

There is no doubt that chronic illness puts an enormous strain on the closest and strongest bonds, and that sometimes the unrelenting pressure is enough to break those bonds. This, of course, is both a consequence of illness and in turn, a cause of greater suffering.

Family relationships tend to be subject to the most intense and enduring stresses because, unlike the ties of friendship, the ties of blood or marriage are more complex and harder to simply turn one's back on.

Living with chronic illness is like having an uninvited and highly disruptive houseguest who is unaware (or uncaring about) social niceties and thus has an adverse effect upon all the other occupants of the house.

Losing friendships (a not uncommon occurrence for those with chronic illness) is distressing enough, but the breakdown of very close emotional bonds within a family can be devastating for all concerned.

How then may we find a way in which to minimise the effects of chronic illness on our relationships with our nearest and dearest?

FRIENDSHIPS:

"He jests at scars who never felt a wound"; Shakespeare.

Whilst we may feel in some ways closer to our friends than to some family members, (the saying about choosing friends but not family being a truism) it is important to recognise that our misfortunes may colour that friendship and that if we are not watchful, may stretch the bond of

friendship to breaking point.

Of course, if we find that our so-called friends become conspicuous by their absence and are frequently making excuses not to visit or call, then we need to call into question the strength of that friendship and whether it warrants emotional investment and expenditure of energy to preserve it.

The answer might be 'yes' in which case, an upfront approach to the problem is probably the best way forward. Often people are severely discomforted by illness and just don't know how to react or to discuss problems, using avoidance strategies simply because they do not wish to cause further distress by saying or doing the wrong thing.

It may however be that the illness has curtailed activities that you previously shared or may even, without you being aware, narrowed your horizons (psychologically speaking) to such an extent that you no longer have anything in common.

That doesn't necessarily mean that the friendship is rendered void, but it does require an element of 'work' to find a new common ground and re-establish a firm basis for ongoing friendship.

It takes two to willingly work at that, and some people may simply not wish to invest time and emotional energy into this.

One of the problems that might be a source of disruption to the friendship is the tendency for the ill person to regard the friend as a 'safe' person to whom all the woes and troubles can be taken (often family are hard to talk to for a variety of reasons we shall look at shortly).

Naturally, it is a wonderful thing to have a 'friend in need' (they truly are a 'friend indeed').

However, it is absolutely vital that the friendship doesn't become skewed by the chronic illness;

the friend must feel that his/her troubles (and joys) are equally valid and that the friendship isn't tainted by arachnoiditis.

This may seem to state the obvious, but I think many of us have a tendency, when weighed down by our troubles, to be somewhat blinkered by them.

Kahlil Gibran's little book, "The Prophet" contains the following advice about friendship,

"And let your best be for your friend.

If he must know the ebb of your tide, let him know its flood also.

For what is your friend that you should seek him with hours to kill?

Seek him always with hours to live.

For it is his to fill your need, but not your emptiness.

And in the sweetness of friendship let there be laughter, and sharing of pleasures.

For in the dew of little things the heart finds its morning and is refreshed."

I have often heard from folk with arachnoiditis who have written movingly about how isolated chronic illness has made them.

In fact, my 2000 survey found that 71% of respondents (who suffered from a variety of chronic

illnesses) felt isolated.

This seems to stem from a feeling of being 'out of the loop' as regards the activities of healthy folk: as one person wrote:

'I'm alone in a world of people in the fast lane, jetters, joggers, and jocks, all in complete command of their healthy bodies.'

Secondly, there is the sense that other people cannot comprehend what life with arachnoiditis is like.

'No-one seems to comprehend the straight jacket I live in.'

One of the solutions for some people is to join a support group (more on groups later).

This is, of course, very helpful and the commonest feeling during the initial period after joining is an enormous sense of relief at finding others who are 'in the same boat'.

However, we do need to beware that our entire network of friends is not based in people who share similar circumstances, because this can lead to the illness that is the common denominator (and related topics) becoming too great a focus.

As for anyone, a variety of friendships and social contacts are likely to be far more enriching, not only to ourselves as individuals but also to our friends.

PARTNERS:

A fellow arachnoiditis sufferer wrote, in an e-mail message:

"Developing and maintaining your spousal relationship is probably the greatest challenge for those of us with arach or other chronic illnesses. And, I don't mean just being 'supportive'. I mean...having a real relationship...the kind we all long for. It will certainly be different than before arach occupied center stage in our lives." (David Gaub).

In the same message, David described how, with the best of intentions, he built

"a wall of misunderstanding, guilt and insecurity"

out of a desire to protect his wife. He tried to act as if everything was OK and he didn't need her to help him. Instead of reducing her worries, he found that problems were compounded. David admitted that he had unintentionally contributed to his wife's struggle.

