

Changing Relationships

A self help guide
for carers



**Produced by the
VOCAL Carers Advocacy and Counselling Service**

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A message to all carers

Beneath every carer there is a mother, father, partner, brother, sister, friend. We don't start out in our relationship to the person we care for as a carer. We start out in a different relationship to them, and sometimes when we become their carer we can lose some of that 'other' relationship.

Having spent many hours listening to carers talking about their relationships, it is clear that one of the most difficult and painful situations they have to cope with is change in their relationships. Not just with the person they care for, but others around them as well. Often carers will say that they can manage the practical things involved in caring but it's the loss of the person or relationship they knew before that causes them pain.

This Self Help Guide won't, I am afraid, make that loss and pain any easier, but it may help you to understand more about what is changing in your life, what those changes mean to you and ways of dealing with them. It can also help to know that what you are experiencing is, maybe, similar to what others have experienced.

This guide comes from the experiences of carers and I would like, on behalf of the Carers Advocacy and Counselling Service, to send heartfelt thanks to everyone who has contributed their thoughts and experiences to it. It couldn't have been written without you.

Anne Chilton
Carers Advocacy and Counselling Service

What relationships are we talking about?

As carers we are always going to have a relationship, good or not so good, with the person we care for. However, we are also in relationships with all sorts of other people as well: parents, children, brothers, sisters, friends. When we become carers our relationships with others who are close to us can change as well. We may not have enough time or energy to give to them, they may not understand our decision to be a carer. Being a carer to a friend or relative may be something that we really want to do or it may be something that we feel we have to do. In whatever way we become a carer, one thing is certain, there will be changes to our lives and in our relationships with those closest to us.

Why are relationships so important?

We all have relationships in one form or another. They are the thing that sustain us, give us pleasure and comfort. They can also cause pain, hurt and leave us feeling that we never want to see that person again – ever! At times most of us will find our relationships with others difficult. The pages of magazines are filled with articles on “how to improve your relationships”. It sometimes seems as though it’s the most important thing in the world to have a ‘good relationship’. So, why do we need them so much when at times they can be the most difficult thing in our life.

What people often say is that their relationships with others gives them:

- a sense of belonging
- security

- being cared for
- having someone to care for

Relationships can sustain us in times of need, but what happens when something happens to change that relationship, When the very thing that gave us security is changed to such an extent that everything seems insecure, scary and different? We may have to quickly adapt to a new situation, we may have to take on responsibility for things that the other person always did, we may have to learn new things. We can sometimes be overwhelmed with the enormity of the changes facing us, practical changes, financial changes and emotional changes.

Carers' relationships – what makes them different from other relationships?

We all have to face changes in our lives, sometimes we choose the changes, sometimes they just happen. However, there is a very crucial difference between the changes that carers face in their relationships and changes affecting others who are not carers. That is **choice**. As carers we often feel we don't have any choice other than to adapt to the changes. It can often happen that we don't have the luxury of time, to sit back or talk it through with a friend. So often we are just thrown into dealing with a new life with no preparation and no time to consider what we really want to do.

You've been married for 35 years in a safe and secure relationship, your partner suddenly has a stroke, your world is turned upside down. Your partner comes home,

you feel relieved that they are still with you. Then it hits you that they can no longer do all the things they did before. They cannot speak, so you can no longer share all the things you did before in a spontaneous way. Maybe they did all the practical things at home, you now have to learn how to do those.

Becoming a carer can happen overnight or it can be that we find ourselves doing more and more for the person we care for until one day we realise that most of our life is taken up with caring.

Your mother used to be an active person but over the past few years she has slowed down. She has become increasingly confused, she's frailer than she used to be. She needs you more and more to help her at home. You promised her that you would always care for her. You may have to give up work to keep your promise.

We didn't make a choice to be a carer it just happened that way. And how do we say at this point in our lives that we don't want to care. We might want to but most often we don't. We just get on with it.

Your son has just finished university, he has an accident. Severe head injuries mean that he will require care for the rest of his life. You had been planning to take early retirement. You were looking forward to doing all those things you hadn't been able to do whilst the family were growing up.

We are often left feeling powerless as things change around us. We are often too busy adapting to the practical changes that are affecting our lives to consider how we are

changing emotionally in our relationship to the person we care for and about. And it's the emotional changes that cause us so much difficulty.

You are soon to become a 'family '. Your eagerly awaited first child is born with a disability. All your hopes and dreams for the future suddenly are changed. Your partner can't come to terms with your child's disability. It's turning into a nightmare.

Sometimes we have had the time to make that choice. We maybe always knew that we would be a carer at some point in our life. When that time comes we want to take on the role of carer. However, it can still cause us difficulty because until we actually become a carer, none of us really know how it will affect us and those around us.

Your daughter suffers a breakdown, she can longer cope with her small children on her own. She needs you to care for her. You have always supported her, this time her partner has left her so it's down to you.

Being a carer can give us enormous pleasure and fulfilment *and* it can be the most difficult thing in the world. It can mean that we have the best and worst of times. It can help us to form better relationships with those we care for, it can also highlight all the difficulties we had in that relationship before. It can feel at times as if you are giving the best of yourself to the person you care for and at others as if the relationship between you is like walking through a minefield.

How this Self Help Guide can help

Whilst all relationships are personal, it can sometimes help us to understand them more if we take a step back and view them from a distance. There are exercises in this guide which will help you to do just that, step back and think about yourself and your relationships. You may feel that the examples used are not directly relevant to your caring situation. This might be so, however, the issues raised, like dealing with feelings, will probably be familiar to you.

