

From Our Irregular Correspondent

The impact on you and others of an undignified death of someone you love – Chronic grieving and post traumatic stress –

One in a series of occasional health and social care papers by Terry & Monica Dennis of Healthcare Alliances and A Dignified Revolution, based on our experience.

Introduction

The death of someone you love, a family member, or someone you have formed a close bond with, such as a close friend, is a sad, lonely and reflective time. However, when the death has been the result of, or associated with, a lack of dignity in their last days and a lack of respect from their carers, the emotional impact can be magnified.

This paper is designed to help people who have been bereaved in such circumstances to understand the impact it might be having on them, and on those around them; and to help their partners, family and colleagues. It will also be of use to anyone who has experienced excessive or traumatic stress.

Grieving is normal

Grief is a normal response to the death of someone you love or someone you have formed a close bond with, whether it is the loss of a partner, family member, friend or other close companion. Although commonly associated with an emotional reaction, you will also experience effects that are physical, behavioural, social, and philosophical.

Your emotional responses might include some or most of the following:

- Anger
- Confusion
- Denial
- Depression or despair
- Emptiness
- Guilt
- Numbness
- Powerful longings
- Relief
- Repetitive thoughts
- Sadness
- Shock

Your physical reactions could include:

- Tiredness and difficulty sleeping
- Digestion problems
- Headaches
- Avoidance of sexual contact (mainly female)
- Greater desire for the comfort of sex (mainly male)
- Over / under eating

Although these feelings and reactions can be overwhelming, they are normal. Accepting them and allowing yourself to feel what you feel is a necessary part of the grieving process.

You will grieve in your own way. It is a very personal experience. There is no right or wrong way to grieve and the sadness of losing someone you love or someone you have formed a close bond with will always be with you.

Things that you can do to help yourself include:

- Talk about it with someone you trust
- Establish a normal, everyday routine
- Sign up for relaxation exercises or join physical activity classes
- Get back into work or take on a project
- Continue and develop your hobbies and interests
- Eat well and exercise regularly
- Make time to be with family and friends
- Avoid negative people
- Expect to get better

However, whatever you do, leave time to grieve as well.

Healing takes time and is gradual. There is no normal timetable for grieving and it cannot be forced or hurried. You could start to feel better in weeks or months; or it might take years. It is important to accept it, be patient and allow the process to take its course naturally.

Stress and complicated grief caused by psychological trauma

As time passes, it is normal for your emotions to become less intense as you accept the loss and start to move on. However, if you do not begin to feel better as time passes, or your grief is getting worse, it might be a sign that there is a more serious problem. This can cause issues with relationships, social patterns and returning to work.

Severe anxiety can result from severe emotional and psychological trauma, which in turn can lead to post traumatic stress (we don't like to tag on the word "disorder", as it is not a disorder – it is a common and normal reaction).

In the same way that the body suffers trauma in an accident, your brain suffers trauma when subjected to excessive stress. Your brain suffers psychological damage through psychological attack, in the same way that your body suffers physical damage from a physical attack. The psychological symptoms develop some time after the catastrophic event – hence the phrase: post traumatic stress.

Some commentators believe that acute and extreme psychological trauma causes your brain to defend itself from further attack, which is the cause of the extreme symptoms.

Severe psychological trauma or acute stress reaction can be experienced in any of the following situations:

- Seeing someone you love or someone you have formed a close bond with being subjected to degrading and disrespectful care as they were dying
- Unexpected death of a loved one or close friend
- Witnessing a sudden or accidental death
- The death of a child
- Being the victim of excessive bullying
- Being the victim of other psychological or physical abuse
- Coming close to death yourself
- Being involved in, or the witness to, a violent crime or attack

The traumatic experience might also be a combination of the above situations.

Another factor that can magnify the impact of loss and lead to excessive stress, is the closeness of the relationship between the person who dies and their carer, for example their daughter or son. In the case of an older parent particularly, the parent/child roles can become reversed with the child feeling responsible for their parent, because they become the carer. In that case, the loss of their parent could be likened to the loss of a child – the saddest loss imaginable.

For about 1 in 3 of people who experience an acute stress reaction, the psychological trauma lasts longer than most grieving processes– often several years – and can start immediately or sometimes up to six months after the event. It can also worsen over time, rather than getting better. These are signs that it is post traumatic stress (sometimes called *complicated grief* in a bereavement context – other similar labels include *compassion fatigue*, *vicarious traumatisatio*n and *secondary trauma*). We prefer to call it chronic grief, as it is grief that does not pass quickly, perhaps not at all.

