

“In the bosom of his family, he was more alone than if he had been at the bottom of the sea or on the other side of the moon.” (Tolstoy, about the dying Ivan Ilych)

Few of us live completely isolated lives: mostly we share our lives with family and friends. Sometimes our illness becomes our central focus and we feel isolated, and forget the awful impact our illness can have on our nearest and dearest.

Sadly, chronic illness can lead to break-up of relationships as it can place intolerable strains on everyone involved.

Step 6 is there to remind us that we are not islands and we need to involve our partners, children and friends in our daily struggle.

Yes, even children should be included: except for the very young, they are likely to be aware that all is not well, and excluding them can make them feel not only that we don't trust them or really care about them, but also they may fear the unknown: they may think their ill parent is dying, for example.

Showing our children that we can win the struggle is a wonderful example to them: life is full of strife and struggle and it is an important lesson to them that even such difficulties as constant pain can be overcome provided we don't lose heart. Also, they can contribute in small ways.

Provided that we don't burden them so that they have a sense that they are in some way responsible, then this experience need not be a negative one.

There is so often guilt that we cannot be the active kind of parent we should like to be: but don't

forget, we still have ears to listen to happy stories and grievances, a mouth to praise and encourage, shoulders to cry on and hopefully a broad mind with which to guide and teach.

Bernie Siegel wrote:

“It is sometimes difficult to share with family members because in a sense they want to cure the situation. And you have to remind them that if you express anger or fear, you're not asking them to cure everything but to be there to support you physically and emotionally.

It might mean giving them a hug so that they feel they're doing something for you besides listen. If they ask how you are, you can say, 'I'm a B plus or a C minus'. The rule is that if you're less than a B plus, you always receive a hug. Then they won't feel helpless. They can listen; they can touch; they can support you.”

For partners, chronic illness can be devastating. As adults, they see our pain, usually even when we hide it. They have their fears about the future just as we do, but they also often have the burden of responsibility for financial security and even the day-to-day running of the household.

All too often, partners feel that they are unable to have their own problems any longer: they no longer have any validity alongside the patient's problems and the partner sees him/herself as unjustified in airing any complaints or concerns.

Anita Tedejat whose husband was chronically ill, wrote:

“When someone you love is falling apart with the dreaded disease that seems to be consuming him little by little, you become steeped in fear and anger and denial and often feel helpless.”

Of course, one of the biggest strains on partnerships is difficulty with the sexual relationship.

Pain certainly isn't renowned for its aphrodisiac qualities!

Sometimes it will be necessary to seek outside help, such as counseling.

If possible, try to make an effort with your physical appearance, just as you would have done before you were ill. In the same way, try to keep your attitude positive and don't let yourself be changed too much by your illness as regards personality: this is why bitterness and depression are such potent foes: they can change you as a person more surely than the physical illness can.

That isn't fair on your partner and family. A physical handicap is one thing for your partner and family to accept, but a mental or emotional handicap is altogether different and your relationships will inevitably suffer.

It is essential to avoid letting your illness become a crutch in your relationship. It is not something to be used as an excuse to avoid difficult or unpleasant situations (such as visiting the mother-in-law).

It is advisable to sit down with your partner and together work out what you can and can't do physically (if your condition fluctuates, do a best and worst case scenario) and from there you can both work out your individual spheres of responsibility within the household.

For instance, if you can't put the casserole in the oven, perhaps you can at least sit and peel the vegetables to go in it (and at the same time, get a chance to chat with your spouse) or if you can't dig the garden, then you can still plan what flowers you want and where they'll go. Try not to just give up taking on that sort of responsibility.

Your illness may prevent you from pursuing activities you previously enjoyed, but it is essential to find interests to replace them: that way you can still share your experiences with your partner and have something positive to bring into the conversation, rather than merely being able to say whether you've had a good or bad day with the pain.

It is absolutely essential that patients (and their doctors) keep in mind the suffering that their illness causes for those around them. It shouldn't be a matter of feeling guilty: after all, it is hardly a matter of choice!

However, recognising the contribution of the illness to the dynamics of the family is necessary in order to avoid unnecessary pitfalls.

By the same token, family and friends must be aware of these stresses and strains too.

Some recommended ideas for maintaining good communication with your family:

1. Educate explore together the problems and the possible solutions.
2. Develop a simple way of expressing your pain and other symptoms; such as a scale of 0-10 for your pain. This allows direct communication and avoids guesswork from your family which can be frustrating and worrying for them and make you feel they don't understand.
3. Tell them what you are going to do; ways you are going to take charge in your own management; a good way to boost your self-esteem and the respect your family has for you.
4. Ask directly about what you need from your family; not knowing what they can do will frustrate them and make you wonder if they care: they are not clairvoyant or mind-readers: so avoid your family constantly trying to second-guess your needs: and give them a concrete way to help which can make them feel positively involved.