Relationships – the basics

Some relationships are just ‘there’, we take them for granted. Like those with our parents, brothers, sisters, people who have always been in our lives. Others, like partners, children and friends become part of our lives.

The easiest way of looking at relationships is to consider what links there are between us and the other person, what we give to them and what they give to us. We also need to consider how things are dealt with between us. By this I mean are things spoken about and discussed or are there things that we feel we cannot mention for whatever reason. Brushing things under the carpet doesn’t resolve them, it just makes for a lumpy carpet!

It has to be remembered that not all of what is communicated by either side will necessarily be good or what we want. At a basic level relationships are made up of a complex mix of things.

However, let's try and keep it simple! and take a look at what happens when a fairly average couple are suddenly in that process of change. The circumstances they are in will probably be different to yours, however, the issues raised and how they are or aren't dealt with will, I am sure, be familiar.

A fairly average relationship



Hugh



Mary

Hugh and Mary have been together for 31 years. They met at a dance and Hugh decided at that moment that Mary was the one for him. They courted for three years before they were able to set up home together. Hugh went out to work, Mary worked for a while until the children came along. Once they were older she went back to work. They had, what they considered, a good relationship. Money was tight but they managed. Hugh did all the work around the home. Mary was happy as a homemaker. They tried to 'accommodate' each other. They didn't like arguing, so when they had 'differences' they would try to ignore them. Sometimes 'differences' would end up with them not speaking for a few days, but it was all right, eventually they would get over it and carry on as if nothing had happened.

They didn't like talking about 'feelings and things like that' ... better to let those things be and just get on with life. Hugh expected Mary to carry on in this way. Mary expected Hugh to as well ... so everything would be kept on an even keel. They were both looking forward to their retirement, spending more time together, gardening, dancing, seeing the grandchildren.

If we look at the links between Hugh and Mary we come up with something like this:



The 'rules' of this relationship are that: they each have their set 'roles' and that there is a limit on what it is acceptable to talk about. In order for the relationship to be balanced, strong feelings must not be expressed. Peace at all costs is the family motto.



Hugh expects Mary to:

- take care of the home
- look after him
- not upset him
- not rock to boat

Mary expects Hugh to:

- do all the practical things in the home
- not talk about feelings
- not rock the boat

In a sense they are quite well matched. Their expectations of each other go well together. There is a mutual agreement not to talk about things too much. There is a sense of balance, if not excitement, about this relationship.

It's likely that without even speaking about it they agree on the issues they don't want to talk about:

- being angry
- being sad
- being upset about anything between them
- sex
- dying

In fact the unspoken agreement between them probably covers anything which might cause either of them to experience strong feelings.

The relationship works until the day that Mary has a stroke. Initially Hugh manages. There is so much to do, he is initially scared that he is going to lose Mary. She starts to recover. He relaxes. He thinks everything is going to be all right. He thinks it will be tough for a while when Mary comes home. She will need a lot of looking after but that's all right. She will be fine soon and everything will be back to normal.

Hugh and Mary don't talk about what's happened. They just want everything as it was. Yet individually they feel a great deal has changed. Both know, but don't say, that life will never be the same again, no matter how much they want it to be as it was.

Becoming a carer

Now, in the first few months there will be a lot of learning for Hugh. He needs to learn how to cook, clean and shop. The things Mary has done before. Mary also has to make changes. She needs to learn how to be cared for, to accept

that Hugh won't do things in the way she did. It's a difficult time for both of them but they keep going because they still think that 'things will get back to normal soon'. It's helped that the family have rallied around. Things have been a little tense at times, but, they've all managed.

Six months later

By now the relationship between them is tense most of the time. Hugh is no longer the gentle, kind man Mary knew before. Mary is no longer the easy-going woman he loved. She gets on at him for not doing things right, she demands his attention all the time. She hates being left alone. He feels trapped.

He's often angry, he's tired a lot of the time. He is beginning to resent all the things he has to do for Mary. It's weeks since anyone cooked him a meal. At the beginning he felt it was a bit of an adventure, learning how to cook. Now he resents it. Mary keeps calling for him all the time. He never has a moment's peace.

The garden is getting ragged around the edges. He resents all these professionals coming into his home. The nurses, doctors and social workers. They all tell him to try different things. They don't know what it's like day after day doing the same things, not knowing if what you are doing is right or not. Worrying if Mary is going to have another stroke. He's given up on some things now, things like ironing. He hates it and what's the point anyway, he's not going anywhere. The children don't visit as often as they used to. He hasn't enough energy to play football with the grandchildren.

He knows Mary can't help the way she is but sometimes he gets short and irritated with her. Why can't she be like she was, his capable companion. He misses her coming up behind him to give him a cuddle. He misses the closeness they had, he misses making love with her. He knows he loves her but feels confused and guilty on those days when he's had enough and just wants to walk out and let someone else take it all on.

He's angry, frightened, tired and confused. There's so much that he misses and so much that he feels grateful for, that Mary is still here, but sometimes that gets lost and all that's left is how he feels inside and not knowing how to deal with it.

And what of Mary ...

She too is struggling. Not only with her disability. Learning to do all those things we take for granted – walking, talking, eating, getting dressed. All her time and energy goes into finding ways of doing all those normal things. She's also having to come to terms with all the things she can't do now. She thought she would be better by now only she isn't. She gets irritated with Hugh because he doesn't do things around the house like she used to. It's hard accepting that she is so dependent on Hugh for so much now.

She's frightened that she will have another stroke. She hates it when he leaves the house to go shopping. She waits to hear the key in the lock. Then she calls to him as he comes in the door.