Clearly, David is a kind and caring man who loves his wife deeply. Yet, by his own admission, it took him years to understand how his wife was feeling about his illness and its effects on both their lives (and their relationship).

This is pretty much illustrative of the toll that arachnoiditis can take upon the strongest of relationships.

Melvyn Bragg's book "The Cumbrian Trilogy" contains a vivid description of the impact of chronic illness on a couple in the early Twentieth Century. Emily has fallen ill with a "wasting disease" and her husband John is finding it hard to cope:

"John felt that he had failed. Emily's illness worsened and a tide of persistent consideration swept quickly over every other feeling in the house, making it impossible for him to reach out sharply to her for fear of jarring the fragile hold."...

"Never to talk directly to her again, never to be able to show her how he felt except by the lap of small attentions." ...

"Feelings uncomprehended, undirected, feelings alone, it seemed, had been given him - and blinded him from understanding."...

"...all that he was had been forever churned into those impulses and sensations which rushed through him and left him unaccountably."

"Now he wanted to claim Emily back to himself- but though he talked to her and reached out to her, it would not work."...

"There was no-one for him to turn to for he needed not an intermediary but a past self. So he sat there, reassuring her..."

"John had now lived so long in that narrow vein of subtly changing hope and despair, each week shortening the distance between them but still the extremes oscillating like a compass needle..."

Put simply, the losses caused by chronic illness tend to change equilibrium between partners and may force role changes. This creates enormous challenge to the integrity of the bond between couples.

We have already looked at losses from an individual's viewpoint, but in the context of a couple, the losses may include:

- Independence
- Privacy
- Shared responsibility
- Financial security
- Autonomy

- Ability to protect
- Equality
- Sexual communication

All couples develop an equilibrium over time; whilst we are told that we should aim for 'give and take' on a roughly 50:50 basis, the reality is that from time to time, one partner may need to give considerably more than the other, but the balance can be redressed at other times, so that overall, there is a degree of equality.

Illness can skew this considerably, and the opportunity to redress the balance is often removed, so that the equilibrium is disturbed on a long-term basis. Unless a new equilibrium can be established, one or both partners are likely to feel dissatisfied or unhappy.

Roles tend to change, and in particular, *perceptions of role* may be fundamentally altered even to the point where the relationship is threatened.

At the best of times, partnerships can be fraught with difficulties. Chronic illness is an immense challenge to relationships, but not an insuperable one.

The different psychological stages that people go through during illness may affect the ill person and their partner in different ways, even assuming they experience the same stage simultaneously, which is often not the case.

And of course, the way in which individuals express their feelings can vary enormously.

During the denial phase, the ill person may try to act as if there is nothing wrong, whereas the spouse may question the veracity of the complaints, or may refuse to discuss medical test results or even to attend consultations.

Obviously, if the ill person has moved on from this stage into the 'fear' stage, then he/she will

feel inadequately supported (or even actively undermined) if the spouse appears to deny the presence of the illness.

If the ill person is in the angry stage, there may be fury at a sense of betrayal that can lead to altercations, essentially because of misunderstandings.

The 'protest' or anger phase may cause the partner to feel considerably aggrieved that their lives have been blighted by the illness, their hopes and dreams curtailed.

This is a natural reaction, but of course can engender considerable guilt because this reaction is perceived as being 'unfair' and even plain 'wrong'. The partner may also feel guilty at enjoying his/herself.

Once the reality of the illness has hit home, whilst the ill person may feel a burden (and even that the partner is better off without him/her) the spouse is likely to be feeling alone and responsible, weighed down by the ongoing burden, with no end in sight, but unable to express this for fear of upsetting the ill partner and compounding their sense of low self-worth.

The truth is, they *are* a burden, but hopefully not an overwhelming one and certainly, blame should not be attached by either side, yet it is human nature to need someone as a scapegoat and sometimes blame may be hurled in a moment of anger.

It is far from uncommon for the partner to harbour a secret fantasy of simply walking away from what seems an intolerable situation. Sometimes this is acted upon, but more often, it is a guilty secret that can be very distressing.

In the bargaining stage, whilst the ill person may hope to keep going, perhaps say until the kids leave home, the partner may have different aspirations, hoping for 'a few good years'.

One of the hardest times is when depression sets in. Partners of ill people may feel old before

their time, beat up and worn down, with no prospect of release. In a sense, they are trapped.

As we have seen, the 'stages' of psychological reaction (grief stages) are not necessarily consecutive or in order, and may be experienced repeatedly at different times. It is obvious then that the interactions between two individuals in the same situations but having different responses may be complex.

The best we can aim for is 'restoration', or 'coming to terms', in which the ill person may be able to accept their illness and its effects and the partner accepts the changes engendered in his/her life, and also begins to feel confident in coping with the stresses and strains inherent in the situation.

Together, the successful couple develop a mutual respect and interdependence, and are able to readjust to changing circumstances.