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PSYCHOLOGICAL EFFECTS OF STROKE

A GUIDE FOR THE CARER

Introduction

This has been written to help anyone who is looking after a stroke patient at home - most usually, perhaps, a husband or wife and quite often a daughter. In it, I have outlined the changes in your life - and more often than not in the lives of a whole family - which are likely to occur and how they may be met. Not every change can be dealt with easily and some of the difficulties may be more or less permanent. But there is no doubt that you can learn to cope and that you can continue with your own life while caring for your patient.

To help you understand the effects a stroke may have, not only on the patient, but also on you and your family, try thinking about the way we normally control our lives and are more or less in charge of what we do. We continually make decisions. We decide when to have a cup of tea, to phone a friend, to turn the television off. All these seem minor, almost trivial activities, he will have even less control over the more major decisions of his life.

This loss of control in the stroke person affects anyone looking after him. For instance, it may not be easy for you to decide when to go out to collect a prescription or to do shopping, because while you are away he may face some small problem, which he cannot resolve for himself. So a large part of your care must be directed to helping him to regain as much control as possible and this will mean that you must find a way of adjusting your own life - and that of the family - around his, so that you, yourself, are in control.

To be able to achieve this state, you need to know and understand your own feelings about what is happening to you; what you can expect from the stroke person and what changes you may find in him; the possible effects of all this on your own personal relationship; and the importance of caring for your own health and well-being. The rest of this aims to help you to understand these things.

Note: You will see that I have simplified the wording by always referring to the patient as 'he', but 'he' could in every case be a 'she'.

What to Expect in Yourself

Feelings of Guilt

'Why do I feel guilty?'

Many husbands and wives experience tremendous feelings of guilt. They often believe they are in some way to blame for the stroke or that the family is being punished for some reason. 'Why me?', 'Why us?' are very common reactions to any kind of shock. Some people, particularly wives, feel they should have cared for their husbands more. They may think they gave them the wrong kind of food or that they should have discouraged smoking or drinking more strongly. They may feel they should have noticed the symptoms of the signs of the impending stroke. And they may sometimes express resentment at the state they find themselves in.

Advice

These feelings are all very normal especially in the early days after the stroke. Most people come to recognise that they are not really to blame and begin to feel less guilty. It is often more difficult not to bear some resentment and those who do may now feel guilty about this. Try not to bottle up these feelings. It will help if you can talk freely about them to professional helpers, such as the district nurse or social worker and to understanding friends. You must believe that you are not to blame for the stroke in any way and you need not be ashamed of expressing resentment.

Distress

'I feel so helpless'

Another normal reaction may be for you to become so distressed that you are reduced to a state of helplessness. You may even feel incapable of doing the everyday things you used to cope with so well. You may get unusually tired and become strangely lethargic.

Advice

Many people in stressful situations develop this feeling of helplessness and it is important not to let it really get you down. There are always times when you feel things cannot get any worse - and of course they do. But there are other times when you think nothing will ever improve - and suddenly everything gets better. Try to keep yourself in a hopeful frame of mind. And do give some time to yourself. You will feel better if you look better, so pay attention to your personal appearance and boost your morale by making as many small successes as you can, e.g., baking a good cake, or managing to mend the lawn mower. This will help you combat the distress and its symptoms.

But seek medical help if you find that the feelings of extreme tiredness and lethargy continue to exist. Do, however, be wary of taking too much medicine or too many tablets unless they are specifically prescribed and if you find your smoking has increased substantially or that you are drinking much more alcohol, take steps to cut this down. Heavy drinking and smoking will not relieve the distress nor are they the most appropriate ways of helping yourself to cope. Above all give some thought to your own health and make sure that you do not become as ill as your charge!

Life Changes

'I have had to take on so much more!'

It is quite likely that you will be experiencing a number of changes to your way of life and one of the most common of these lies in taking over the day-to-day responsibilities of your partner. It is most often the husband who looks after the finances and wives are often greatly concerned at suddenly having to manage accounts. They sometimes feel so unable to do this that they make no attempt to put their affairs in order.

Similarly men who have never taken any domestic responsibility are appalled at having to cope with all the household tasks. There is a real danger in these cases that the home organisation will become less good and both husband and wife will feel inadequate. It may also be noticeable that your patient has become very dependent on you. This will make it difficult for you to organise your own life - as one wife said it is 'like having a young baby again'. Some carers report that they feel a different person because husband or wife can produce so much change in you. It is, however, inevitable.

Advice

Do ask for help where you need it. Friends will help and there is professional advice to be had. Financial advice can come from banks, building societies and insurance agencies. The local Department of Social Security can help you to understand the benefits you are entitled to. The Stroke Support Group has advisory and information staff who will try to answer your questions by telephone or letter. The social services may be able to help you with domestic problems by providing a home help. The social worker, health visitor or district nurse may sometimes supply aids which make home life more comfortable for the patient and so, of course, for you.

Avoid trying to be over protective to your partner, try to encourage him to be more independent - and allow yourself some time to do the things you enjoy.

Conclusion

You will find yourself having to work out a new way of day-to-day living. This will not be easy. Once over the shock and while trying to come to terms with the new situation, you may attempt to take on too much. Gradually you must learn to adjust and make a more realistic assessment of the support you can be expected to provide - and of the time you need to keep for yourself. This may seem selfish, but in the long term it will help the stroke person as much as you.

