Supporting a child when someone in the family has a terminal illness

Compassionate, Individualised, Holistic and Supportive Care
The diagnosis of a terminal illness and subsequent treatment process can be a frightening and difficult time for any patient and their family.

For families with young children or teenagers there are usually additional concerns about how the children will react to being told and how they will cope with the changes the illness will bring into their lives.

The following information is based on what we know to be children’s natural reactions in this situation. These vary widely and can sometimes seem difficult from an adult’s perspective. You might find that the things you are worried about are to be expected given the age of the child.

We hope this booklet can help you to work out whether a child affected by someone having a terminal illness is coping in an age appropriate way, or not.

If you read this and are still worried, you can contact the Counselling Support Service for further information and support which might be for yourself, or the child, or both of you.

Children almost always know when something is ‘wrong’. This is usually because adults are behaving differently, even if they are trying hard to appear ‘normal’.

Children have very vivid imaginations and their fantasies can often be worse than reality.

Not being included in talking about what is happening can leave children feeling anxious or confused and this is the point where their imagination can step in.
Children have an ability to deal with the truth that adults often underestimate. Sharing information and feelings about the situation can help children to understand that confusion, hope, fear, anxiety, anger, sadness and intense love are all appropriate when a person they care about is seriously ill.

Families can cope with terminal illness and, after the first shock, they often find they can manage it better than they thought possible.

Our difficulty in talking to children often comes from our own anxieties and discomfort about the situation. Giving yourself a chance to get used to the news before you begin to talk to the children may help.

A child’s reaction to being told someone in the family has a terminal illness will vary according to developmental age, personality and experience.
They may be upset, cry or be angry; however do not be surprised if they show no emotion at all. When children feel overwhelmed they may instinctively protect themselves by withdrawing from emotion.

They may do something that to an adult appears uncaring, for example by asking ‘What’s for tea?’ and going back to play, but this is just their way of dealing with what has been said.

There are big variations in how a child may respond according to age.

The following pages give detailed information about the age groups 3-5 years, 6-8 years, 9-11 years, 12-14 years and 15-17 years.

**Age 3-5 years**

It is normal for children in this age group to see themselves as the centre of their world and the cause of everything that happens. They are unable to apply logical thought or reasoning to events in their lives.

They still rely on a lot of non-verbal communication. Their communication is often through play, so drawings might be more effective than words.

They will automatically assume that others know what they know and think like they do.

They use magical thinking which means they might believe that a bad or angry thought could be the cause of an illness or death.

This age group does not feel responsible for the illness of a relative – something which is very common in 6-8 year olds.

Two emotional responses are clear:

- Anxious reaction to being separated from their main carer.
They can be unable to tolerate expressions of strong emotion from their parents because they are frightened by it.

In this age group social activity outside the family is minimal. However, those who do go to kindergarten or nursery school can see that as a safe haven and a beneficial routine. Encouragement by teachers to draw pictures to describe their feelings can be helpful.

**Response to terminal illness**

Most stressful at this age is being separated from the main carer. This can be experienced as traumatic.

This age group has difficulty understanding the significance of events and tends to focus mainly on visible signs in the person who is ill (e.g. hair loss, loss of mobility).

Change in interaction is the most distressing, such as a parent’s inability to play with them as before.

Children of this age very often do not ask questions because they do not know what to ask. It is still very important to supply information in a form that they can understand.

Children in the age group express their distress through play and fantasy rather than words with the result that parents often underestimate their distress.

- Communication about the illness is helpful.
- False reassurance and evasion are unhelpful.
- Anxiety about who will care for them is common.
At this age children say and do what they feel. They have not yet reached the stage where they inhibit their expression of emotion based on what they would predict other people’s responses to be. Under stress they still behave predominantly like younger children.

This group of children may have the beginnings of the capacity for logical thought, but may also still use the illogical, ‘magical’ thinking of younger children. This can easily lead to them being confused about what is happening.

Adults often try to protect them by withholding information which can lead to further confusion and the child creating their own explanations.

Very strong feelings are experienced by the child – sadness, anger, anxiety, guilt, feelings of rejection.

They may have strong fears about the well being of their other parent and/or other adults who they are close to.
Children of this age find it difficult to distract themselves by activities (unlike older children) so they are more likely to feel overwhelmed by their emotions.

They also have a tendency to personalise external events, for example by automatically assuming that when a parent expresses negative feelings they (the child) are to blame.

Though these children are more independent than a pre-school child, they are far from self-sufficient. They need the parent’s assistance, nurturing, reassurance and encouragement to maintain a sense of security, wellbeing and self-esteem.

They can easily experience the disruptions caused by an illness as rejection – they need constant reassurance that they are valued and loved and that they will continue to be cared for.

Although children in this age group can gain reassurance from the structure provided by school, they can also feel pressurised by the need to perform in the school environment.

Friends are not yet important enough to provide solace and distraction.

At this stage teachers and the teacher’s reactions are more important than their peer group.

Response to terminal illness

For this age group terminal illness is a period of high anxiety and stress.

