

# What can I say? I do?



Death is an inevitable part of life.  
Even if your own life is to be shortened  
by a terminal illness, you are still alive.

## You still have time.

Time to spend with your **children...**

Time to spend with the **people you love...**

Time to **make the most of your life...**

Time to make **cherished memories...**

Time to **plan...**

Give your family the chance to share the precious time you have left with them – live life to the full and make some really special memories together.

You may be unsure about how to talk to your children, who is the best person to talk to them, how much to tell them and when to tell them – this booklet gives you suggestions and guidance to try and help you through this difficult and overwhelming time.

Parents often worry that they will say or do the wrong thing, but in reality the worst thing has already happened and there will be very little that can make this situation worse. Working together as a family can help to make the situation easier to deal with – now and in the future.

Small things can have a lasting effect on children and young people's memories. Communicating well at this confusing time prevents problems later.

*Don't think you need to have all the answers*

*Let the children lead you*

*Don't feel you are on your own, Simon Says is here for you if you need help or to talk*

*Look after yourself and take one day at a time*

*Remember all children are different and react in numerous ways.*

*You cannot prepare for all eventualities*

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## DEDICATION

*Everyone at sometime in their life is affected by bereavement and the team at Simon Says are no different. Chris Sherman worked for Simon Says for many years and played a huge role in helping the charity get to where it stands proudly today.*

*Chris's dedication and support to the many families affected by bereavement has without doubt proved invaluable to countless people over the years. Her compassion, understanding and caring nature made her a very special and unique person – her dignity, courage and especially her wicked sense of humour made her an unforgettable friend.*

*This pack is dedicated to the memory of Chris Sherman. Chris, you will be truly missed by everyone who was lucky enough to have known you.*



## Background of Simon Says

Simon Stanley was a 37 year old teacher from Southampton when he died from cancer. His wife Sally found there was no bereavement support locally for their two small children. Their experiences led to the establishment of “Simon Says” as a registered charity.

Research has shown that the Stanley’s experience is not unique and there is a wider need to provide resources and information to children, parents and professionals who work with children and young people eg: teachers, health professionals. It is estimated that approximately 7500 children<sup>1</sup> of school age (5 - 16 yrs) in Hampshire have a parent or sibling who dies. This number does not include the death of other close relatives or friends.

Simon Says was registered as a charity in 2001 with a formal launch in 2002.

Patron of Simon Says is Sally Taylor, MBE

<sup>1</sup> Source: Child Bereavement Network

## What does Simon Says offer?

The death of someone important can have a devastating effect on a child or young person. However, with appropriate support and information, children and young people can be helped to understand what has happened and can be helped to rebuild their lives.

Whether the death was sudden or expected, Simon Says works closely in practical and creative ways to support children and young people in Hampshire when an important person in their life has died or is dying. We do this by:

- Running a telephone help line (023 8064 7550)
- Offering support groups for children (up to age 11 yrs)
- Offering support groups for young people (age 11 – 18 yrs)
- Providing written information and resources
- Providing a befriending service
- Recommending counsellors who specialise in child bereavement, if the need arises
- Offering support, training and advice to schools and those professionals working/supporting bereaved children

## When to tell the children

Telling a child that someone they love is suffering from a terminal illness and is going to die will be one of the most difficult things you will have to do – there will never be the ‘right time’, or the ‘right words’ to do this.

*Nobody can avoid grief, only postpone it.*

It is natural to want to protect your children and adults will often try to soften the pain and shock of bad news. Some family members decide not to explain a situation to children because they think they are too young to understand. Sadly when dealing with terminal illness and death you cannot avoid a child’s pain and sadness. As much as we want to, we cannot protect children from death, grief and sadness, but we can help them to deal with it.

Children are often stronger than you think possible and, just like adults children need time to adapt to what is happening now, and time to prepare for what is going to happen in the future. If they are not told what is happening, they are denied the chance to help the person who is dying, to get closer to them or to say the things that matter.

There is never a good time to tell children that someone they love is going to die – but putting it off makes it increasingly difficult to face the truth and can make it difficult to explain why you waited. Children are helped by adults who are honest and direct. Not being truthful with children can make things worse in the long run.

