

EMOTIONAL CHANGES AFTER A SERIOUS BRAIN INFECTION



INTRODUCTION

Many people who have had a serious brain infection will experience some kind of emotional change afterwards.

In this booklet we talk about some of the most common emotional changes people experience after a having had a serious brain or nervous system infection, why they happen and what you can do about them.

It's aimed at people who are recovering from a brain infection and may have some associated disability, but there is information for family and friends as well.

In the "Beyond the Hospital" project, the Oxford University Clinical Research Unit (OUCRU) (www.oucru.org) has collaborated with Hospital for Tropical Diseases, Ho Chi Minh City, Vietnam (Bệnh viện Bệnh Nhiệt Đới) (www.bvbn.vn), to obtain a better understanding of our patients and their family members' concerns and emotions in regard to brain infections. Much of the information was derived from our direct interaction with the patients and involved family members. Many of those who suffer through a severe brain infection will experience unusual emotional changes. Therefore, this guidebook is designed to present the common emotional symptoms due to a severe infection of the brain or the nervous system, as well as why these symptoms take place, and what you can do.

The purpose of the guidebook is to provide guidance for patients, who are in the process of recovery from a severe brain infection.

There are also additional helpful information dedicated to caretakers, family members, and friends.

To further enhance in the booklet, we hope to receive your feedbacks and comments. Please, contact...

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TIPS FOR FAMILY AND FRIENDS

It can be very difficult for family and friends to cope with changes and new burdens if your family member or friend has had a brain infection or if they are adjusting to a disability. It can be hard to know how to help someone with their emotions so here are some suggestions.



Talk to each other

Sometimes it's hard for people to talk about their feelings, even with someone close. So let them know that you're willing to listen and ask them what you can do to help. Sometimes there won't be anything you can do, which can be hard. But just being there for them and encouraging them to speak if they need to, is often all it takes.

Spend some time with them

Coping with the effects of a new disability can make people feel very lonely. So simply spending some time with your friend or family member can really help. You may not have time to visit them as often as you'd like, but even a short phone call will show them that you're thinking about them. Try to help them move out of their beds or out of the house. Gentle movement is very important for rehabilitation, but also can affect their moods and emotions.

Keep them involved

If your family member has a new disability, try and ensure that they continue to feel like a valued member of the family. Maybe their role will change but there is always something that they can do to contribute to the family. If they have children, try & ensure that the children continue to involve them in their lives as much as possible.



Nutrition is very important for recovery

Good nutrition doesn't have to be costly, but choose foods which are high in protein and energy, and vitamins. Some important foods include eggs, fish, bananas and oranges.

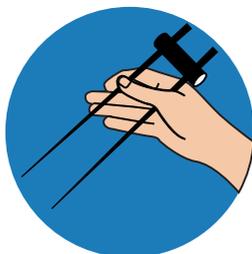
Don't do everything

It's normal to want to do as much as possible for someone you love. But it will be better for your friend or family member if you help them to do things on their own rather than do all it for them. So encourage them to give things a go. This will help them support themselves when you have to go out to work or shopping

Adapt the home

Sometimes small changes can make a big difference to someone's comfort. If your friend or family member finds it hard to access the toilet or get around the house, think about how you can adapt it to make it easier. Some ideas include putting hand rails next to the toilet, so they can lower and raise themselves from it, or attaching a rail on to a wall so that they can do exercises. Sliding doors are often much easier to use than regular doors for wheelchair users.

Further ideas can be found on the internet or through organisations like DRD (see directory)



Help them stay active

Being active helps to lift our mood, so encourage your friend or family member to do whatever they can. It will help if you do it together. Even if they can't get up and about, there may be chair-based exercises they can do and they're likely to have exercises to practise if they're having physiotherapy.

Be patient

It takes time for things to improve, so you'll need to be patient. This isn't always easy, especially when you're coming to terms with everything that's happened as well. So make sure you're looking after yourself and have someone to talk to too. Try to divide the tasks with other family or neighbours so you can take a break from caring and care for yourself.

Tuan's Story

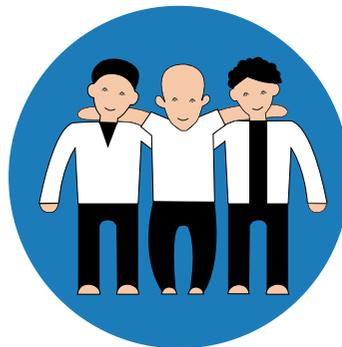
I am Tuan. I'm 39 years old, married with 2 lovely children. I was a joyful farmer who loved working in the rice field and I had many good friends in my village. Suddenly last year, I fell sick with severe headaches and fever. I was taken to many doctors until they found I had tuberculosis meningitis which caused my brain damage. I spent a long time in hospital, far from my village. This had a big strain on my family and our finances. My wife had to sell her motorbike and couldn't go to work because she had to care for me. When I was discharged from hospital, I could not walk and was not able to be independent. Not only did I have physical changes, but my emotions changed too. In the beginning I could not express my needs and my feelings with words and I felt very sad and hopeless.