It is vital for these children to be given information about the illness, including the possible symptoms, treatments, and the relationship between the treatment and the patient’s behaviour and appearance. If not, the patient’s changed behaviour is likely to be experienced as rejection.

Like younger children they can experience expressions of extreme emotion in others as frightening.
Their own expressions of feelings are stronger and more varied than pre-school children.

Conflicts with siblings and peers often increase.

There may be a drop in the level of school work.

**Age 9-11 years**

This is a relatively tranquil age developmentally. Their general outlook on life is pragmatic and positive.

At this age children’s capacity for logical thinking is developing rapidly and enables them to make better sense of what is happening to them than younger children can.

They can feel guilty and responsible for a parent’s illness, but are able to use information more logically to alleviate their distress.

They are more able to ask for information but can feel deeply resentful if not included in family discussions or if information is withheld.

They usually welcome the opportunity to talk about what is happening (unlike 12-14 year olds).

They rarely share their emotional reactions with anyone.

Children at this age are more able to contain anxiety. Adults can mistakenly interpret this as indifference and not provide support.

Children themselves may not understand their own behaviour. Emotions may be delayed in appearing and both the child and the adults caring for them can feel confused by this delayed reaction.
Children in this age group are much more engaged in activities outside the home which gives them greater opportunities to distract themselves and gain respite from what is going on at home. This has benefits but can also become a form of avoidance.

They tend not to confide in friends about emotional issues.

They rely on adults to initiate discussions about illness.

Other adults outside the family are now important. Children in this group will often feel more comfortable talking to a teacher, school nurse or counsellor rather than a family member who they do not want to upset.

Response to Terminal illness

At this age children are able to understand relatively detailed information about the illness without becoming overwhelmed.

They crave information and if it is withheld will often jump to very inaccurate conclusions.

This is the youngest age group who can grieve in the present for the loss that lies in the future.

They often keep feelings hidden – particularly from family members.

They may have irrational fears such as ‘Did I cause it? Could I have prevented it? Did I make it worse in some way?’

Sometimes they experience anger which they show in defiance, stubbornness, conflict with siblings and peers at school but their anger is less than at adolescence.
They are more distressed than younger children by the patient’s changing appearance and ability to function, probably due to a greater understanding of the significance of these changes.

There is a strong desire in this age group to cover sad feelings and ‘be brave’.

They worry about the health of other family members and experience anxiety when separated from their primary care giver, as with younger children.

**Age 12-14 years**

The beginning of adolescence! The cognitive, psychological, social and biological changes of this stage all interact to make this a particularly complex period.

Children this age show much less interest in information about the illness. They will sometimes take active steps to avoid receiving information. Information seems to provoke anxiety rather than provide relief.

However they are still capable of harbouring disturbing misunderstandings. Young adolescents need clarification more than they realise, or ask for.
They can understand abstractions – they more quickly grasp the implications of illness than younger children. However, they are also struggling to control their increased emotional volatility and very detailed information threatens to break through the defences they build against unmanageable feelings.

The developmental task of this age group is to begin to withdraw their emotional investment in their parents. A terminal illness conflicts with this task and creates significant internal conflict for the young person.

The young adolescent struggles with wanting to distance themselves from parents while simultaneously needing to remain engaged with them. This can lead to extreme avoidance of feelings and disturbing facts.

This can also lead to an exaggerated need for privacy. This is part of the process of developing a separate identity. When the family situation leads to pressure to engage more closely with the family, such as in terminal illness, the adolescent’s retreat is likely to become even more exaggerated.
Paradoxically, while the adolescent is attempting to withdraw emotionally from their parents, they are completely intolerant of their parents’ withdrawal! Absences are experienced as abandonment.

This stage is characterised by a profound focus on themselves. Children at this stage show a lack of empathy which is often perceived as unfeeling.

All strong feelings are a mine field at this stage and children make various attempts to control and contain them by avoidance, denial or distraction.

There is a powerful tendency in children of this age to withdraw into themselves and their own inner world.

They are moving to a place where the world outside the family is more important than the world within the family, but this is still a transitional process.

Finding their place within the social group is very important. Group membership is often more important than individual friendships.

Most young adolescents are more comfortable talking to peers and other adults than to their parents.

There is tension between the importance of family and the importance of peers. Some young adolescents regress into behaviour more typical of an earlier age and retreat into the family.

Response to terminal illness

Staying positive is an important need and may be achieved by avoiding or minimising facts.

There is denial and avoidance of feelings.

There may be a broad range of behaviours; decreased school performance, argumentative and oppositional behaviour, sleep problems, anger, social withdrawal.
They show intolerance of changes in family routines, particularly when it interferes with their social contact with peers, and ‘unreasonable’ resistance to helping parents with domestic chores etc.

In middle to late adolescence young people’s understanding and responses are nearing those of adulthood. However, they are still negotiating their separation from parents and home and these are processes which can be complicated by a Terminal illness at this time. Whereas some of their responses and behaviours are mature and responsible, others can be quite the opposite.

This age group possesses the ability to use abstract ideas which means they can have a deeper understanding of the various aspects of the illness than younger adolescents.

