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Caring for someone with a brain injury

1. The early stages after injury

The period immediately following your relative's brain injury is a frightening and confusing time. The outcome can be very uncertain and it will probably be the first time you will have had any experience of brain injury. It is important to access information and support as early as possible. If your relative was recently injured then we hope the information in this section will help you to start making sense of the situation.

Understanding hospital systems

The treatment pathways for different kinds of acquired brain injury vary. In the case of very serious injuries, a person will normally be taken to the local Accident and Emergency department, where they will be assessed and their condition stabilised. They should then be transferred to a neurological centre, if it is considered appropriate and there are beds available. If not, they will be admitted to a general hospital and may be treated on a non-specialist ward.

It is very important after brain injury that your relative rapidly receives the best specialist care possible. If the treatment is provided in a general hospital then the doctors there should consult with neurologists and neurosurgeons at a nearby neurological centre.

It is worth remembering that, on many occasions, people with minor brain injury may not spend any time in hospital and consequently don't get referred to appropriate rehabilitation and support services.

Coping with the hospital stage

After a brain injury, the stay in hospital is often far more distressing for family and friends than it is for the person with the injury, who may be unconscious or have no awareness or memory of this period.

Your main concern at this time will be the well-being of your relative, but you should also remember that the best way to help is to look after yourself and you shouldn't neglect your own well-being.

You will probably want definite answers in the early stages, which the medical staff often can't provide. Rest assured that, if this is the case, you are not being deliberately kept in the dark. If the injury is very severe then stabilising and managing your relative's condition will be the main priority and the long-term difficulties will only become apparent at a later stage, such as when rehabilitation starts, or even when they return home.

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In the early stages it really is a matter of taking each day as it comes. It is important to ask the consultants questions, but try not to feel too frustrated if they don't have all the answers.

Remember, the Patient Advice and Liaison Service (PALS) are an independent source of advice and support. PALS can help to deal with any concerns you have about your relative's treatment and help to arrange meetings with consultants. There is a PALS office at every NHS hospital and you can find details at the hospital reception desk or on the PALS website at www.pals.nhs.uk.

What you can do to help your relative

It is normal to feel quite helpless when your relative is in hospital and to feel desperate to be able to do something constructive. There are many factors involved in the treatment of different kinds of brain injuries so we can't advise on specific activities here, as some things may be beneficial in some instances but harmful in others. Helping your relative can take many forms and the following can all make valuable contributions:

- Communicate as much as possible with the medical staff. They will be able to suggest any appropriate ways for you to help.
- Organise visiting hours with family and friends, so that you provide adequate support for your relative, without overwhelming them or causing any disruption to their treatment and recovery.
- Provide interest and stimulation. Just talking to your relative about everyday things helps, as does providing books, magazines, DVDs, etc.
- Help with personal care and grooming under the advice and supervision of nursing staff.
- Try to arrange the week's tasks at the start of the week so you can stay organised and don't have to keep asking the staff.

What you can do to help yourself

This is a time during which you will probably have to do a great deal of reorganisation in your daily life and it is very important to remember to look after yourself.

The following advice is worth keeping in mind:

Lean on others

- Seek help from professionals, such as hospital staff, the PALS service and your GP.

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- Be very clear and assertive in telling people in authority what you want and what you need from them.
- Seek the help and support of relatives, friends and neighbours.
- Involve all of the family in taking on household tasks.
- Ask one particular person in the family to deal with any enquiries from concerned relatives and friends, since this can be particularly stressful.
- Be aware of other sources of support at the hospital, such as the chaplaincy or other sources of religious guidance.
- Talk to other families on the ward in similar situations.
- Ask to see a hospital social worker.

Rest, take breaks and make time for yourself

- Do not feel that you or members of your family have to spend 24 hours a day sitting at your relative's bedside. You will cope best if you are able to go home for a while and get as much sleep and rest as possible.
- If you are having a lot of trouble sleeping, speak to your GP who will be able to discuss relaxation techniques, therapy, medication, or referral to counselling.
- Try to make time for activities that you find enjoyable, such as hobbies and socialising with friends.

