



Last Updated 31/10/2011

After someone close to you has died you may experience many different kinds of emotions, some of which you may not be proud of. You may have structured your recent life around caring for the person and their passing will have created a void in your life, leaving time to fill, time to think about recent events, time to consider things you might have done better and time to face up to your worst fears of a future without your loved one. Although your experience was a very personal one, and no-one will have ever had, or have exactly the same experience, other people have had similar experiences. This leaflet lists emotions and reactions commonly experienced after bereavement and suggests ways to avoid some of the post-bereavement pitfalls.

### Common post-bereavement feelings

#### Fear

- Of getting MND personally
- Of being left alone, of having to leave loved ones.
- Of 'breaking down' or 'losing control'.
- Of other loved ones getting MND.

#### Helplessness

- Caring for people with MND can make you aware of powerlessness as well as inner personal strength.

#### Sadness

- For a death after a long period of illness and care.

#### Guilt

- For being better off than others, i.e. being alive, not ill.
- Regrets for things not done.

#### Shame

- For having been exposed as helpless, 'emotional' and needing others.
- For not having reacted as you would have wished.

#### Longing

- For all that has gone before MND affected your life.

#### Anger

- At what has happened, at whoever caused it or allowed it to happen.
- At the injustice and senselessness of it all.
- At the shame and the indignities.
- At other people's lack of understanding and inefficiencies.
- "Why me?"

#### Memories

- Of feelings, of loss or of love for the person with MND.

#### Let down

- Disappointment for all the plans that cannot be fulfilled.

#### Hope

- For the future, for better times.

#### Numbness

- Your mind may allow the loss to be felt only slowly. At first you may

**MND Scotland is the only charity funding research and providing care and information for those affected by MND in Scotland.**

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## MND Factsheet 13 Coping after Bereavement

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feel numb. People often see this wrongly as being 'strong' or 'uncaring'.

### **Dreams**

- You may find yourself repeatedly dreaming about how your loved one was both before and during the illness.

Mixtures of the above feelings and emotions are very common after bereavement, but will lessen in time. You may experience these emotions immediately or some time later. The feelings can be very strong and frightening, you may feel you are losing control or 'going mad', but for most people the feelings become less intense over time.

Many people find that crying can give relief but it is also common to have other responses, such as a desire to be alone.

If, after a reasonable time, these feelings are still uppermost in your mind it could be that you might benefit from bereavement counselling. MND Scotland has a counselling service which is fully confidential and staffed by counsellors trained in MND and bereavement counselling. This service can be contacted by any of the methods listed at the foot of page one of this factsheet.

Some common pitfalls after bereavement include increased vulnerability to accidents and increased intake of alcohol or even drugs.

You may become more prone to accidents due to the stress of bereavement and the lack of ability to focus on the here and now.

While the extra tension may lead you to increase your intake of substances which

you feel dull the pain temporarily, or help you to sleep.

It is important to seek help if either of these are happening repeatedly.

### **Family and Friends**

Death can bring people together and lead to new friendships, but it can also create tensions and strains. Some families are able to support one another, but this is not always possible and conflicts can sometimes emerge. Relationships between partners can also be affected. Someone diagnosed with MND will usually live for quite sometime. During that period family and friends will have had many issues to consider. The finality of death can bring a lot of deep emotion suddenly to the surface.

### **Children**

Like adults, children appreciate having their thoughts and feelings acknowledged. Children often find it easier to draw or play out events and feelings and it helps them for adults to pay attention and demonstrate an interest in what they are doing. Allowing them to reveal what they think and feel in this way will help them cope.

Children may seem fine one moment, then in great distress and quickly fine again. This can be confusing for adults. It can help children to let them keep to their usual routine, such as school and activities, if they want to. But they may also wish to be included in any family rituals, such as funerals, and participating will help them cope better in the future. It can also help if the school knows what has happened.

The pain of bereavement is often eased by some or all of the following activities.

The information in this leaflet is believed to be accurate at the time of production. MND Scotland cannot give detailed medical advice, this leaflet should be regarded only as general background information.

### Talking

- Many people find it helpful to talk about what happened and how they feel, over and over again. This can be an important part of the healing process.

### Support

- Sharing with others who have had similar experience can help. For some, help with the practicalities of everyday life from caring friends and family is a welcome release. For others, it is a relief to have ordinary things to concentrate on. Many people say that they want to be asked but would like to choose which approach is most helpful.

### Privacy

- Some people want to be left on their own. You may also find it easier to be with a few select people than with groups of people you don't know.

If any of the following become a feature of your life after bereavement it is important that you should seek help.

- If you feel you cannot handle intense feelings.
- If you feel that your emotions are not falling into place over a period of time and you feel chronic tension, confusion, emptiness or exhaustion.
- If, for a long period, you have to keep active in order to blot out feelings.

### Further Information

Factsheet 7	Bereavement and Children
Factsheet 31	Sources of Support
Factsheet 32	MND Scotland

- If you continue to have nightmares and poor sleep.
- If you have no person or group with whom to share your emotions and you feel the need to do so.
- If your relationships seem to be suffering badly, or other relationship-problems develop.
- If you have accidents.
- If you continue to smoke, drink or take drugs to excess since the event.
- If your work performance suffers.
- If you note that those around you are particularly vulnerable or are not healing satisfactorily.
- If, as a helper, you are suffering from exhaustion.

### Where to find help

- Your family doctor
- MND Scotland Counselling Service 0141 945 1077
- The Social Work Department of your local Council
- Cruse Day by Day Helpline 0844 477 9400 for adults and 0808 808 1677 for under 18s,
- The Samaritans 08457 90 90 90.

Your library or Citizens' Advice Bureau will have the address of these and other local organisations that can help you.

Our MND Care Team is there to provide support for anyone affected by MND. They can provide accurate information and ensure you receive support and care. Call us on 0141 945 1077.