Terminal illness of a loved one means that family life will change for all involved. It is important that children can trust the adults in their life, so they can believe what adults tell them in the future – especially as their life may go through a lot of painful changes in a short space of time.

Telling your child early will help to reduce problems and difficulties in the future. Children are very sensitive to change and anxiety in their family and easily pick up on feelings of unease and distress of those around them. Often children know when something is wrong, however much adults try to hide it. If they are given suitable, appropriate explanations they are likely to be able to deal with the situation better, and ask the questions they want to. If they are kept in the dark and things are not honestly explained, children can often blame themselves – they may think that mummy became ill because they didn’t tidy their bedroom or didn’t behave themselves.

If children are not told the truth, they can often make up their own ‘truth’, which can be a lot more harmful and damaging than the reality. If children are told as much as possible about what is happening – although they are still going to be very scared, they will not have to live in fear of the unknown. If no one is talking openly about the situation, it makes it a lot more difficult for a child to ask questions.

If a child doesn’t understand a situation it can make them lonely and afraid.

## Who should tell the children?

Often this depends on the relationship the child has with the person who is dying. It can be helpful if the person who will continue to care for the child is present when the child is told their relative is dying. It is important that children can build relationships of trust and closeness with adults who will continue to look after them in the future. At a time when so much is unsettled and upsetting, having a constant presence in a child's life can be extremely reassuring.

If you cannot bring yourself to tell your child about your death, find a relative, friend or a caring professional who you can trust to help you.

Ultimately, no-one understands your child better than you, so you will almost certainly know how best to tell them, although it is never easy to find the strength to do so.





# How much do children and young people understand?

## Younger children 0-8 years

- Children of this age don't know the name for what they are feeling. They just know that the world feels all different and horrible and their tummy feels funny and somehow it comes out as a tantrum in the supermarket.
- They may be clingier than usual, or more scared (of real things or pretend ones like giants and monsters).
- They may behave as though they are younger than they actually are - young children often seem to lose skills that they have mastered so they may go back to wetting themselves or waking often in the night.
- They may 'act out' the story of what happened to the person who died. They may have tummy aches or headaches or their toys may.
- Remember that a lot of the time they will behave as though nothing has happened. This is normal. They will remember too, but not all the time.

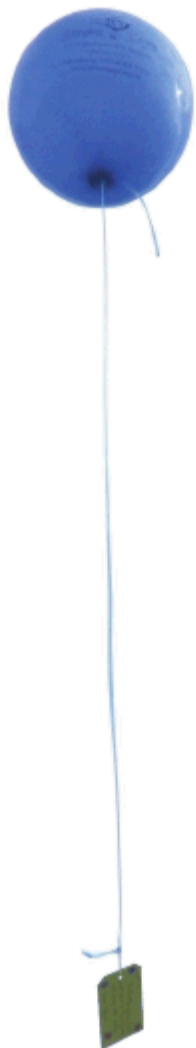
### *What can help:*

- Tell them about what they are feeling, comfort them, and help them to feel safe while making sure they know that having a tantrum, thumping their little brother or refusing to stay in bed is not OK.
- Help them to know that it is alright to feel sad, frightened, lonely – and that sometimes you feel that way too.
- Keep routines going, like bed times.
- Don't be afraid to say 'no' if that is what you would always have said in the past. You can add extra cuddles and reassurance, and be a bit flexible when you – or your child – need you to be.
- Make sure they understand what has happened. Use words that others are using (like dead) even if you think they are too young to understand them; they will hear them anyway and it will be reassuring to hear you say them.
- Talk about the person who has died, tell them stories about the person, and remind them what the person was like. Together you can create a memory store, to keep memories alive.
- Children are very supportive of each other; by attending a support group they will have the opportunity to meet others their age who have also been bereaved and they can share experiences and support each other.

## Older children 8-11 years

- At this age children/young people may know what the feeling is called, but they may not connect it with the death of someone important.
- They are looking for reassurance, comfort and a sense that the adults are still in charge, as well as an acceptance that they too are suffering and struggling.
- Children of this age often try to comfort their parent; they may hide their own distress or act it out at school. They may be unusually well behaved or may show signs of unacceptable behaviour. They may be uncharacteristically clingy or behave as though they are younger than they really are.