Around 40% of people with post traumatic stress develop the condition when a person close to them dies suddenly. Up to 30% of people who experience post traumatic stress have a chronic form which lasts for the rest of their life. Chronic post traumatic stress or grief usually involves periods of intensity followed by remission or decrease – although some people experience symptoms that are unremitting and severe.

Post traumatic stress affects men and women differently

- Women are twice as likely as men to develop it after a stressful experience
- Men are more likely to be irritable, restless and impulsive; women are more likely to be withdrawn and detached
- Men tend to be anxious; women more likely to become depressed

Recent research suggests that the brains of females are more sensitive to the hormones, produced at times of anxiety, which are thought to be involved in stress management.

Other indicators and common emotional symptoms of post traumatic stress are similar to the normal symptoms of grieving, but are often more extreme:

- You re-live the original trauma through flashbacks or nightmares
- You avoid reminders or talking about the event
- You have moments of confusion, poor concentration and absentmindedness
- You have a raging, passionate anger
- You become preoccupied with your loss
- You feel excessively guilty
- You do not enjoy everyday activities
- You have a sense of depersonalisation--nothing seems real
- You feel helpless
- You feel isolated and detached – emotional numbness
- You are anxious, jumpy and irritable
- You find it difficult to relax
- Others will comment on your lack of insight into how you are behaving
- Others will find you are hypersensitive – interpreting almost any remark as critical

The physical reactions can be more intense as well:

- You might feel extremely tired and fatigued, even on waking up
- You might be clumsy and make more mistakes than normal
- You might have diminished interest in sexual relations / reduced intimacy
- You might develop muscle aches and pains
- You might experience ongoing substance misuse, such as alcohol and drugs

In addition, because the immune system is impaired over a long period, it results in you being susceptible to viruses and infections that you would normally fight off. This leads to regular/recurring colds, coughs, infections, etc.

It is also common to become passionate about doing something to address what has happened, driven by an obsession with resolving the cause. This can take over your life, to the exclusion of most other interests. This passion is associated with:

- An excessive feeling of injustice and a strong determination to do something about it
- An overwhelming desire for recognition and appreciation of your experience
- An overwhelming, all consuming preoccupation with the perpetrator(s) and the need for justice, but not revenge
- Difficulty on focussing on anything other than the issue
- Bitterness and anger associated with the death
- Lack of trust in others

This sort of activity can be seen widely when people who have lost loved ones in traumatic situations throw themselves into projects and activities:

- Calls for changes in the law (Sophie's law, Robbie's law, etc)
- Calls for existing laws to be enforced
- Setting up charities and trust funds
- Movement and campaigns
- Writing memoirs about the experience
- Commemorative and fundraising events

These activities can benefit the sufferers by providing a:

- form of catharsis about the event
- means of keeping busy
- sense of purpose

Clinical Aspects

This is not a clinical paper, but if that aspect interests you, research indicates that changes in three areas of the brain are associated with post traumatic stress:

- Hippocampus (memories)
- Prefrontal cortex (thoughts)
- Amygdala (reactions)

People with post traumatic stress tend to have an enhanced thyroid function and higher epinephrine and norepinephrine levels than normal. Another side effect is changes in the levels of cortisol which kills off neuroreceptors in the hippocampus, an area of the brain linked with learning and memory.

There is no clear agreement from the experts about what causes post traumatic stress or complicated grief but it does involve a complex interaction between your genes, hormones, environment and personality.

But the primary purpose of this paper is not treatment. As stated at the start, its purpose has been is to help you to cope with the situation by increasing your understanding of what is going on and the impact it might be having.

Coping and coming to terms with chronic grief

By far and away the best form of help with coping with chronic grief is love and support and understanding from people close to you.

In addition, some people have found solace in participating in the arts, such as writing, music, painting, crafts, poetry and reading. Others have found more physical interests helpful, such as walking, exercise, sport and other similar activities.

Talking therapies, such as counselling and cognitive behavioural therapies are also useful. Medical solutions (ie drug therapies) should be a last resort as they mask the symptoms and rarely address the root cause.

