

Concerns

If you have any concerns about the treatment and rehabilitation you receive, or about your experience at the NSIC, please raise them with a member of staff. If you are particularly happy about the service you have received at the NSIC, you are welcome to let us know, preferably in writing. All NHS Trusts have a commitment to monitor and improve the quality of their services and therefore comments from users of those services are especially helpful.

How can I help reduce healthcare associated infections?

Infection control is important to the well-being of our patients and for that reason we have infection control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. We ask that you, and anyone visiting you, use the hand sanitiser available at the entrance to every ward before coming in to or after leaving the ward. In some situations hands may need to be washed at the sink using soap and water rather than using the hand sanitiser. Staff will let you know if this is the case.

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Author: Clinical Psychology
Issue date: October 2017
Review date: October 2020

Leaflet code: WZZ-1853
Version: 2.0

Coping with Spinal Cord Injury

Patient information leaflet

If you require a translation or an alternative format of this leaflet please call PALS on 01296 316042

Safe & compassionate care,

every time

Coping with Spinal Cord Injury

Introduction

This short booklet highlights some of the issues associated with coping with a spinal cord injury. It is largely based on our clinical and research work into people with spinal cord injury. These findings come from the experience of people who have been injured for weeks, months and many, many years.

It's a major trauma

Few people can be prepared for the experience of a spinal cord injury. There are few life events that can prepare us for such a sudden change.

Normal emotions

Many people are concerned about the impact on the person with this type of injury. However, research has shown that most people have a very normal emotional response to the injury. People may get depressed because of the loss they experience, may get anxious because of their fears and doubts about the future, and may also get angry and experience a sense of injustice. These can all be part of the normal emotional reaction to a spinal cord injury.

Personal responses

There are no set responses to the injury. Each person is an individual experiencing their own individual response.

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Spinal Injuries Association

**Main Office Telephone: 0845 678 6633
Freephone Advice Line: 0800 980 0501
www.spinal.co.uk**

Back Up

**Main Office Telephone: 020 8875 1805
www.backuptrust.org.uk**

Aspire

**Main Office Telephone : 020 8954 5759
For free legal advice call: 0800 030 20 40
www.aspire.org.uk**

When people are initially seen after their injury, important concerns reported often include: “How will this change the relationship with my partner and children”; “Will it stop me enjoying life, my hobbies and going out?”; “Can I ever work, move job or gain promotion?”.

You cannot be expected to know how to deal with all the consequences of your injury at this stage. You cannot expect to know everything but it is important to have some faith that there is a way forward, that it is possible to deal with it and that it is possible to get back to enjoying life again.

Our research shows that general rehabilitation outcomes can be enhanced when your emotional concerns are addressed and do not impair your ability to engage in rehabilitation. Reappraising threats and fears as challenges allows you to learn, overcome and achieve your potential and get back to your life and aspirations.

The final outcome is really up to you. One of the most important things to do in the early stage after injury is to decide what you are going to do about it. Research and clinical experience have shown that most people learn to manage the consequences of their disability and go on to live a quality of life that is consistent with their previous (pre-injury) expectations. This might seem strange and unlikely at this stage, but it is important to recognise that over time and with appropriate support, people do learn to cope with it and work at all the issues. You will resume control and be able to get on with your life; this is not an unrealistic reassurance.

Negative assumptions

Many people have negative assumptions about disability and spinal cord injury. Prior to injury, most of us exist in a community which has a number of negative social attitudes towards disability. In fact, many aspects of the disability arise from the negative attitudes of society, rather than being a necessary part of the person with spinal cord injury.

Initially after the injury you may have to deal with your own negative assumptions, many of which are irrational and may lead you to make the wrong assumptions about the consequences of your disability and what the future holds for you. Such irrational negative assumptions can cause emotional disturbance.

Stress

Stress is a normal and necessary response to life changes. No one exists without experiencing stress. As a normal part of life, it helps us learn to deal with life's difficulties. In any individual's lifespan, we can expect to encounter a significant number of stressful events. Stress in itself is not a bad thing but it can become a bad thing when it leads to a stress reaction.

Stress reaction

A stress reaction occurs when we don't do anything about a stressful situation or when the way we respond to it is unhelpful. The longer we leave or ignore stresses, the more they become increasingly difficult, which can lead to a whole new series of psychological, physiological and emotional changes leading to further problems. A stress reaction is an unhealthy situation because it makes it more difficult for us to deal with the situation.

The relationship between thoughts, feelings and actions

Stress reactions occur when stressful situations are not managed. In such situations, judgements or appraisals are made by the individual. The person decides that they either have the skills to cope with the situation or they haven't, and they need to take evasive action or acquire some new skills. Therefore an appraisal of stress is very important. However, our view of events is not always rational and correct, and this can lead to an inappropriate response. In many ways it is not what happens to your life that's important, but what you think about it.

If you think you are only going through the motions of life and feel there is no point in doing anything, then you feel apathetic and as a result of those feelings you are less likely to do anything. Unless you do something about a situation, the more the assumption that life is over is confirmed and greater the level of apathy and withdrawal. This is a downward spiral that can result in a lot of negative thoughts and feelings.

