with at one time or another. Most of us will experience

the death or serious illness of a loved one, the breakdown of a relationship, or the loss of employment, and will need to find ways to cope with the difficult circumstances that arise from these events. Head injury has been described as one of the most serious challenges a family will face, particularly because of its wide-ranging and long-lasting consequences (for both the injured person and their relatives). This book will help to guide you through the ‘maze’ of head injury so that you feel equipped to cope with the challenges it presents.

What is coping?

In simple terms *coping* refers to the wide range of things that we do or think to try to deal with the situation that we are in. While this might sound straightforward, coping is actually a very complex process. No two people (or two families) are likely to respond to and cope with *even the same situation in exactly the same way*. Furthermore, some coping strategies are more effective or helpful than others, or more appropriate to use at one time than another.

The types of coping strategies that we will use in a stressful situation is partly determined by:

- ◆ How we normally cope with stress (i.e. we bring our previous experience to this).
- ◆ How others around us cope.
- ◆ The amount and type of support we have.
- ◆ Factors related to the situation itself (e.g. the nature and severity of your relative’s problems).
- ◆ The judgements and decisions (sometimes called appraisals) we make about the stressful situation that we are facing. These appraisals are important because they are central to helping us decide what to do next in any given situation (i.e. what course of action, if any, we will need to take):
 - ◆ if we judge a situation to be serious and possibly threatening to us we are likely to take one kind of action (i.e. to protect ourselves, or to prevent further harm)
 - ◆ if we judge it not to be harmful to us we are likely to take a different course of action (i.e. we may not take any action, or we might just ignore it).

This process of appraisal and trying to work out what an event means for us is likely to take place after head injury and can help us understand why different people (even from the same family) might react emotionally to and cope with similar types of head injury differently.

To complicate matters further, how we cope tends not to be a static process and can change with time, particularly as a situation alters. Therefore, judgements about a situation may alter (again depending on many factors, such as the



extent of your relative's recovery or the information you have been given) and your reactions and coping strategies are likely to change alongside this.

Coping with head injury

Considerable research has focused on the vast range of strategies used by families to cope with head injury. The main conclusions are:

- ◆ The process of coping with a relative's head injury is constantly changing. Because of the wide-ranging and long-lasting consequences of head injury, families need to draw upon a varied range of strategies to deal with it; some of these strategies might be familiar (as they may have been used previously to manage other stressful situations), while others are new and have to be learned.
- ◆ Families often find themselves shifting between different ways of coping depending on the situation facing them, or when a strategy is no longer helpful. Because of this families often say that that it can feel as if they never have a 'grip' on a situation. However, it is also good to try many different ways of coping.
- ◆ Adult relatives face the demanding task of helping other family members (particularly children) and friends cope. This can be stressful, especially if they are finding it difficult to cope themselves.
- ◆ Families tend to report less distress when they use coping strategies that focus on *active problem-solving* (e.g. actively seeking out information about issues, thinking positively, optimistically, and realistically about a situation, and seeking support, perhaps via counselling).
- ◆ Strategies that involve *avoidance* (e.g. trying not to think about the problem, wishing it would go away, or avoiding dealing with the issues associated with it) have been found to be generally less helpful and can lead to higher levels of emotional distress for relatives.
- ◆ Families require help and support to cope at all stages of their relative's injury (especially in the longer term when they are likely to be the main (or only) source of support to the injured person). Despite this there is a tendency for services to provide most support in the early and middle stages of recovery but to withdraw in the later stages (at a point when they might be most needed).

What helps in coping with head injury?

There are a number of useful approaches to managing many of the specific head -injury-related problems that your relative might be experiencing. You will find more details about these in later chapters which focus on common post-injury problems. Whatever the type of changes you have noticed in your relative, we know that the following general approaches are often helpful:



1. Become knowledgeable about head injury by seeking information and advice.
2. Know what resources are available, and how to access them.
3. Use strategies to overcome problems. There are many ways in which post-injury problems can be managed, ranging from using simple strategies and aids to altering your environment.
4. Learn to look after yourself and know what forms of emotional and practical support are available to you.

Increasing your knowledge about head injury

You may have heard people say ‘knowledge is power’, and this is certainly true in the case of coping with head injury. Since most people have no (or little) prior knowledge of head injury, the experience can be confusing as well as distressing. Many relatives have told us that they feel as if they have been transported to an alien planet—they do not know the ‘language’ of head injury, and so can feel ‘stupid’ and ill-informed and do not know what questions to ask; thus they worry that they might come across as being uninterested or uninvolved with their relative. Research tells us that seeking information about head injury is one of the most useful coping strategies that families can use. Clear and up-to-date information can help address anxieties, encourage realistic family expectations, and promote more effective coping. Families that are better informed tend to feel more able to cope and often have lower levels of distress. In addition, understanding the nature and extent of your relative’s ongoing difficulties can also help you pinpoint particular problem areas and ensure that you are targeting your efforts where they are most needed.