I now understand that my brain damage could cause emotional changes, and adjusting to a new life with a disability caused great emotional stress. In the beginning sometimes I felt angry with the doctors or nurses or even with my wife and my children. Sometimes, I felt very sad and could easily cry. I didn't want to talk, didn't want to see my friends who came to visit me. Other friends and neighbours were afraid to visit because they thought I might transmit the illness to them. This made me feel isolated.

My poor emotional state meant I wasn't interested to look after myself physically. I sometimes refused to eat and drink. I just slept a few hours at night. I didn't have interest in any hobbies and I didn't even want to watch the football matches on the television as before. To be honest, on the worst days I sometimes wondered, "Why do I need to live as I cannot work like before and I am dependent on my family? It would be better for me to die, so that I would not be a burden for others". It was not easy to accept the changes to my body and brain and all the problems that caused, but after a few months I started to realize all the emotional changes such as worry, anger, sadness and guilt were caused by the illness and the stress that came with it. I was lucky that my family patiently accompanied me with these emotional changes. When I saw how lucky I am to have survived and to have a caring family I decided to try everything I can to improve and be positive.

I started going to the pagoda every week to pray – this helped me relax. Sometimes my wife puts on a CD of meditation or nice music which calms my mind. I practise breathing deeply to calm my body too. My good friends often sit with me and patiently listen to my problems and help me to think more positively.. They were glad I survived such a dangerous illness! As I got a little stronger my wife or friends help me into a chair to sit in the sunshine and watch my children play after school, or push me in my wheelchair around the neighbourhood so I can greet old friends. I even met another man who sells lottery tickets in my area. He was disabled from a motorbike accident many years ago. It's been very helpful to hear how he has adjusted to his new way of life. We are good friends now and he often comes to watch TV with me when it's too hot outside.

I now realise I am not a 'disabled' person, but I am 'differently able'. I realized that the only true disability in life is a bad attitude, so I had to change my attitude. Together with my family and friends, every month I am coping better than before.



WHY DO I FEEL DIFFERENT?



A serious illness that leaves you with some disability is sudden and shocking and affects every part of your life. It's a lot to deal with, not just for you but for everyone around you too.

Feelings of shock, denial, anger, grief and guilt are normal when you're faced with such a devastating change. Also, there may be physical changes in your brain which affect your moods. Dealing with these feelings can be hard and everyone does it differently. What can make it harder is that the people around you may not realise what you're going through. This booklet can help you recognize some of your feelings, and how you can help yourself. It can also help your carers and friends understand what you may be feeling.

The stages of loss



WHAT KIND OF PROBLEMS CAN THIS CAUSE?

Anxiety

It's normal to feel anxious after a major illness – you may worry that you're not going to get better, or be frightened about getting around on your own. You may also be worried about money or your family. These fears are all perfectly normal and you should feel less anxious about them over time.

If you're becoming anxious about a wide range of things, or if you can't tell what you're feeling anxious about, then you should speak to someone about it. It can affect your recovery if you're always anxious, so make sure you get some help.

Other patients have told us they feel anxious about many things. These are normal feelings and there are solutions:

- Will I ever get better?
- How will I have enough money?
- Will I get a job?
- Will my wife/husband stay with me?
- Will I be able to have a loving relationship with my husband/wife?
- Will I be able to look after my children/ parents?
- Will my friends stay in touch?
- Will my friends think I've changed?



Frustration and anger

So many things change after brain infection that it can be hard to accept. Feeling angry or frustrated about this is normal and you're going to feel this way from time to time.

But if you don't deal with these feelings properly, they can build up and affect your mood and the way you behave towards other people. It can also affect your health and recovery if you're angry all the time.

Difficulty controlling your mood and emotions

A brain infection can affect your ability to control your mood and emotions. It can mean that your mood changes very quickly, sometimes for no reason at all. It can also mean that you're more emotional than you used to be and you cry or laugh at even the smallest things. Some people start to swear, when they hadn't used to before.

It can be upsetting, especially if you weren't an emotional person before your illness. Some people say they feel embarrassed, so they stop going out or try to avoid social situations.

Depression

It's normal to feel down or hopeless after a illness or with a new disability. But depression is when feelings of hopelessness and sadness don't go away. Other signs of depression are loss of interest in daily activities, sleep changes (not enough sleeping or oversleeping), anger or irritability, fatigue and lack of concentration. They last for weeks or even months and if they do go away they may come back, over and over again.

Depression can appear at any point, perhaps months or even years down the line. But if you know the signs and understand that the way you're feeling may be down to depression, it can help you realise that you need some support.



Severe depression is very serious. It can make you feel that you want to give up on life and you may think about harming or killing yourself.