What to Expect from your Partner

Personality Changes

'He's not the person I married'

The personality of the stroke person often changes. You will probably notice this more than anybody else although it may not be easy for you to describe it to outsiders. This change is a direct result of the stroke. It will, of course, be a great shock to you to realise that the person best known to you now seems like a stranger. He is very likely to become less social, more inward looking and may appear to lose his own special character.

In many cases this is because the stroke person feels as if he has ceased to be a person in his own right and is unable to regain control over his environment. He is likely to be sadder and more pessimistic than before. And as we have said a change in his personality often affects his whole family.

Advice

Although you cannot change his personality you should try your best to understand the changes. You need to know the way your partner now thinks and to feel you are able to share secrets between yourselves. Above all you need to try and give him *confidence* in the way he now is, to help to build up a positive view of himself and to adjust to the new situation.

Show respect for him and let him see it so that he can feel worth while again.

Emotionality

'My husband sometimes laughs and cries for no reason at all'

A stroke person often becomes very emotional. He is likely to show signs of depression. Sometimes this is the direct result of the stroke and the damage he has suffered. In other cases it may be reaction caused by a sense of helplessness at his present condition. Other common emotional reactions are extreme changes of mood, which more often than not take the form of outbursts of weeping and occasionally uncontrolled laughing. A few patients have outbreaks of swearing which are often associated with speech and language problems. You may find this extremely disturbing but it must be remembered that he has no control over these outbursts. He is likely to be irritable, distressed, frightened and uncertain of what the future may offer and he may express this by bursts of anger which sometimes result in physical violence. Try to realise the acute frustration he is facing and see that this may be his means of communicating.

Advice

It is difficult to deal with extreme emotional outbursts. You should not be frightened of telling your partner that he makes you feel uncomfortable and unhappy. Try not to give in to any unreasonable demands he may make when behaving in an emotional way. This is only likely to encourage such outbursts. However, do be sensitive to the extreme stress he is experiencing and try to keep a reasonable balance between providing sympathy and support and giving in to every whim and fancy.

Lack of Interest

'I can't get my husband to do anything'

You may find that your partner ceases to show interest in anything. He no longer wants to do the things he used to enjoy, and he may sometimes sit for hours without appearing to notice the world around him. This is partly because he finds it harder to concentrate and partly because he may feel unable to make decisions for himself and so quickly loses interest in what is going on. He may also become more easily fatigued, which of course leads to tasks being left unfinished or never started. And he may find it difficult to withstand stress of any kind and so become inclined to withdraw from all activity for fear of incurring it.

Advice

Do remember that your partner may get very tired especially early in his illness. Encourage him to rest at certain times - maybe in the afternoon. At the same time you need to help build up his confidence and to let feel that he is still the boss (or she is still queen of the household). Encourage him to make his own decisions - which shoes to wear, which TV programme to watch. Ask his advice even when you do not need it. But do also take care that there is no physical difficulty, such as an eyesight problem, which might continue to his lack of interest.

Confusion

'My husband seems so muddled'

A stroke person faces so many difficulties - his memory probably lets him down, he cannot control his movements, there may be visual and language problems- all these can contribute to a general feeling of confusion. In extreme cases, a stroke can age people very suddenly. One wife declared that her husband had aged ten years overnight.

Advice

Your husband may have suffered a severe injury to the brain - and if he has, it is not surprising that he should seem confused during the period of rehabilitation and even after it. Try to organise the home and your lives so that some of his difficulties are smoothed away. Establish a simple routine for each day. See that everything he needs is readily to hand. If necessary, rearrange the furniture so that he can get around without anything having to be moved. Finally, do talk to him about his confusion and perhaps together you will find ways of relieving it.

Communication

'He can't always make himself understood nor understand what is said'

You may find that your partner is no longer able to speak as well as before the stroke or to understand everything you say. A number of stroke people suffer from some kind of speech or language problem. This is called dysphasia or aphasia. In some cases the ability to read and write may also be affected. It is not until we become closely involved with somebody who has difficulties in communicating that we realise just how significant our ability to speak and understand is.

Advice

It is important that you should continue to talk with your partner and encourage him to communicate with you. Do not try to hurry him or finish sentences for him. Instead, try to encourage him to communicate in any way possible including the use of gestures and hand signals. Don't speak to others about him in his or her presence. It can be very upsetting. Remember not to shout or to treat him as though he were simple or deaf. This will cause frustration. Above all continue to make him feel an important and wanted part of the family.

Recovery

'Will my partner ever be the same again?'

All stroke people experience different rates and degrees of improvement. Some can be expected to make an almost complete recovery, but others are still left with some impairment. The main question to be asked is whether a complete recovery can be expected, or whether your partner will have to adjust to a new situation. Remember that after a major life event probably none of us is ever exactly the same again. You will probably both fear another stroke but though there is risk that one may occur, you should try to treat it as you do the many other risks in life - after all just crossing the road can be a hazard.

Advice

Nobody can really give you an exact answer to the question you must want to ask: Will my husband experience another stroke? Living in uncertainty is never easy, but if, as I have suggested, you can adopt a positive approach to this, you will help both your partner and yourself.

Conclusion

It is likely that your partner's behaviour will change in ways which affect you both, and it will help if you try to think of your relationship in terms of *control* and *dependency*. Your husband is likely to have lost some control over his life and so has become more dependent on you. You may have to take on more tasks and to give up some things which you enjoy doing. These changes need not be permanent and they can be dealt with by both of you. It is simply a question of recognising that both your lives have changed and working to find a new but acceptable way of living.