She longs to be able to reach out to Hugh to tell him all these fears and worries she has. About what will happen to her, to him, to them. Hugh doesn't like to be upset so she doesn't. He seems so short-tempered these days. Best not say anything or they may put her away somewhere. She's heard them, the family, talking downstairs but she can't really hear what they are saying. She feels isolated from her family now. They stay downstairs, she's upstairs. And Hugh looks so ragged now, his shirts are not ironed properly, not like she used to do them.

Mary's stroke has not just affected her. It has affected the whole balance of their relationship. It has raised feelings and thoughts in each of them which they are finding it hard to deal with. The relationship which gave them so much comfort and joy is now becoming a prison for both of them.

What's happened.

To begin with Hugh and Mary have coped with a massive change in their lives. Their whole world and way of dealing with it has been turned upside down. We can now look at what has happened in this relationship to identify some of the important changes which are common to nearly all relationships where caring causes a change.

The main issues that we will look at are:

- role changes
- communication
- dealing with feelings
- the process of change

- ways of coping
- what you can do if it all gets too much

As we look at each issue you will be given an optional exercise to do which will help you to link in with your own caring situation.

Doing the exercise won't provide a magic solution to any difficulties you may be experiencing in your relationships but they may just add a little to your understanding of what is happening.

Take time to read them through and allow about 10–15 minutes for each exercise. If it feels too difficult to do now come back to it later. Remember there are no right answers. The exercises are there to help you think about your relationships.

Roles and responsibilities

One of the most significant changes is that Hugh and Mary's roles within the relationship have changed. Prior to the stroke both knew what was expected of them. They had their roles worked out within the relationship.

Hugh did all the practical things around the house, Mary was the home maker. It was probably Mary who remembered the grandchildren's birthdays. She and Hugh would go together to buy the presents but she was the one who remembered. Mary would tell Hugh when something needed repairing and he would do it.

These are fairly stereotypical roles. Regardless of that, in all our relationships we will have roles and responsibilities that go along with those roles.

By roles we mean the things that say who we are and what we do in that relationship. It may be that one of your roles is to be the one who always takes charge, or you may be the one who follows on. In a sense our understanding of our role in a relationship gives us a sense of security. We know what is expected of us and we know what we expect from others. Whilst everyone is happy with their role everything is fine. The problems arise when we decide we want to change our role or when changes are placed upon us. Like when we become carers.

Difficulties can occur because at heart most of us don't want to change. We might like different things in our lives, but changing our role means more than just doing something different. It means we may have to learn new things, we might have to take on more responsibility, we will probably have to change how we view ourselves and others.

As we've mentioned before most of us don't really want to make these changes. When everything is changing in our world it can often feel as if what we know about ourself and our role in the world is the only security we have. Most of us, if we are really honest, would say that given the choice, in difficult, and not so difficult times, we would prefer others to change not ourselves. This is human nature. We all at some time or another wish that others would do things differently or change, to make our lives easier.

So, the first thing that Hugh and Mary could find themselves struggling with is their change in roles. Maybe they are both sitting back hoping that the other will change.



Exercise 1

This exercise will help you explore your role and relationships before you became a carer. It is important that we do this first so as to give a 'baseline'. We can then look at how things changed when your role changed to being a carer. Think about what your life was like before you became a carer.

What sort of things did you do before you became a carer: Here we are focusing on the things that made up your life before caring, for example, did you work, did you go out a lot, did you have hobbies and interests? etc.



Exercise 2

Now think about your relationship with the person you now care for. Here we want to look at what it was like before you became a carer.

Some people might find it upsetting to do this sort of exercise. They may feel sad at what is no more. If you feel upset give yourself a little time to be upset, cry if you want too. There is no reason why you shouldn't feel sad or upset. Losing something that once meant a lot to you is sad.

What was the relationship like with the person you now care for, before you became a carer?

For some people the relationship will have been good, for others the relationship will have been difficult even before they became a carer. Although we cannot say that a difficult relationship can be made better when one party to it becomes a carer, it can be seen that in some relationships the change in roles can make a more balanced relationship.

For example, imagine a situation where a son cares for their elderly father. Maybe the father was quite dominant when

the son was younger. Maybe the son felt that he could never do enough for dad, maybe dad tried to control the boy's life. When he becomes ill and needs his son to care for him the balance of the relationship can change. Maybe dad now becomes dependant on the son he once tried to control. Maybe the son can now show his dad, by caring for him, that he is able to do things without dad telling him what to do. In this situation the balance has changed and it is possible that the relationship between father and son changes for the better. They both need to change roles which ultimately changes the balance.



Exercise 3

Here we will look a little more at the roles and responsibilities you had in your relationship before you became a carer. Think about the things you did together, what sort of roles did you have. Was one of you always responsible for certain things?

What sort of roles and responsibilities did you have in relation to the person you now care for?



Exercise 4

What sort of roles and responsibilities did the person you care for have in relation to you?



Exercise 5

We can now look at how those roles and responsibilities have changed since you became a carer.

What is different now in relation to the the roles and responsibilities you have as a carer?

We will look later in the guide about how you felt about these changes and how you dealt with them. But, for now, we need to look at the next issue that causes difficulty with relationships ... communication.

Rules of communication

Every relationship will have 'rules' about what can and cannot be talked about. Obviously, we don't usually sit down with our family and work out these rules. Hugh and Mary certainly didn't have a set of written rules about what could or couldn't be said. They would have learnt as they went along. Maybe, early on in their relationship, Mary showed that she felt uncomfortable when Hugh got angry. He picked up on this and felt that maybe Mary 'disapproved' of him being angry. So, he soon got the message that it wasn't OK to be angry. Or maybe Hugh would get embarrassed if Mary got upset, if there was a soppy film on TV and Mary started to cry he would get up and make tea. Again Mary would soon get the message that Hugh didn't like it if she got upset. In time they would not display either of these feelings, not because they didn't feel them, but, because they felt the other wouldn't like it or be able to cope with the feelings.