Whereas, if we believe we can do something about a situation, we often feel better and are more likely to do something about it. So it is important to examine carefully the assumptions we make and acknowledge the relationship between what we think and what we feel. What we think determines what we feel.

Do something

It is important that if we experience a stress reaction, we do not just give into it but instead do something about it. The more we avoid dealing with a problem, the greater the problem seems. By avoiding dealing with it, we are only putting off the issue to encounter it at a later time when we could feel even less capable of dealing with it.

Relaxation

Relaxation is an important way of allowing us to take time out of difficult situations, as well as rebuild our physical and psychological reserves. There are many ways of relaxation. This can be done by instruction, autohypnosis, listening to relaxation training media, watching television, listening to music or reading. Think of the things that you enjoy and have enjoyed in the past that have made you relax, and try to incorporate them into your rehabilitation programme.

Realistic thinking

Much of what has been discussed here is about positively encouraging people to do something about managing the consequences of their disability. Positive thinking does not mean simply looking on the bright side. It is important to think realistically about what the possibilities are and what can be done. Work out the balance of that which has changed and not changed when you are negotiating the changes that result from your spinal cord injury.

Do not always focus on those factors that have changed. Rehabilitation by its nature focuses on the difficulties and problems. It is important for you to look broadly at the impact of the injury on your life and ensure you see the many things that have not changed. Things that may not have changed may be the importance of relationships. Another factor may be your capacity to pursue your current employment, or your ability to change your employment and learn a new task.

Religion and philosophy

Many people after a life trauma re-evaluate personal convictions. This may be through religion, philosophy or general political awareness. This is a normal part of our response to life's traumas and will often be a focus for much new learning.

Accommodate and accept

Many people use the phrase 'coming to terms'. This is a military term which implies surrender. It is not an appropriate way to describe how you deal with the consequences of your injury. The important thing to do is to recognise the real issues, begin an understanding of those issues, and accept that they are part of your life now. Acceptance is extremely important and can be difficult. Acceptance does not mean giving in but it does mean recognising that changes have occurred, identifying your strengths and needs, and getting on with your life goals, be it making or getting on with relationships, recreational activities or career development.

Taking time out

Of course, this is a difficult situation in a difficult time. It is important to allow yourself to take time out from all these problems and concerns, to find time to treat yourself to doing something you enjoy which can distract you from these concerns for a time. It is also important to encourage your family to do the same. They may travel long distances to get here to visit and may need your permission to take it easy for a time. This is probably a time when you need to treat yourself, family and friends more than at any other time in your life - go ahead, plan it.

Coping

Coping is something we do that helps us gain a sense of control of the situation and mobilise appropriate thoughts and actions to deal with it.

Making a decision to deal with it

In many situations in life we may not know how to cope with them because they are new or we feel they are overwhelming. We often struggle within ourselves about whether we can cope, and if we decide we can, this in itself can lead to greater coping. Therefore, once we decide to 'go for it', we can often feel better.

Identifying the sources of stress

The first step in doing something about a situation is identifying the source of stress that you experience. In spinal cord injury, this may be something about being in a hospital environment, having difficulty dealing with the experience of symptoms and making negative predictions about the future.

Get good information – get to know

Related to identifying the sources of stress is getting accurate information on the new needs that you have experienced as a result of your injury. It is important to see the situation as one where your needs have changed and you learn to manage the consequences of this change. For example, getting information about your bladder and bowel, relationships and accommodation, are all very important components of your rehabilitation and daily living needs.

If you have a problem that you do not understand, ask someone to explain it to you or find someone who you can talk to easily. The Spinal Injuries Association is a self-help group controlled and run by people with spinal cord injuries. It offers a variety of services, including an information and welfare service (www.spinal.co.uk).

Other Charities, such as Back Up (www.backuptrust.org.uk) and Aspire (www.aspire.org.uk) can also provide you with useful information and vocational support.

Do something – active coping

Once you have identified the sources and got some information about the problems, then it is important to do something. This may mean getting actively involved in your rehabilitation by going to therapy departments, or it may be by contacting local authorities and trying to explore accommodation options. The needs are great but it is important to break them down and solve them a little bit at a time. In this way, problems become more manageable.

Thinking and planning

As humans, we have all got an ability to think and plan. It is important for you to spend time thinking through the consequences of your injury and planning ways of resolving these issues.

Letting go – putting things aside

There will be occasions when you will be unable to do anything about a problem. You then need to put the issue aside and come back to it when you are in a better position to manage or resolve it.

Getting good advice

Like any other new situation, there are many issues that you will be unfamiliar with and it is important therefore to get good quality information and advice. It is important that you select your sources carefully because conflicting or unhelpful advice can cause difficulties later on. You may also find it helpful to talk to former patients about the issues they have had to deal with and how they have coped.

Support

More than any other time in your life, you will find a need now to obtain emotional support. You get this support from yourself, friends, relatives and family. Sometimes, however, it is important to go beyond this sphere.

Getting support and receiving counselling is a good way of coping, both by expressing your feelings confidentially and allowing yourself to develop your coping skills.

Acknowledgement of feelings

People have many different feelings after a spinal cord injury. These feelings need to be acknowledged and recognised. There are some changes that will occur in your life which will be permanent that you will never be able to resolve, and there will be certain feelings associated with these changes. Letting go, grieving and moving on are all part of this process and situation.