Whatever approach you take, learning more about the illness, talking to others, relaxation techniques, positive lifestyle practices, and minimising negative lifestyle practices are other important components of the healing process.

Postscript: Your family and friends can be unrecognised victims

Post traumatic stress and chronic grief can also have devastating, far-reaching consequences for sufferers' relationships with their spouses, partners, families, friends and work colleagues.

For example, the relationship breakdown rates of couples who have lost a child are high. Similarly, the divorce rate of US war veterans who suffer from post traumatic stress are twice the national average.

You might find, therefore, that you experience problems with family and social relationships and encounter difficulties with, and possibly the loss of, your job.

People who care about you will help you to heal by asking you about your feelings, spending time being with you, and listening when you want to talk.

However, you also have to be prepared for the fact that many people look the other way – they do not want to become involved in someone else's grief. It might be that it reminds them too much of their own mortality, or it could be that they are worried about upsetting you, or they just don't know what to say, or they could be in denial themselves, or they might be embarrassed.

However, it might be that they are experiencing a loss as well – their mental health can be affected because the person they know and love has changed. Although probably less acute than your experience, it can be just as devastating for them, as their world is turned upside down.

Numerous studies have found that partners of war veterans with post traumatic stress have a greater likelihood of developing their own mental health problems. They also have more impaired and unsatisfying social relationships, lower levels of happiness and reduced satisfaction in their lives. They can also feel resentment that their emotional needs are not being recognised or being met. They can find the experience as emotionally draining as you do.

The burden on your companion, therefore, can be high. For different reasons, both of you could be grieving – and grieving is essentially an individual and lonely experience.

Your partner will not know what is swirling around in your head. They will not know that today you are having a “sad day” or an “anger day” or a “good day” or a “bad day” or a “smiley day” or a “frown day”. Instead, they will experience the outward effects of your inner reactions:

- Sad, happy, angry mood swings for no apparent reason
- Active and energising days followed by lethargy and disinterest
- Irrational moments
- Forgetfulness

What might be helpful is to create boundaries and establish processes to help protect the relationship. For example:

- Do things that take both of your minds off the issues – theatre, music, cinema, sporting event, hobbies or physical activity
- Ask them regularly how they feel generally, and probe specifically about how they are reacting to, and coping with, your own emotional rollercoaster
- Have a “partner day” – a day, perhaps once a month, when you focus solely on the needs of your partner
- Agree times when your loss, or your response to it, is not discussed – perhaps one of the weekend days or over mealtimes
- Create some space between you by having days and possibly nights away with other friends
- Go on regular short breaks, perhaps to places you have not been to before

If you both work hard at maintaining the partnership, then it will ultimately reward you both with a deeper and more satisfying relationship.

The series of articles

This paper is one in a series of related articles available on our web site. The full list and web links are as follows:

- Coping with change (and handling stress):
www.healthcarealliances.co.uk/?CopingWithChange
- Coping with very difficult colleagues (including personality disorders):
www.healthcarealliances.co.uk/?VeryDifficultColleagues
- Coping with toxic organisations (and group think and social rejection):
www.healthcarealliances.co.uk/?ToxicOrganisations
- Coping with chronic grief (as a result of bullying):
www.healthcarealliances.co.uk/?ChronicGrief

[Click here](#) to see all our articles.

We can provide help and support

We are available every Monday in Cowbridge, to talk through your issues. It is completely free of charge – except for the price of a cup of coffee and possibly a sandwich. Totally unconditional and absolutely confidential.

There are two time slots available every Monday – 10 am and 2 pm. It's first come, first served.

We look forward to hearing from you – see the contact details below.

© Monica and Terry Dennis, Healthcare Alliances / A Dignified Revolution
Britannia House, 11 High Street, Cowbridge CF71 7DP
First prepared November 2010; last updated January 2011

We would like to thank all the people we have worked with us over the years for sharing their time with us. We would also like to thank our friends and colleagues who commented on early drafts of this paper – for obvious reasons of confidentiality we cannot name you, but you know who you are.

We welcome comments on this paper which:

- disagree with us
- agree with us
- amplify the points we make
- give a different perspective

Please send your comments to:

correspondent@healthcarealliances.co.uk or
info@dignifiedrevolution.org.uk

All *From Our Irregular Correspondent* papers and comments can be accessed directly by [clicking here](#), or by following the links to information services from the home page of the Healthcare Alliances website:

www.healthcarealliances.co.uk