

"When you are living with chronic illness you live with loss on a daily basis"

(Eugenie G. Wheeler, Joyce Dace-Lombard ,

"Living Creatively with Chronic Illness" Ventura 1989)

This sentence sums up an aspect of chronic illness that we all live with.

Loss is a fundamental component of suffering and can take a bewildering array of forms.

For instance: losses may include very obvious, concrete ones such as loss of physical function but also, more notional ones such as resilience and autonomy.

Loss doesn't just affect the ill person, but those around them; it is no respecter of persons!

Loss tends to force role-changes, can alter the equilibrium between partners and affect family dynamics.

One sufferer put it like this:

"There is no way to measure the bankruptcies of the heart that invariably accompany chronic pain as patients struggle with the destruction of relationships, jobs, homes and

hobbies."

(Anna, taken from European Initiative on Pain website)

Below are some of the more common losses.

Health: an obvious loss, but one that encompasses not only physical but also emotional and even spiritual well-being.

Energy: illness is of course a constant drain on physical resources as well as a source of considerable mental strain, which is enervating; note also that depression is itself the cause of a loss of energy; loss of sleep compounds the problem to an enormous extent.

Control over life: one of the most invasive and pervasive problems; in this day and age, we like to consider ourselves masters of our own destiny, but ability to 'self-actualise', to make this a real part of our lives, appears to be irretrievably damaged by the constraints enforced due to illness.

Choices in life: whether we fight it or not, the reality is that chronic illness can strip us of a variety of choices; sometimes of course, choice is an illusion, but it is human nature to need to choose our own options, rather than have them imposed upon us by an outside force.

Ability to plan for the future: chronic illness may render the future at best uncertain, at worst, a fearsome place; of course, none of us has a crystal ball, and we are all, fit or ill, subject to the unknown around the corner (the saying goes that the people who make God laugh are men with plans).

However, it is natural to want to plan ahead to some extent. Indeed, it would be impractical and inadvisable to live solely for the moment. Furthermore, the present may be hostile territory, if the illness is rampaging through it, so that looking for some light at the end of the tunnel is only

natural.

The problem is that setbacks tend to cause a potent discouragement of looking ahead. At times, I have felt like a tortoise, keeping my head firmly in its shell, because it seemed that every time I peered out, a dirty great spade appeared out of nowhere and whacked me over the back of the head just to make sure I retreated again!

Role: where we fit into our lives and those of people around us in a personal, occupational and community sense; our ability to contribute meaningfully seems lost; illness may make us have to redefine our roles in life.

Job: chronic illness is frequently associated with inability to sustain the necessary physical and mental output that most occupations require. Sadly, it may well be that intermittent work is still possible, and very much desirable, but it is unlikely that most employers will be sufficiently flexible to tolerate the ups and downs.

Financial security: naturally a corollary of loss of income; often the spouse will be working, but this may also become impossible if the ill partner requires enough daily care to interfere with work commitments.

Independence: one of the most depressing aspects of chronic illness, especially if functional ability is impaired to a significant extent. Having to rely on others, whether it is for the basics in life, or even 'optional extras' such as trips out, wears down the spirit.

Privacy: alongside dependence may come a loss of the option of solitude: this should be guarded against as far as possible; however, for those who value their privacy highly, and are perhaps solitary by nature, this can be a real burden.

Socialisation: the other side of the privacy coin; this is an extremely common problem: isolation is one of the primary difficulties experienced in chronic illness; this may be both physical and, more importantly, notional, in that the ill person feels a sense of irredeemable isolation regardless of how many people are around him.

Dignity: some of the highly personal aspects of illnesses such as arachnoiditis may necessitate assistance from others in matters personal hygiene, for example; this can be highly embarrassing and emotionally fraught for both parties involved.

Social life: various aspects of chronic illness may render trips out of the house difficult to the point where the benefits seem outweighed by the problems encountered; often social life is significantly curtailed; this can have profound effects upon not only the ill person but also their spouse/family.

Activities: hobbies, interests outside the home: these may both be put 'on the back burner' for a variety of reasons; this can narrow the horizons and limit the ability of the ill person to maintain a perspective on the outside world.

Relationships: chronic illness carries with it so many stresses and strains that it puts even the strongest relationships to the test; this might be manageable if it was once in a while, but the challenges of illness are relentless and day-to-day. This can erode relationships in a persistent fashion, until they become unrecognisable.