*What can help:*

- As with younger children, don't be afraid to say 'no' if that is what you would always have said in the past. You can add extra cuddles and reassurance, and be a bit flexible when you – or your child – need you to be.
- Drawing and making things together is a great way to talk about difficult things.
- Remember that at this age, like the younger ones, a lot of the time they will behave as though nothing has happened. This is normal. They will remember too, but not all the time.
- Make sure they understand what has happened. Remember that their understanding will mature as they grow older. Therefore they will ask different questions and will be able to understand and make better sense of what has occurred. The answers you give to their questions will need to grow as their understanding grows.
- Talk about the person who has died; share stories about him/her, encourage children of this age to make a storyboard picturing events prior/during/after the death, make a memory store together to keep memories alive.
- Children/young people are very supportive of each other; by attending a support group they will have the opportunity to meet others their age that have also lost someone important in their life and they can share experiences and support each other.

*Teenagers*

- Life is full of very complicated feelings if you are a teenager and trying to deal with bereavement just adds to the complications.
- The main thing to remember is that 12-18 year olds tend to be very unpredictable – one minute they are looking after you very nicely and the next they are slamming out of the house in a temper. They may seem to be inconsolable until their phone goes and then they seem to be able to chat happily to a friend.
- Friends and the outside world are very important. You may feel they are given priority over your needs – it helps to try to make space for both. Teenagers can be wonderfully supportive of each other.
- Teenagers often take things very personally so it may feel deeply unfair that this thing has happened to them. Feeling hard done by can make people cross and aggressive. Acknowledging that it is not fair, that it is hard, will help.
- Teenagers may want to talk to you all the time – often in the middle of your night – or they may hardly acknowledge your presence. Try to talk when they are open to it – it will be appreciated. Try not to put pressure on them to confide in you – they may be more comfortable talking to others, but, do keep checking that they are OK.
- Sometimes talking is just too complicated and painful – you can keep communicating by leaving them a little note (like a post it on the fridge or their bedroom door), sending text messages, e-mail. Don't be put off by not getting a response – your effort will be appreciated, deep down.
- Teenagers are notorious for their risk taking behaviour – experimenting with drink, drugs, sex, and unacceptable behaviour. When they are trying to cope with a death in the family this may become more pronounced. As with younger children – try and keep to the old expectations while making some allowances

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## HOW MUCH DO CHILDREN AND YOUNG PEOPLE UNDERSTAND?

### *What can help:*

- Keeping the channels of communication open, whether directly or via text, notes or phone calls.
- Make sure your teenager knows what is going on; this may mean telling them more than once!
- Try to acknowledge their feelings and experience while recognising that some will be like yours and some will be different.
- Ask them for help when you need it without burdening them too much; sometimes teenagers feel that no one takes any notice of them and their nearly adult abilities.
- Try not to feel hurt if they choose to spend time with their friends rather than the family. Similarly if they seem to confide in others rather than you, try to be pleased that they are talking.
- Help them to keep themselves safe and reassure them that, in time, things will feel more back to 'normal'.
- Young people are very supportive of each other; by attending a support group they will have the opportunity to meet others who have shared a similar experience, but have learned to manage their loss, and this will provide a more positive perspective to the young person's future and will help to eliminate any guilt they might be feeling.
- For some young people, the death of someone important can tip them into really dangerous behaviour such as serious drug use, suicide attempts, self-harm, running away. Seek help as soon as you feel worried. Even if you can't get the young person to accept it, you need it for yourself.



# How to tell the children

Sit quietly with your child, so that you are both at the same level. Physical closeness and comfort can be very assuring for children during times of upset and distress – what you may say may not be as important as a cuddle or a shoulder to cry on.

It will be difficult to begin and it can be helpful to break this process into stages: warning them you have bad news, explaining the situation you are in and reassuring them.

## Warning

Let your child know in advance you have some bad news. By letting them know that you have something bad to tell them, it helps to prepare them, which in turn can help decrease the shock.