More often than not these are 'unspoken' rules. We often learn as children how our family relate to one another. We pick up very quickly whether or not it is acceptable to express feelings such as sadness ("be a brave boy now and don't cry"), or anger ("hold your tongue now!").

We often don't realise how these rules limit our communication until we hit a situation where we find

ourselves experiencing strong views or feelings but hold back from saying anything.

Communication

It's not just what we say or don't say that counts, it's the way we say it.

Being able to communicate well can be the key to helping us deal with the changes in our relationships. A lot of the difficulties that Hugh and Mary are experiencing could be easier if they could tell each other how they were feeling.

However, it can also be the most difficult thing to accomplish. In our heads we know what needs to be said. We steel ourselves to say it and then when the moment comes ... we don't say anything or we say something else instead. We all do it. We don't want to upset the person we care for, we worry about what they might think of us, we worry about how they might feel.

What we can sometimes forget though is that the person we care for might be wanting to say things to us as well. They might not want to upset us either. So, we can end up in a situation where both people are not happy but neither will take the risk to say what is on their mind.

There are some important points linked to communication we maybe need to explore further. They are very basic, but sometimes remembering the basics can make it less difficult.

The first thing to remember is that *if we don't say what is causing us upset then it won't go away*. It will still be in

your head or causing you discomfort in one way or another.

The second thing is that *whilst other people might not like what you want to say, you still have a right to say it.*

And finally, *communication is a two-way process*, it's not just about saying what you want to say, it's also about listening.

Underlying all of this we also need to remember that people can and do change ... if they are given the opportunity to do so. And that includes the person you care for.

As well as looking at what we do feel able to say, we also need to pay attention to the things we feel we cannot talk about. This may be particular subjects, such as the person's illness, feelings, like being angry or sad, and things that are specific to our relationship, such as loss of a sexual relationship. Why is it so difficult to talk to those we care for about the things that cause us difficulty? Well, as we have said before, we can often worry about causing more upset. It's perfectly natural to worry about this happening. Especially if the relationship is not so good now, we can worry that by raising difficult issues it will get worse. Few of us ever consider that it might actually help the relationship improve! If two people are willing to change their relationship and work together, accepting that they may say and hear things that upset them, then anything is possible.



Exercise 6

Think about the things that are causing you difficulty at the moment in your relationship.



Exercise 7

Now think about what stops you from speaking to the person about those difficulties.

If you have come up with a list of reasons why you can't talk about things I daresay they have included some of the things we have already looked at; fear of not being listened to; fear of upsetting the person; fear that things won't change if you do say anything. As we've said before these are normal fears but we've also said that if things aren't spoken about they don't go away.

It's useful to consider the following when broaching difficult issues:

- think about what it is that you want to say
- write it down if necessary
- think about how the other person might react to what you say
- think about how you might deal with their reaction
- think about the best time to speak to them

You might find it helpful to read through one of VOCAL's other publications, **VOCALISE, A Guide to Self Advocacy for Carers**. This booklet gives a lot of information and helpful hints on how to put your views forward and getting people to listen to you. It is available free, to carers, from VOCAL. You will find the address at the back of this booklet.

In talking to carers about their relationships it is clear that one of the areas they have most difficulty with is dealing with feelings. Not only their own but also the feelings of the person they care for. Feelings and what we do with them form a crucial part of communication.

If you think about communication you can see how it breaks down into:

- the content – what we say
- the tone – how we say it, and
- the feelings behind the content and tone.

How often have you found yourself either saying that everything is 'all right' or 'fine' when inside you feel angry, upset or sad. Despite our feeling that we are covering up our feelings and not letting people know how we really feel we cannot delude ourselves. Inside we know how bad we feel and often others can detect this as well but are usually too polite to mention it. So we just carry on, carrying all those difficult feelings around with us. As we've noted before, they don't often just disappear, they stay inside us causing all sorts of other difficulties, such as headaches, depression, fatigue. Feelings have a way of expressing themselves whether we like it or not.

Mary and Hugh are dealing with *things* but not really dealing with their *feelings* about doing those things. Hugh is tense and irritable, Mary is tense and sad. How they feel is affecting their relationship and how they are together. They cannot change what has happened but they could change the 'atmosphere' between them if they talked more about how they felt. However, they may feel that they have enough to cope with now without getting into those feelings which they never liked talking about anyway! Being able to talk about and listen to our own and others feelings is an essential step towards making our relationships more enjoyable.

Dealing with feelings

Sometimes dealing with feelings can seem like the most difficult thing in the world. Yet, oddly, they are the one thing that we all share. Our concerns are often about not being able to deal with other people's feelings as well as our own difficulty about being honest about our own feelings.

Let's look at some of the basics of feelings and then we can look at how we can deal with them. The easiest way of looking at feelings is to consider that we only really have four basic feelings. Yes, that's right, just four and they are:

- sad
- angry
- happy, and
- anxious

These are the basic feelings, any other feelings are a combination of the above. For example you may feel excited. This is a combination of happy and anxious. Feeling upset could be a combination of angry and anxious. Feeling 'down' or depressed could be a mixture of sad and anxious or it could be angry and anxious. Try and see if you can identify how you feel using the four basic feelings, combine them to see if you can hit on what it is you are feeling.

If we take each of the feelings and look at what it means and how we can deal with it, we will be well on the way towards finding out more about how we can deal with our relationship difficulties.