Sexuality: chronic illness often impinges on sexual relationships in a very pervasive fashion; unless the problems are tackled as they arise, the effects can spiral out of control and be tremendously damaging to both partners.

Temper: previously placid and tolerant people can become taciturn and snappy under the duress of incessant pain; often this makes them feel guilty at being bad-tempered. Some of the anger may well be displaced: everyday occurrences supposedly the source, but in reality, the underlying frustration and anger of the unfairness of the illness are responsible.

Patience: it is very common for people who are constantly ill to be irritable and impatient; this is partly a physical irritability associated with unrelieved pain (and the associated hormones such as adrenaline), lack of restorative sleep and also, of course, the psychological impact of the impairments occasioned by the illness.

Sense of humour: similarly, it is an uphill struggle to keep a sense of humour in situations which have nothing to laugh about, only things to cry about. This is one of the first casualties of illness.

Carefree self: even the most 'happy go lucky' person will have their light heartedness worn away by the persistent demands of chronic illness and from the damage it does to so many aspects of life; this applies equally to the partners who are bound to feel weighed down by the responsibilities.

Optimism: often an early victim of chronic illness. It is exceedingly hard to maintain a positive outlook in the face of continual difficulties and setbacks.

Hope: a more serious and damaging loss; often this comes later in the illness, although episodes of a loss of hope can occur at any time; prolonged despair and a sense of there being no way out, can be a feature of depression.

Perspective: chronic illness skews our perception of everyday life; it blinkers us and limits our horizons; it is therefore enormously difficult to maintain perspective and a sense of proportion.

Pride: the ability to feel a sense of achievement is likely to have been curtailed in many aspects of life; a pride in appearance may also be diminished.

Self-Esteem: chronic illness can be terribly degrading to the sense of self; the way in which we perceive ourselves, our sense of worth and our relationship to others can be devastated by the many losses illness imposes upon us. This can be further worsened by depression, in which diminished self-esteem is a cardinal feature; there may be a vicious circle.

Peace of mind: the constant challenges and attacks by the illness can destroy peace of mind.

Faith: there is no doubt that unrelenting illness is one of the greatest challenges to spiritual beliefs; indeed, suffering is a source of much theological debate: how could a loving God allow suffering? For those whose faith has been a source of comfort in the past, its loss can be devastating and leave them feeling bereft and rudderless.

Identity: the ravages of physical illness may impact upon appearance, but nothing is more damaging to a sense of who we are than the psychological destruction that can occur. The healthy person we once were may become unrecognisable, not just to ourselves, but also to those who care about us. This can be profoundly distressing.

The losses I have already addressed may conspire to rob a person of their personality. Indeed, it is not uncommon for someone to feel that have been dramatically changed by the circumstances of their ongoing illness.

Their occupation, interests and relationships may all have foundered and their inner self been bombarded by the exigencies of lurching from crisis to crisis, interspersed with periods of mind-numbing depression.

“Perhaps few persons...can realise the influence which long-continued and unendurable pain may have upon both body and mind...under such torments the temper changes, the most amiable grow irritable, the soldier becomes a coward, and the strongest man is scarcely less nervous than the most hysterical girl.”

S. Weir Mitchell, 1872.

“In life it's almost always true that things could have been worse; unfortunately, the knowledge of this reality rarely diminishes one's pain.”

Dr. Ann Kaiser Stearns

We must also not forget that loss affects the carers profoundly.

Maggie Strong, author of *‘Mainstay’*; a very helpful book about caring for someone chronically ill, wrote:

‘To become chronically ill is to lose yourself as a healthy person; you grieve. To be married to someone ill and to watch a man or woman you love suffer means you mourn.

You mourn the lost marriage, the lost family, the suffering of the mate and your lost self- the one who could feel dependent, who could ask to be indulged, the lighthearted you. And often with chronic illness you mourn a lost or reduced sexuality.’

This far from exhaustive list makes depressing reading. However, I must make an important point.

Some of these losses are by no means inevitable and it is possible to regain lost ground; in addition, if one regards illness as a minefield, then awareness of the location of the dangers can be of paramount importance in avoiding some of the pitfalls.

It is inevitable that losses such as these, sustained either gradually or suddenly, are a source of deep sadness, anger and anxiety. Indeed, one of the aspects of coping with chronic illness is coming to terms with these losses and going through a grieving process just as one would for other losses in life.

Next, we will be looking at ways in which we adjust to these losses.