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A guide for parents of terminally ill children

Now that you've been told your child is terminally ill you may feel a sense of denial, shock, anger, guilt or fear. People's feelings and reactions vary. There is no set pattern or order as to how you may feel as an individual. Whatever feelings you have, at any time, are perfectly acceptable and understandable.

This leaflet aims to be an easy to read guide, using a question and answer format, examining briefly the most frequent issues parents raise in this situation. It has been written by a father who experienced his child having a terminal illness and is based on what they as a family found helpful.

How may I feel initially if I am told my child is terminally ill?

You may feel shock and a sense of denial. You may find yourself "switching off" from any further information after being given a diagnosis you don't want to hear. It is alright to feel this way. You may need time, understanding and compassion from those around you. Don't be afraid to keep asking questions of the medical staff – they are there to help you.

What feelings may come after the shock and denial?

You may feel guilty. You could believe that you are to blame for something you did, or neglected to do in the past. "If only" is a phrase commonly heard at the time.

You may also express feelings of anger, either at yourself, your partner, the medical staff, or even at your child for being ill. You may question your belief in a God who, you feel, allows children to suffer.

The most common anxiety is fear. Fear of the unknown, which may be due to lack of information, or fear of the pain you think your child might have to endure.

It is not wrong to feel guilty, angry or fearful. You may find it helps to express these emotions to family, friends or a professional, rather than shutting them up within yourself.

Should I tell the rest of the family?

Openness is usually easiest to live with. Allowing family and friends to share the information may help to ease your sorrow and gain the support needed throughout this worrying time.

Other children in the family can be very sensitive to the strange silences and may know something is wrong. They may feel jealous and resentful of the extra attention the sick child is receiving and may feel isolated and rejected.

They too need time to come to terms with their brother or sister's illness and need just as much support and understanding as you, the parents. It is important for them to continue to play and enjoy the company of their brother or sister for as long as possible.

You, of course, have the right to decide which family or friends you want to tell. The greater the knowledge others receive from you, the more support and understanding they can give in return.

How can I cope with the stress?

There are numerous ways which may help. Here are just a few examples of the physical and mental techniques you could use:

- Physical exercise is of tremendous value, enabling you to burn off anger, leaving you feeling calmer and more in control. Regular exercise keeps the joints and muscles relaxed which can stiffen with tension when stressed.

- A healthy diet is a very important factor when struggling with stress. By not eating properly your body will lack the vital vitamins and minerals needed, leaving you tired, unable to concentrate and prone to various illnesses.
- A good sexual relationship with your partner can act as an effective way of relieving stress and achieving total relaxation, as well as asserting your support for each other.
- Keeping a diary of your thoughts may benefit you. Putting your emotions into words may allow pent-up feelings to be released.
- Talking about your worries with family members, friends, or trained counsellors may serve to alleviate inner tensions.
- Taking up or continuing a hobby or sport such as painting or golf, could keep your mind preoccupied and away from the distressing thoughts surrounding your child's illness.
- Using relaxation techniques such as yoga, mediation or keep-fit, may give positive results. These techniques should be practised in a quiet environment away from distractions, perhaps with the assistance of soothing background music.
- Holding back tears may be detrimental to you, although many people may urge you to keep control, especially if you are male. There are times when it is best to cry freely and without control.
- Keeping a sense of humour allows you, as a person, to control the overwhelming feelings of depression. Just because you laugh at something or with someone, it doesn't mean you don't care.
- Drugs such as anti-depressants may have their part to play in the short term, but over a long period of time they could end up hiding the emotions that need to be released.

Can I ever accept?

Acceptance is different from giving up. Being able to accept may mean you are 'coming to terms' with your grief. But it is something only you can achieve in your own way and in your own time. The feelings of anger, guilt and pain may never disappear, but being able to accept may leave you feeling calmer and more at peace with yourself and others. Try not to waste the precious time you have left together, brooding on the future.

Where should I let my child die?

In the past, people have died at home, usually in the presence of other members of the family. There is still much to be said for this, as to be moved at a terminal stage, away from a familiar and loved environment may prove to be extremely upsetting.

Children's wards are no longer the grim, dreary establishments they used to be. Walls are colourfully painted, there is usually an abundance of toys and children are encouraged to move freely around the ward. The medical staff now recognise that the families of the sick child are as important as the patient themselves, which is reflected in the flexibility of visiting times and availability of accommodation for worried parents.

In a hospice, emphasis is put on providing a calm, peaceful atmosphere for the patients. Nursing staff may wear ordinary day clothes rather than uniforms. The whole family is encouraged to be involved, especially brothers and sisters. Even after the death of a patient, hospice staff may visit the family to give continuing support for as long as it is needed.

My child has died. What next?

Coming to terms with the death of your child will not happen overnight. You may experience periods of intense suffering and pain, accompanied by irrational thoughts and actions.

Crying, sobbing, hysterical behaviour, or isolating yourself from others are all normal reactions. This is alright. You may find yourself feeling very much alone and unable to share your feelings. Your relatives and friends may be busy with their own lives and feel uncomfortable around you and so be unable to meet your needs for comfort and support.

Help can be obtained from doctors, clergymen, counsellors and other parents, but it is important to remember that these people can only help you with your grief. It is your grief.

The way to recovery may occur when you start to take an active part in life again. The pain of your child's death becomes less intense but not forgotten. Birthdays, holidays and the anniversary of the child's death can trigger periods of intense pain and suffering, but in time the pain may become less frequent.

People Who Can Provide Support

This section is for you to add the names and telephone numbers of those whom you feel would help you in the coming months by giving you support. Keep it handy.

Doctor:

Tel: _____

Health Visitor

Tel: _____

Local Bereavement Support Group

Tel: _____

Minister

Tel: _____

Samaritans

Tel: _____

Paediatrician

Tel: _____

Friends

Name: _____ Tel: _____

Name: _____ Tel: _____

Name: _____ Tel: _____

Name: _____ Tel: _____

Other useful contacts

Tel: _____

Tel: _____

Tel: _____

Tel: _____

Tel: _____

This guide was designed and put together by Steven Watson and Jane Robinson to help the parents of terminally ill children, 2005