Sadness

Feeling sad is often about feeling a sense of loss about something. We can feel sad about losing what we had before or about things that we wanted to do which we now feel we won't be able to do. We can feel sad about the loss of real things, like not being able to do the things we used to do. We can feel sad about the hopes and dreams we had for the future. We can also feel sad about the hopelessness of things, feeling that things will never change.

When we feel sad our whole body can often feel sad. We can kind of slump into ourselves. We can cry, sometimes for no particular reason, tears can just flow from us and all we know is that we feel sad. It might seem obvious to say but to cry when we feel sad is the most natural thing in the world. If, though, we try to put words to our sadness it can help. Trying to find the way of expressing what we feel sad about inevitably means that we have to explore within ourselves what we have lost. Carers often hold back from doing this because they feel that no matter what they have lost, the person they care for will have lost more. Whilst this is a common feeling for carers you must not forget that your feelings are just as real and just as valid as those of the person you care for. If you do not acknowledge your feelings of loss you will find it harder to deal with their feelings.

Often the feelings of loss are shared but sometimes we try to hide them. Again we are back to not wanting to 'remind' the person we care for of their own losses. Remember Mary and Hugh, they had lost not just Mary's

physical abilities when she had the stroke, They had also lost their dreams for their future together. Not just individual losses but a shared future loss.



Exercise 8

Think about the times when you feel sad. Try and put into words what it is you feel sad about.



Exercise 9

Think about how you deal with being sad, for example do you talk to others about it, do you cry, do you bottle it up.



Exercise 10

Now think about how you deal with other peoples sadness. Do you feel uncomfortable about dealing with it, do you try to ignore it or do you feel confident in dealing with it.



Exercise 11

What makes it difficult for you. Is it your own feelings or fear about dealing with other people's sadness.

When we feel sad we can often feel angry as well and this can sometimes make it seem even more difficult.

Anger

Feeling angry is a good thing. You may not agree with this but if you think about it, feeling angry has a purpose. It is a feeling that tells us that we are not happy about something. Remember that feeling angry is different to being angry. We feel angry when something has upset us, it is our way of knowing that all is not right. Anger is quite an energetic feeling. The surge of energy that anger gives you and finding that you have been able to do something that you have not been able to do before can be quite exhilarating. The energy in anger can help us to move ourselves forward. However, it can also be destructive. We all say things when we are angry that maybe we mean a little bit but end up saying in a way that causes pain and hurt to others.

In dealing with angry feelings in other people it is useful to remember that:

- it's no point trying to argue with someone who is very angry – it just makes them more angry
- listen to the other person
- try to understand what they are angry about
- if someone is angry they are often angry about something
- what they are angry about might not be the underlying fuel for their anger
- talk about what has been said when the person is not so angry

We can often feel angry and express that anger when underneath we really feel something else. For example, the person you care for may feel angry because they feel frightened of being so dependant on someone for their everyday needs. This fear may express itself in anger at the person who cares for them. They may be angry because the carer does not do things in the way they used to.

Mary feels angry with Hugh because he doesn't keep the house like she used to. Underneath she may feel unhappy because this is something she did for Hugh which she can no longer do. In this situation it is important to listen for what the person is really being angry about. Like Mary they may be angry but underneath feel sad.

Hugh is sad that the children and grandchildren don't visit as much as they used to, but, underneath he may feel angry at them because he feels they are not supporting him as much as they could. In this case Hugh is using another feeling to mask his angry feelings.

As we have said before some people find the expression of some feelings more difficult than others. This will depend on which feelings they feel it is acceptable to express. So Hugh feels it's more acceptable to be sad than angry. Mary feels it's more acceptable to be angry rather than sad.

Covering up feelings

Now this highlights a very interesting point. If you think back to the feelings Hugh and Mary found it difficult to express in their relationship before Mary's stroke, you will recall that Hugh felt it was unacceptable to be angry and

Mary that she couldn't be sad. Hugh still can't be openly angry feeling – sadness – to mask the angry feelings. He probably feels it's more acceptable to be sad than angry in the scheme of things. Whilst Mary is using anger to mask her sadness, a feeling she knows Hugh can't deal with.

So both are covering up what they really feel with something else. Which makes it harder for the other to deal with as they are not showing their real feelings. We often do this, cover up what we really feel. Maybe because we feel there are some feelings which it is not acceptable to show. This might work for a while, however, unless we are honest about our feelings they will stay lodged inside us. You can't get rid of anger by being sad. It's like pretending that baked beans on toast is really roast beef. You can kid yourself some of the time but not all.



Exercise 12

Think about how you deal with being angry. For example do you get angry and then pretend it's not happened, do you rage and then feel guilty, do you bottle it up.



Exercise 13

Now think about how you deal with other people's anger. Do you feel uncomfortable about dealing with it, do you try to ignore it or do you feel confident in dealing with it.

Remember that our feelings are ours alone. Other people cannot deal with them for us, neither can we deal with other people's. We can listen, try to understand, offer a tissue or a shoulder to cry on but we cannot stop other people's feelings. Our feelings are about us as individuals, they tell us how we are experiencing our world and offer clues to what needs to change.

Happiness

Now you might be surprised that happy feelings can cause difficulties, but they do. Carers can sometimes feel that it is being disloyal to the person they care for. If the person we care for can no longer do things they did before or if there

are things they will never be able to do, then we can end up feeling guilty about feeling good about ourselves and the things we can do.

We might wake up one morning feeling good about being alive, being able to go for a walk, being able to read a good book, being able to come and go as we please. Then we think about the person we care for who maybe cannot do those things. What do we do then, well some of us switch off the good feelings and feel guilty instead. Feeling guilty about feeling good.