Make financial arrangements

- Talk things through with your bank manager in order to reschedule any debts and budget for your new circumstances.
- Organise personal finances and payment of bills. This can be a particular problem if your relative was previously responsible. If possible, arrange for a willing and responsible friend or family member to take on the duty. Alternatively, contact your local Citizens Advice Bureau for advice on local sources of support.
- Seek advice on the benefits you and your relative may be entitled to. If your relative was on benefits before going into hospital then these may be affected.
- Check on any insurance policy your relative has, particularly medical insurance.
- Talk to your relative's employer to find out if they have an occupational pension which is initiated following serious injury.
- If your relative has been in an accident you may be able to take legal action against the person or organisation responsible. It is important to seek advice from a solicitor with expertise in brain injury claims (see the Headway booklet Claiming compensation after brain injury and Headway's Personal Injury Solicitors list).

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For further sources of up-to-date financial information see 'Useful organisations'.

Make arrangements with employers

- Keep both your own and your relative's employers informed about the situation and make sure that arrangements are in place regarding time off and statutory sick pay.
- Check whether your employer has a scheme for compassionate leave. Your contract of employment or company handbook should contain details of this.
- If your contract has no provision for compassionate leave then your employer has no legal obligation to grant you time off, so it is especially important to be as communicative as possible with your employer in order to help them understand your situation.
- Your relative will be entitled to a minimum of 28 weeks statutory sick pay, or more if allowed in their employment policy. For the employer to consider dismissal, they must have excellent medical grounds to say your relative will not be capable of returning to the job in any capacity.
- A good point of contact if you have any concerns about employment matters is the Advisory, Conciliation and Arbitration Service (ACAS). You can contact their confidential helpline on 08457 47 47 47.
- If your relative is self-employed you may need to check if they are insured for accidents or illness. If not then you will need to make arrangements to ensure that tax is paid and that any business associates or clients are informed of the situation. You might want to appoint a willing friend or family member to deal with these matters. The local Citizens Advice Bureau can offer assistance and signpost to local sources of support.

Keep records

- Try to keep records of events. This often proves to be useful at a later date as it can be very difficult to recall everything accurately if it isn't written down.
- Ask for a copy of any letters the hospital sends to your relative's GP. These can provide valuable supporting evidence for benefits and compensation claims.
- Keep notes of the date and time of the injury, the treatment your relative receives and the professionals who provide treatment and care.
- If possible arrange for a responsible friend or relative to keep these records on your behalf.

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Look after your physical health

- It is important to remember to eat a healthy, balanced diet
- Make time for exercise
- See your GP with any health concerns of your own.

Understand and manage your emotional reactions

It is important to remember the following points:

- There is no right and wrong way to feel at a time like this and ALL reactions can be considered completely natural.
- Emotional reactions change rapidly at this time and it can be impossible to predict the stages of your emotional reactions.
- Coming to terms with a relative's injury is a complex and ever-changing process and you may find yourself feeling emotions that you thought you had left behind.
- Don't expect everything to make sense initially. Speak to other carers and families who have been through a similar situation. Try to make time to speak to other families on the ward and make contact with your local Headway Group or Branch and the Headway helpline.
- Try to keep returning to any written materials you have received. It will be difficult to take things in at first, but the information will gradually start to sink in.
- Your GP may be able to refer you to local counselling services. You can also find directories of counsellors at www.bacp.com and www.bacp.co.uk.

This factsheet is adapted from the Headway booklet 'Caring for someone with a brain injury', which includes more information and case-studies.

To discuss any issues raised in this factsheet, or to find details of our local Groups and Branches, please contact the Headway helpline free of charge on 0808 800 2244, or by email at helpline@headway.org.uk. You can also find more information and contact details of Groups and Branches on our website at www.headway.org.uk.

Headway produces a range of booklets and factsheets covering brain injury related issues. Booklets can be ordered from www.headway.org.uk/shop.aspx or by telephone on 0115 924 0800. Factsheets are freely downloadable from the website.

Brain injury survivors and carers can receive free copies of appropriate booklets from the helpline.

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