## Explaining

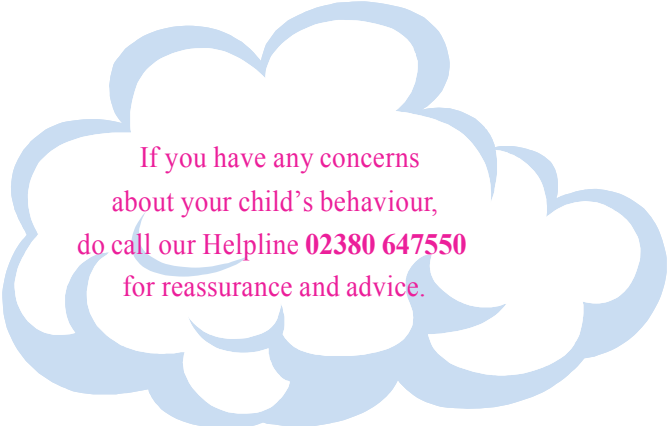
Tell them what is expected to happen in general terms. This helps the child to understand the situation more fully and to come to terms with what is going to happen. You could explain how ‘daddy’ went to the doctors today because he is very poorly and although they have tried, they cannot make him better. Children will not want to hear what you are telling them but they deserve to know. Explain in language you know they will understand. Let them know that nothing they did caused the illness (if not a communicable disease) reassure them that no-one can catch it, including them.

**Reassuring** the child is extremely important. When faced with such devastating news, it is vital that the child knows no-one else has the illness and so no-one else is expected to die, but will stay with them. It is important if a parent is dying that the child is constantly reassured that the other parent is not expected to die as well.

Often with younger children it can be helpful to use other means as well as words alone to explain what is happening. Books can be helpful as can drawing pictures or playing with toys. Children can often act out situations they feel incapable of talking about. After you have told them what is happening, you could suggest the child draws a picture to show how they feel, then ask them to explain about it. You may find that your child does not fully understand, so it may be that you have to explain several times and this may take some time. Try not to force the pace. Children will absorb and process information at their own rate.

It is important that you check how much your child has understood. You will probably need to do this several times, over a period, to ensure your child actually understands and is not simply agreeing with you. Let them know they can ask questions and give them the opportunity to express their feelings. Find out what is their biggest worry, whether they have any questions, if there is anything you can do to make them feel better.

A lot of the feelings and emotions that your child will experience may be too deep and upsetting for them to understand and they may be incapable of acknowledging and expressing them.



If you have any concerns  
about your child's behaviour,  
do call our Helpline **02380 647550**  
for reassurance and advice.

Understanding and coming to terms with terminal illness can only occur at the child's pace. You cannot make them understand and many children will not want to understand. Misunderstanding is common which is why constant communication is vital. Reassurance, patience and understanding are essential when talking to your child about terminal illness and the death of a loved one, no matter how hard this is for you. Do not worry about crying or getting upset in front of your child – they are already upset and seeing you upset will help to validate their feelings.

## How children may react

There is no right and wrong reaction and everyone will react differently to such devastating news. Parents should be prepared for their child's reaction – common reactions include shock, anger, fright, guilt, anxiousness, sadness or grumpiness, but in truth the list is endless.

Many children will cry and it is important to let your child know that crying is OK. It is not harmful for your child to see you cry, quite the opposite. If grief is hidden, children can believe that grief is not an acceptable feeling. Some children may be afraid to ask questions or talk about the situation to their parents because they don't want to upset them. Often crying together and sharing feelings can help a family to re-establish or strengthen the family unit as it underlines the fact that you are all in it together and will continue to be together throughout this very difficult time.

Don't worry if your child appears uninterested – it is quite normal for children not to ask questions straightaway. They may need time to digest what they have been told.



At some point, it is likely your child will have questions - try to answer these as honestly as you can. You will probably find they will ask questions completely out of the blue rather than when you ask them if they have any questions. Remember that it is OK to say 'I don't know' - sometimes there are no answers. Be honest with your child and explain to them that you will do your best to find answers to their questions. This is unknown territory for all of you, the important thing to remember is that your child knows you are being truthful with them.