If you've had feelings or thoughts like this, then you need to speak to your doctor straight away and get some support.

WILL IT GET BETTER?

When emotions are overwhelming it can be easy to think that they'll never get better. But they do.

Feeling low, anxious or angry, or not being able to control your emotions are all very common after a brain infection, especially in the first few months. However, this will probably get better as time goes by. Even if these feelings never completely go away, you'll probably find them easier to live with over time. And remember, there are things you can do to help yourself.

WHAT CAN I DO ABOUT THE WAY I FEEL?

Talk to someone about it

Talking about the way you're feeling with someone who understands can really help. You may want to do this with a priest or religious leader or it could be a family member or friend – whoever you feel most comfortable confiding in.

The fear of getting ill again or spreading your illness to another family member may worry you, so talk to a doctor. Find out what they think caused your illness and if there is a risk of it happening again. Don't be afraid to ask questions. It's important that you understand what's happened and why. Ask a close family member to come with you to help ask these questions. This will help them understand too.

Take it easy on yourself

Many people find that they have to learn what's 'normal' for them again after they've had an illness and disability. This means listening to both your body and your brain and not expecting yourself to do too much, at least not to begin with.

There's no need to be embarrassed about the way you're feeling – there's a lot to cope with. Be honest about the problems you're having. Often family members just want to know how they can help, so they'll appreciate it if you tell them.

“Accept that you’re going to have bad days and don’t push yourself too hard when you do. Take each day as it comes.”

Keep going

Many people feel that they lose their sense of purpose after a life changing illness. This can really affect your confidence and make you feel down. That’s why it’s important to stay connected to the people and things in your life as much as possible. This can be hard, as you may not be able to do everything that you did before. But there will be things that you can do, so focus on these.

Set yourself small goals to work towards, one step at a time. Keep track of the progress you make, as it can be easy to forget, especially if things don’t happen as quickly as you’d like.

These goals may be physical goals – walking or moving a little more each day, or mental and emotional goals – deciding to visit the pagoda or church (with your carer’s help).

*“Grant me the serenity to accept the things I cannot change,
Courage to change the things I can,
And wisdom to know the difference”.*

Relaxation

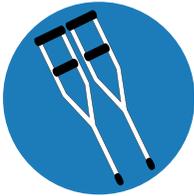
If you’re becoming frustrated or angry you need to find ways to release the tension you’re feeling. That way you can focus your energy on more positive things, like getting better. Doing something physical can help you let off some steam. Even simple things like pounding a pillow or allowing yourself to have a good cry can help get it all out too.

Many people find that their religion and beliefs help them a lot. They find that relaxation or meditation helps them to calm down when their feelings get too much. There may be a CD of calm music, or chants or prayers for relaxation and meditation. Try asking your pagoda or church.

Try to be as active as you can

Although you may not feel up to it, it's important to be as active as you can. When we're active our body releases chemicals into our brain that make us feel happier. If you are not able to walk, sitting up in bed or moving to a chair will have a positive effect. Try to move your limbs a little bit each hour. If you can get up, just a short walk can have a good effect – whatever you can manage. A bit of sunshine can also help your mood brighten.

If you can visit a physiotherapist they can show you and your carer some exercises you could do in bed or in a chair. They can also give you some ideas of some simple equipment which might make your life easier such as a reinforced spoon or a walking frame.



Try and learn a new skill

You may find it frustrating that you cannot do the things that you could do before. However if you are able to learn a new skill, such as sewing, repairing things or using a computer, you will keep your brain active and may be able to find employment in the community. You may also be able to work from home.

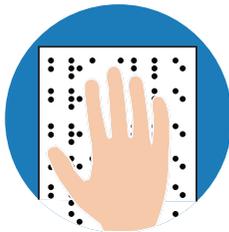
For people whose hearing or vision is affected, it is possible to learn sign language or braille to enable you to communicate with others. It is worth contacting relevant schools to see if they can provide assistance.

If you have internet access, there is a variety of computer software which can help you to read & communicate further.

There are a number of organisations who provide job opportunities to people with disabilities. (see the directory)

Share experiences with people in a similar situation

Sometimes, you may feel that no one understands what you are going through. It can be useful to meet people who are in a similar situation who have perhaps undergone an illness or injury. You may meet them by chance or you can actively look for them through peer support groups, internet chat rooms, facebook or organisations who support people who have been affected by an illness. (See the directory for further contacts)



WHERE CAN I GET HELP AND SUPPORT?

There are a number of organisations who offer support, either financial or emotional to people who are not able to live independently due to an injury or illness.

Look in the newspaper, call up the telephone help service (number?) or if you have access to the internet search for services in your area.

It can also be useful to speak to your local ward committee, a local social work group or Women's Union or Youth Union to see if there is any help they can provide. If you are registered disabled, you will be entitled to some financial support from the government.

See the Directory of services for a list of organisations who can provide support.





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