A special word about guilt

Guilt is an awful thing to feel. The real purpose of guilt is to makes us feel bad about things that we know we shouldn't do. Things that we know are wrong. However, the way it is often used means it isn't really a feeling at all, it's something that stops us feeling things that we think we shouldn't feel. When we allow ourselves to feel, for example, happy, then think that we shouldn't be feeling happy, then we press the guilt button. So, whatever we were feeling originally is replaced by guilt.

What can sometimes happen then is that we can get into a very negative cycle. We can feel something good, switch it off by feeling guilty and then end up feeling angry because we feel we should be allowed to feel good and then we feel guilty again. Not a good place to be. So, if you start to feel something and then feel guilty ask yourself if you have really done something wrong or if you are just not allowing yourself to feel something. You are just as entitled to feel happy as the next person and so is the person you care for.

The things you feel happy about now may be different to the things you felt happy about before. Sometimes it can be difficult to feel happy because of the sadness we feel about the things we have lost. It can be useful to remember that sometimes we have to be sad and mourn the loss of what was, before we can be happy in the things that we have now.



Exercise 14

Do you ever stop yourself from feeling happy. How do you stop yourself.



Exercise 15

If you ever feel guilty about being happy, think about what you do instead of being happy, do you get sad or angry or down.

Anxiety

Feeling anxious can be about many things. We can feel anxious about the things we have to do, about how people will react if we say how we feel, about what we do feel, about anything in fact.

Anxious feelings are another way in which we stop ourselves saying what we really feel. We might be so worried about what might happen that we allow our anxiety to overwhelm us. Again it can often be a 'do nothing' option to be anxious. There has been a lot of research carried out which looks at whether or not the things that we worry about actually happen. As a rule of thumb, the research suggests, only about 2% of all the things we worry about actually happen, so, that means that

most of us spend a huge amount of time and energy worrying about things that probably won't happen!

Again, understanding our feelings and what is happening to us can help us to at least be more in control of our anxiety, even if we can't get rid of it altogether. Learning to relax and maintain a degree of control can help, as can talking about what we are really anxious about. The first step is really to understand what it is that we feel anxious about. For many carers the anxiety can be linked to worrying about the other person's care needs. We worry about how we will manage if their condition gets worse. We worry about what the future holds for us and them. And we worry a great deal about what will happen if we reach a point where we feel we can no longer care.



Exercise 16

What things do you feel anxious about in your caring relationship.

Some of things you feel anxious about may be practical things, others may be emotional. Practical concerns require practical answers. Emotional difficulties need emotional solutions. This may seem obvious. However, we can often try to sort out emotional difficulties with practical solutions. If we are feeling worried it may be that having someone to talk things through with is all we need. This can help us to sort out what it is that we really need to allay our anxiety.

Summing up

When dealing with change in our relationships there may be a change in our roles and responsibilities. How we deal with those changes will be linked to how we communicate and how we deal with our feelings about what is changing.

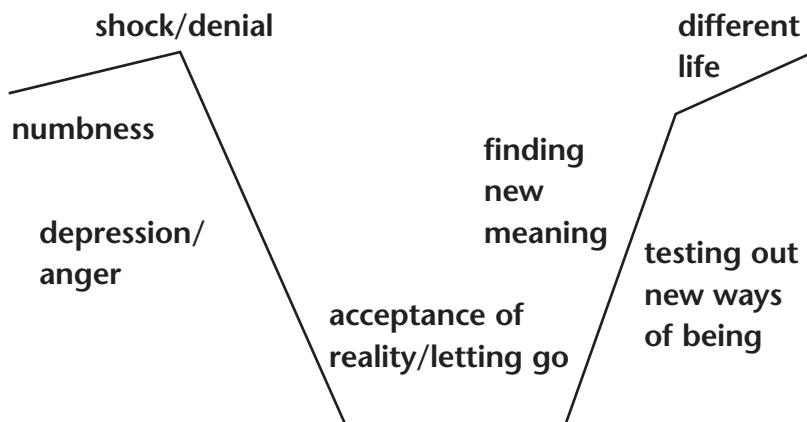
As well as all of the above we need to be aware of how we deal with the whole process of change and what feelings we can expect to experience within that process.

What happens when we are confronted with change

Some changes are sudden, as in a crisis, others move up on us gradually. Whatever way they come they will all involve a process. How we respond to change is similar in whatever circumstances the change occurs. The process is more or less the same whether the changes are seen as good or not so good. Even if you win the Lottery you will still go through this process of change. Within the process we can expect to feel different things at different times.

Let us begin by looking at what happens when we are faced with change.

The Process of Change



The first thing that happens, no matter whether the change is for the good or not, is that we tend not to believe it is happening. We may feel numb as if in shock. This stage may last anything from a few hours to weeks depending on what type of change we are dealing with.

Have you ever lost your door keys? At first you cannot believe that you have lost them. You keep expecting to find them. You keep searching the places where you expected them to be. Even though you may have checked several times you still keep going back. It's like you expect them to appear as if by magic. It's exactly the same process when we hear that someone close to us is ill, we don't want to believe it is happening. We cannot take in what is happening to us. We try to minimise the potential changes by assuring ourselves that we will manage. We don't want to even

contemplate the changes we may have to deal with. We want life to be exactly as it was before. It is nature's way of protecting us, it gives us time to prepare for the changes that we must make in the future.

Hugh and Mary were in a state of shock when she had the stroke. Feeling numb and unreal whilst all the essential medical things happened around them.

