

# THE CHALLENGE OF CARING.

## WHO ARE CARERS?

If you are the principal caregiver to someone with a disability, you may suddenly find that people are calling you "The Carer" where before you were that person's wife, husband, parent, friend or child. You are pitched overnight into a new and highly responsible role, but it can take a long time to find out what that role means for you and for your family. It can take a long time, perhaps quite a few years, before you know how much your relative or friend will recover. In the early months you may have no idea what the future holds, you live from day to day, you keep an open mind, stay hopeful. All at once you are wondering how you are going to get the best services, maybe in an area where appropriate services are thin on the ground. Perhaps you have the trauma of a court case to contend with. Maybe there are children to bring up, a job to do, worries about lost income. And all the friends who were around for the first year or so offering to help - do they stick around? Can they give you the help you need? Can you find ways to keep your social network from falling away? Do you feel like the whole family has had the brain injury?

## SOME ISSUES THAT OTHER CARERS HAVE EXPRESSED...

"..... Does he look alright? He sounds all right. The neighbours think I am making a fuss over nothing. No-one understands just what problems he has, we all have."

".....Our own GP doesn't recognise my daughter's problems. He won't let me go in with her, says she is old enough to go on her own. But she doesn't remember why she's gone, and she won't remember what he tells her. And the doctor just tells me I am hysterical. Doesn't he know what a subdural haematoma can do? Hasn't he read the neuropsychology report?"

"....I just keep thinking, what's going to happen to him when we die?"

"..... they give us a week's 'respite' every so often in the local nursing home, but when I see the state he's in when I go to pick him up, I just want to break down and cry. One time he was dehydrated, and they said "well we left a jug of water on the table", but Peter's not going to know to drink it. I told them, exactly what to do, but they never listen to me - I'm only a patient's wife."

".....He's too difficult to be accepted by any of the facilities round here, so I have to cope alone 24 hours a day with someone all the professionals in the area say they cannot handle. Sometimes I am so desperate I feel I should be dialing 999, but there's no help, so where does that leave us?"

"... I love my wife. She is the same person she always was deep down. I know she's still in there. She's just different now. I thought this was a welfare state. How come she's been abandoned this way?"

"... He has gone from the strong one in the relationship to being a dependent and unpredictable person. He doesn't have insight into his own problems, and goes on taking decisions as if there were nothing wrong. Life is one long argument - about money, about his drinking, the business is ruined. I am exhausted.

### **NATURAL WAYS OF COPING...**

Often when a brain injury happens to a family, there is a very real sense of loss.

Five Stages of Loss:

❖ Denial and Isolation.

At first, we might try to deny the loss has taken place, and may withdraw from our usual social contacts. This stage may last a few moments, or longer.

❖ Anger.

We may then be furious at the person who inflicted the hurt, or at the world, for letting it happen. He may be angry with himself for letting the event take place, even if, realistically, nothing could have stopped it.

❖ Bargaining.

We may even make bargains with God, asking, "If I do this, will you take away the loss/pain?"

❖ Depression.

We might feel numb, although anger and sadness may remain underneath.

❖ Acceptance.

This is when the anger, sadness and mourning have tapered off. The person gradually accepts the reality of the loss. (Based on Kübler-Ross' model.)

This is a process and can take time. Where possible, try to look forward and not backward.