The process of obtaining information after head injury is complex, however, and can be problematic. For example, there tend to be many professionals involved in helping people with head injury and families typically do not know what the different roles of all these people are—again, they do not always know who to seek help from. This can be exhausting, as you might end up having to ask everyone the same question before you find the information you need, or so overwhelming that you ask no one. We try to assist with this throughout this book by trying to explain any technical terms as we use them (but you might also want to refer to the Glossary at the end if you need to find the meaning of something quickly). We have also provided a ‘Who’s who’ section in Chapter 3 to help you navigate your way through the head injury pathway and understand the roles of those you might encounter along the way.

When seeking information, the following can help.

- ◆ Obtain general information about head injury: this is a good first step in feeling as if you are taking back some control of the situation. There are



many excellent websites that can also provide you with general information and facts about head injury. We list these at the end of the book but would like to draw your attention to the **Headway** website at www.headway.org.uk as it is particularly helpful. Headway, the UK's national brain injury association, is a charity set up to provide information and support to people affected by all kinds of brain injury, including head injury. A network of local branches and groups exist throughout the UK offering a wide range of services. There are local variations in what Headway can provide and some of the services we make reference to may not be available in your area. However, Headway have a national helpline number (details provided in back of book). You can use this to gain general information and find out what is available in your area.

- ◆ Use this general information to help you seek more detailed and personalized information about your relative's head injury and its consequences. Not everyone with a head injury will experience all the problems and issues we go on to describe, and some will experience the same types of problems in different ways and to different extents. Therefore it is helpful to be able to ask very specific questions about your relative's particular patterns of difficulties. With this more detailed information (that is, importantly, tailored to your relative) you will be able to build up a much clearer picture of your relative's strengths and weaknesses, as well as ways to help them. Obtaining this information, being clear about what it means, and remembering it (especially if you are under stress) can be difficult.

If your relative is fully aware of their difficulties (after head injury this may not always be the case), a good starting point is to talk to them and get their perspective on the problems.

Alternatively, talking to the doctor or other health care professionals involved in your relative's care may help you understand what is going on. Make specific time with professionals to have your questions answered, and ask them to write down the key points that have been discussed. Staff members are likely to be busy and you may feel uncomfortable asking for very detailed information; however, doing so will increase the likelihood that you will both understand it and remember it, and so it is likely to be beneficial to you, especially in helping reduce any distress and confusion. It will also save time for staff in the long run.

It is important to take time to absorb the information you have been given and follow up on any issues of concern. It is helpful to write down any questions arising from the initial information you were given, to make time to seek the additional information you require, and to ask for other sources of information (as and when you feel ready to take more on board). The quality, timing, amount, and usefulness of information given to families about head injury varies significantly across services. Therefore it is important to take a proactive



approach to seeking the information you need for you and your family, at all stages in your relative's recovery. Be persistent if your questions are not answered adequately.

Become aware of what resources are available

We have already referred above to Headway, the UK's national head injury organization. Your relative's doctor or Headway should be able to provide you with information on the specialist support available locally, such as organizations and support groups that you and your relative can access. You might also be able to access specialist **rehabilitation** services and professionals if they exist in your area. Important contact details are provided at the end of this book.

Use strategies to overcome problems and find ways around your relative's difficulties

As you will read in this book (and as you may already be aware from your own personal experience), many individuals after head injury continue to experience its consequences in everyday life. In the longer term (e.g. once your relative leaves hospital), it is important to find ways around any ongoing problems in order to reduce everyday stress levels within the family. If your relative is accessing support from rehabilitation services, their therapists will be able to advise you on the strategies best suited to your relative's problems. There are also a number of things that you can do to minimize the problems encountered—helping to ensure that your relative is as independent and safe as possible. These general strategies include:

- ◆ making simple changes to your home or your relative's work environment (such as labelling drawers, and reducing noise and other distractions)
- ◆ drawing on your relative's particular pattern of strengths
- ◆ having a clear routine to the day
- ◆ using simple aids (e.g. written reminders, alarms, diaries, to-do lists).

These can all help your relative and reduce the stress you may all be feeling.

Finding ways round ongoing difficulties (sometimes called compensation by rehabilitation professionals) is usually much more effective than searching or working towards a cure or complete recovery.

Some families worry that compensating for the problems (e.g. using a diary to get around memory problems, or using pictures to help your relative communicate) will hinder recovery in some way. We want to reassure you that using aids and making changes to your environment will not hamper your relative's recovery at all.



The many existing resources (leaflets, books, websites) can provide you with practical advice to help deal with the common problems seen after head injury. These will provide a good starting point, but the ideas suggested may need adapting for your relative's specific pattern of difficulties; there is no 'one size fits all' approach. You and your relative will need to try different things out and see what works best for you and your family. In some cases (e.g. if the problems are complex or difficult to understand) you may need more specialist assessment and advice.

Looking after yourself

Head injury is stressful and challenging not only for the individual directly affected but also for other family members. In order to deal effectively with the problems that can arise from your relative's head injury it is important to look after yourself and to know what support is out there for you. This is explored fully in Chapter 9.