The next thing is that we may deny that the change will cause us any difficulty. We may even deny that the change has happened at all. We are still in a shocked state. We may say that it doesn't matter we will manage the changes and continue as before. Think of all the Lottery winners who say that the win won't change them – of course it will but initially it's too difficult to imagine how their lives will change let alone start to make those adjustments. So, we cling hold of what is safe and familiar.

When Mary came home from hospital they both were just waiting, and hoping, for things to get back to 'normal'. The real impact of their changed lives had not really sunk in. They muddled on as best they could waiting for it to get better.

Once we accept that change is happening to us we tend to start feeling down or depressed. We may begin to wonder if we can manage. We know that life is changing but we, as yet, do not know fully how life will change or how we will manage those changes. It is quite usual at this stage to also feel angry. We question ourselves, could I have done something to make it different? We get angry, why me? why him? why did it happen to her? it's not fair! We may

feel guilty about having these thoughts and feelings. It's natural to feel these things, after all, our lives have changed as well. It's maybe not the life we wanted for ourselves.

As we begin to grapple with the implications of the changes we may feel daunted by all that is changing. It may be that the whole of your life feels as if it's been turned upside down. You may start to feel less confident in your own abilities to cope. You may feel that everyone else seems to be coping better than you. It maybe that your usual sources of comfort, your partner, family and friends are also caught up in dealing with the changes, and are not able to give you the support you need. You may feel isolated, frightened for the future, sad at the loss of your way of life, your hopes and dreams for the future. You wonder if you can carry on and may sometimes feel like walking out but then feel guilty about even thinking this.

Hugh reached this stage after about six months. His usual source of support, Mary, isn't available to him. She's tied up in coming to terms with what her disability means to her. The family don't visit as often. Hugh is probably feeling quite depressed, although he probably won't acknowledge or even recognise that he is. He's feeling isolated and alone and maybe wondering what it is all about.

This stage may continue for sometime. Some carers feel worried that they are experiencing these sorts of feelings. They are usual and normal and if you accept them they can help you in the next stage.

We know when we are in the next stage. It's when we hit rock bottom. When we realise that this is it now. Things are

not going to go back to how they were. This is how it is now and we begin to find a degree of acceptance in the situation. Some people find it a very sad time but often tinged with a lessening of tension. They are beginning to accept the reality of the situation.

Once Mary and Hugh begin to accept their 'new reality' they can begin to move on. Maybe Hugh will recognise that he is Mary's carer now as well as her husband. He may contact his local carers centre. Maybe Mary will accept that she can no longer do the things she used to and find other ways of gaining enjoyment for herself. Maybe the family will see that sitting and chatting to mum / grandma is still the same even if it does take much longer to reply.

In amongst all this change Mary and Hugh may also realise that they need to say honestly how they feel about their relationship. To find new ways of communicating.

Moving on from this stage we start to build a new life for ourselves centred around our view of the situation. This might mean being a carer or it may mean that we feel we need to look at other alternatives. We may not actually want to be a full time carer. It may be the time when we start feeling more confident about being a carer. Or it might be the time when we decide that we cannot do it without more help.

There is no real time frame for how we move through this process. It is not a straight run through. We tend to start at the beginning, go forward, go back, move forward again and so on. Learning all the time about what is happening to us, giving the experience meaning for ourselves.

Sometimes we can go through the whole process in minutes, at other times we may be stuck for days, weeks, months, in one particular stage. In between the condition of the person we care for will also be changing and we may be presented with new changes and challenges before we have even begun to deal with the previous one. We may find ourselves dealing with new situations before we have even begun to work out what the last change meant for us.

All we can do is learn to understand that we will have feelings and thoughts about what is happening to us and that we are going through a process. We can help ourselves within that process if we can talk about how we are feeling and if others listen to us. This can help support us in finding a meaning for all that is changing in our world.



Exercise 17

Think about the changes that have occurred since you became a carer. Go over the change graph, do you feel stuck anywhere in that process.

Some of the things that can change

For Hugh and Mary there has been a fundamental change in their relationship. Even if they manage the changes in their roles and responsibilities; the way they communicate; and how they deal with their feelings, there are still some areas they may find hard to talk about. The two areas people find it most difficult to talk about when the relationship involves caring for another are: dying and their sexual relationships.

Death and dying

That we will all one day die is the only thing we can say for definite that will happen to us. We may win the lottery, we may run a marathon, we may meet the perfect partner. All possibilities, but for sure we will all one day die.

Dying is also the one thing that many people fear talking about the most. Some fear it's tempting fate, others that it is something that should only be mentioned in hushed whispers. Yet for many carers the reality is that the person they care for will die. For some this maybe a day they dread, for others the day that will relieve them of the responsibility of caring. Being able to talk to the person you care for about how they feel about dying is not an option many people would choose. However, it may be that the person you care for already has thoughts and feelings about their own death that they would like to share with someone. They may have things that they want to tell you, things that they may never have said before. Maybe they want to tell you how much they love and care for you, how

much they have appreciated you caring for them. Yet they may never be given the opportunity to share this with you. They may feel that by raising these issues that you will get upset. Of course, you probably will, both of you will probably get upset, but this can allow you to feel closer than ever before.

Talking about dying and what you would like at your funeral may seem a little morbid but it does also acknowledge the reality of life: that we all die at some point.

Being able to work through grief before a death has been found by many to be helpful. After all we are often involved in all other aspects of the lives of those we care for. Why should we distance ourselves from the last part of their living?

Carers frequently say that they feel guilty about even thinking about the death of the person they care for. The guilt is sometimes because the carer feels that their life is 'on hold' until that point. Often we can feel very confused about what we do feel around this issue. We may secretly feel life will be better for us after the person dies but what we might really mean is that we want to be relieved of the responsibility of caring, not necessarily the death of the person we care for.