The focus on the self of early adolescence is replaced by the ability to see a situation from another’s perspective (i.e. they can be empathic). Young people at this stage are more aware of, and more responsive to, other’s feelings and concerns.

However, they can still fluctuate between empathy for others and self centred thinking. Empathy is still gradually evolving.

They are more selective about who they confide in.

There is a tendency to have a few more intimate relationships with individual peers (unlike the group friendships of early adolescence).

Dependence on these relationships can be intense. Often adolescents can be unrealistic in the expectations of friends to provide support and understanding which may be beyond them.

The unavailability or withdrawal of friends is experienced as deeply distressing.
Response to terminal illness

Children in this age group are more realistic, practical and flexible in their thinking about terminal illness. They are more likely to understand the facts and their implications.

They are more likely to accept information from the adults around them.

They are more willing to adapt because of the situation.

Maintaining high standards of school work can be seen as important and may lead to the child making high demands on themselves, especially if they think their academic success is important to the person who is ill.

They may be fearful about the future – often around practicalities like financial concerns.

Anger is present but is usually muted at this stage.

Increased use of alcohol and drugs is more likely as a way of trying to manage difficult feelings.

It is important to include them in information regarding progression of disease.

What about school?

For children of all ages there may be a drop in the level of school work. This usually picks up again after a period of adjustment. Speaking to the school and letting them know what is happening is always a good place to start so the school can offer active support as well.
Some children may refuse to go to school. This may be because they will worry about becoming upset in front of other children and that then they may be teased. Others may worry that something will happen to the person who is ill while they are at school and so will want to stay at home in order to ‘prevent’ something happening. If the person has been taken into hospital or the hospice while they were at school before, their worry may be that this will happen again.

Forewarning a child that another admission may happen and explaining why, for example to sort out a problem with pain, may allay some of their worries, as will asking the child what they are most concerned about.

School is a familiar place for a child and they may be able to use it as a place to forget what is happening to the person who is ill. Like adults, children also need a break from thinking about the person’s illness.

Getting support from the school can also ease some of your worry. Some teachers, although not all, will understand what is going on for you as a family and actively offer advice and support for your child when they are at school.
How to approach speaking to a child

Sometimes using an approach with some structure can help when you are unsure about where to start. Especially when you feel confused yourself!

Think about what information you need to give

There are three important things to tell children:

- That the person is seriously ill.

- The name of the illness (even young children may be aware of some illnesses such as cancer as they may have heard about them at school or on TV).

- Your best understanding of what may happen. If you talk about what you know right now then this can be updated as the illness or treatment changes. It is important to be consistent and honest with children.

Think about when to speak to them

It will help if you can choose when you feel you can do this. A good time may be at a weekend or during a school holiday. This will allow you to spend time together as a family so that you can answer any questions that may arise.

However, children often pick unpredictable moments to ask questions such as on the way to school. If this happens, it may be a case of you gathering your wits and saying you will sit down and talk with them after school or seizing the opportunity knowing this means being late for school. You will know which is best for you and your child. Either way is fine; there is no right or wrong way to do this.

If you have children of different ages then you may decide to sit down and tell them all at once. This may work well if the children are close in developmental age as their levels of understanding will be similar. However, if there are wide
age gaps, it may be that you will have to tell each child independently.

However, trying to have these difficult conversations more than once may feel too overwhelming, so you may choose to speak to the children all at once anyway. If so, you can try first explaining what is going on with the illness in simple terms so that the youngest will understand. They may then want to go off and play while the older children can ask any questions they may have, as they will probably look for more in depth information.

Think about how you will tell them - the sort of words you will try to use

You know your children best and it is important to pick the words that you think they will understand. If they have had a previous experience of someone being ill, such as an important person in your lives, or a pet, this can often be a good starting point. ‘Do you remember when..?’

Be prepared to become upset yourself. This is ok - allowing the children to see that you can show your emotions and that you can recover, is a good way for them to learn not to be afraid of their own feelings.
It may help you to practice what you are going say beforehand.

www.winstonswish.org.uk
Winston’s wish offers practical support to families and professionals concerned about a child when someone is seriously ill or has died.

www.macmillan.org.uk
National organisation with information about cancer.

www.rippap.org.uk.
Website to help children when a parent has cancer.

www.parentlineplus.org.uk
Information on parenting issues.
Suggested Books

When Someone Has a Very Serious Illness
Marge Heegaard
Fairview press 1993 ISBN 0 96205 024
A work book that aims to help children understand their feelings when someone close is seriously ill.

My Mum Has Cancer
Carolyn Stearns-Parkinson
Park Pres 1991  IBN 0963028707
An American story about a child whose mother is in hospital for cancer treatment. Suitable for children age 3-6 years.

The Secret C
Julie Stokes
Winston’s Wish
Straight talking about cancer for children; explains what cancer is and how it may affect patients and their family.

This booklet was written by the Hospice in the Weald Counselling Support Service.

The Hospice Counselling Support Service offers a wide range of counselling for patients and families under Hospice care.

Support is available for any family member or professional working with a child who may want advice on how to explain terminal illness to children. This can be done face to face or by phone and usually includes suggesting written materials that might be helpful.

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