There are no easy answers to this difficulty other than to say that it is an issue that many carers struggle with. Talking about it with other carers who are maybe experiencing similar dilemmas can help, as can counselling. Details are to be found at the end of this booklet about agencies that can offer support and counselling.

Sexual relationships

If death and dying are difficult to talk about then so is sex, sexuality and our sexual relationships. When we are carers all sorts of areas of our lives are affected by our being carers. The one area that receives little, if any, attention is that of our sexual relationships.

Even if you are not in an intimate personal relationship your caring role may be affecting you not allowing you the time to meet someone special with whom to have a relationship.

In most intimate relationships that are experiencing difficulties sex will be an issue. It's extremely difficult to make love to someone you resent, are angry with or who has been difficult to deal with. This is reality.

One of the most common questions carers have is whether or not it is 'safe' to have sex with their partner, for example, if their partner has had a heart attack or stroke. Doctors and health visitors can often provide these answers. If you don't feel able to ask them you could contact any of the many helplines related to specific disabilities.

If your partner has received an injury that restricts mobility then finding the most 'comfortable position' may be a problem. Again, because this is 'couple specific' it is difficult to provide an answer. However, SPOD (Sexual Problems of the Disabled), is an organisation that can provide a whole range of information on issues related to sexual relationships and people with disabilities. Their contact number is at the end of this booklet.

Another issue that carers can find difficult is the loss of their sexual relationship. By this they often don't just mean sexual intercourse, they mean the physical contact that is part of an intimate relationship, the hugs and cuddles that make us feel wanted and attractive.

Again this is a loss and needs to be acknowledged as such. Recognise that your partner may be missing that comfort as well. If you can talk about it and share that loss you may be able to find new ways of expressing those intimate gestures that mean so much to both of you.

Even if you cannot talk to your partner about any of this you can talk to someone yourself. Counselling is available and it can help.

So, what does it all add up to?

In the end the only thing we can say for sure is that caring can and does affect our relationships. Whether we are in a couple, like Hugh and Mary; if we care for an elderly parent; if we care for our child with special needs; our relationship with that person and others around us will change by virtue of us being carers.

I hope you will have seen that change is not easy, but that it can be worked through. That caring can leave us experiencing strong feelings and that these are normal and need to be acknowledged. No matter what we feel it is our experience and cannot be dismissed. If we do dismiss or ignore it then we are ignoring ourselves.

Dealing with the changes brought to our relationships can be difficult but we don't have to deal with it on our own.

The Carers Advocacy and Counselling Service at VOCAL can provide one to one counselling support if you feel this would help. We also run workshops and courses on Self Advocacy and Understanding Relationships. Just call us ... it could help.

Organisations you can contact for help, information and advice.

There are many organisations offering information, advice and support to carers in every caring situation. Some of these can offer general advice, some are relevant to specific illnesses, disabilities or conditions. However, your local carers centre will be able to help, either directly or by pointing you in the right direction if you have a specific problem or query.

VOCAL Carers Centre
8 Johnston Terrace
Edinburgh EH1 2PW
Tel: 0131 622 6666

VOCAL offers information and advice on all issues relevant to carers. Including support groups, respite services and benefits.

Carers Advocacy and Counselling Service
8 Johnston Terrace
Edinburgh EH1 2PW
Tel: 0131 622 7625

The Advocacy Service is a free and confidential service for carers who require a little extra support in getting their

views heard. All the Carers Advocates are trained volunteers who are carers or former carers. The Carers Counselling Service offers one to one counselling support for carers. Both services are available to carers and former carers in Edinburgh and the Lothians.

Carers of East Lothian Carers Centre

149 North High Street

Musselburgh

EH21 6AN

Tel: 0131 665 0135

Carers of West Lothian Carers Centre

Dovehill Centre

24 Main Street

Uphall

EH52 5DW

Tel: 01506 858841

Alzheimer Scotland – Action on Dementia

Helpline: 0808 808 3000 (freephone 24 hours)

Information and support for those caring for someone with Alzheimers.

Cancer Information Service

Tel: 0808 800 1234 (freephone 9am–7pm Mon–Fri)

Offers practical information, emotional support and publications on all aspects of living with someone with cancer, including talking to someone about cancer. They also produce a specific booklet on Sexuality and Cancer.

MIND

Helpline: 0345 660 163 (9.15am–4.45pm Mon–Fri)

Produces publications related to relationships and caring for someone with a mental health difficulty.

Multiple Sclerosis Society

Helpline: 0808 800 8000 (freephone 10am–10pm daily)

Parkinson's Disease Society

Helpline: 0171 233 5373 (9.30am–5.30pm Mon–Fri)

Saneline

Helpline: 0345 678 000 (12noon–2am every day/night)

Provides advice, information and support for those caring for someone with a mental illness.

SPOD (Association to aid the sexual and personal relationships of people with a disability.)

286 Camden Road

London N7 0BJ

Tel: 0207 607 8851 (office hours)

SPOD offers specialist advice and information to people with disabilities and their carers on all aspects of sexual difficulties. They produce a range of leaflets about sex and disability.

Your local Carers Centre will have information about many more agencies offering advice, information and support. Contact them, they will be able to point you in the right direction.

The Carers Advocacy and
Counselling Service
8 Johnston Terrace
Edinburgh
EH1 2PW

Tel: 0131 622 7625

Providing a free and confidential
advocacy and counselling service
to carers in Edinburgh and the
Lothians.

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For bulk orders please call 0131 622 7625
(cost £1 per copy inc p & p)