Sometimes children may ignore the situation and avoid the person who is dying. This is usually because they don't know what to say and are unclear of their feelings – do not take this personally. It doesn't mean that they blame you or they don't love you. It just means they are trying to understand what they have been told and make sense of a situation which can seem senseless to an adult, let alone a child.

## What can grief feel like?

The death of a special person is always a shock – even if that person was suffering from a terminal illness and the death was expected. No amount of planning can actually prepare anyone for the death of someone they love, and the new reality of living a life without that person.

Because everyone is different, everyone experiences grief differently. This is especially true for children and it is important that your child understands this. Some people may cry a lot and some may not cry at all – it doesn't mean the person who isn't crying is less sad than the person crying a lot – it simply means they are experiencing their grief differently. Other common feelings related to grief include anger, guilt, depression, disbelief, loneliness, and relief, but really, the list is endless. It is important to remember that there are no right and wrong feelings. As with many emotions grief is often a new feeling and for this reason can be very scary to experience. People will experience different feelings at different times.



## Questions the children may ask

As you know, children are unpredictable, so they will not sit down and discuss a subject the way adults do. They will ask the most difficult questions, often out of the blue in a very direct way, giving you little or no time to think about answers. They may ask what it feels like to die, why their special person is dying, what it's like inside a coffin or if it's dark in the ground. It is helpful if you can be prepared for questions like these, so your reaction does not upset the child and stop them from asking more questions.

*Here are some typical questions from children and ideas to help you answer them...*

### Why do people die?

Explain that death is a natural part of life and everything that is living will eventually die – it is important to reassure them that all living things usually live a long healthy life, but eventually all things will reach the end of their life and their body will wear out and stop working and this is what dying means. Use plants, flowers, animals and elderly people to help explain this.

### When will my special person die?

Let them know that, for example, the doctors have told you that the special person is poorly and they cannot make them better, they have told you how long they think the special person will live but they can not be sure when they will die as there is no time limit on illness.

### Why my special person?

This can be hard to explain because in most cases there is no real reason. Death is not fair and there are no honest answers to explain why a death will occur. It can help to explain that everyone in the world has someone that loves them, so everyone who dies will be missed by someone and they are also asking why it had to be their special person.

### Does dying hurt?

Reassure them that dying does not usually hurt when someone has been ill for a long time because doctors can give them special medicine to help take the pain away.

### Why can't the doctors save my ..... ?

Explain to them that sometimes doctors cannot save people because they don't have the medicine that will make them better so they cannot stop them being poorly – even though they have tried their best

### Where do dead people go?

Ask the child where they think dead people go. By turning the question back on them, you can gain an insight into your child's thoughts and establish how much they already know. Let them know where you think dead people go – maybe as a shiny star in the sky or as a beautiful butterfly, or you may wish to talk about religious beliefs. The most important thing is to explain it in a way you are comfortable with. Let your child know what you think happens to dead people, but it is OK for them to believe in something else because no-one actually knows.

### Will I see my special person again?

It is important to be honest if they ask this question as you can give your child false hope if you tell them they will see that person again. Let them know that they can see their loved one in their head any time they want to – they just have to think about them. Explain how that person will always live on in their hearts because they loved them and in their heads/minds too because they will always have their memories of them which no-one can take away. You may want to suggest your child keeps a special photograph of their loved one so they can actually see them whenever they want to.



### Will I always feel sad?

Be honest – explain that they will probably always feel sad that their loved one has died but they will not feel sad all the time. Explain to them that the sadness (grief) will come and go. Find something to compare it to such as the sea – sometimes the sea will be calm with no waves and sometimes the sea will be very choppy with lots of big angry waves – and this is what sadness for a loved one who has died can feel like. It is important to let your child know that it is OK for them to be happy and laugh even though they are sad that their loved one has died – it would make their loved one happy to know they can still laugh and be happy.

### What happens to a body when someone dies?

Turn the question back to your child and ask what they think happen. This allows you to find out what they already think. You can let them know that when the special person dies their eyes will be shut and they will stop breathing and the body will feel cold. Reassure them that the special person is peaceful now and no longer in any pain or discomfort.

### Was it my fault?

NO! Be absolutely clear about this. Explain that death from a terminal illness is never anybody's fault – it is just a very sad part of life.



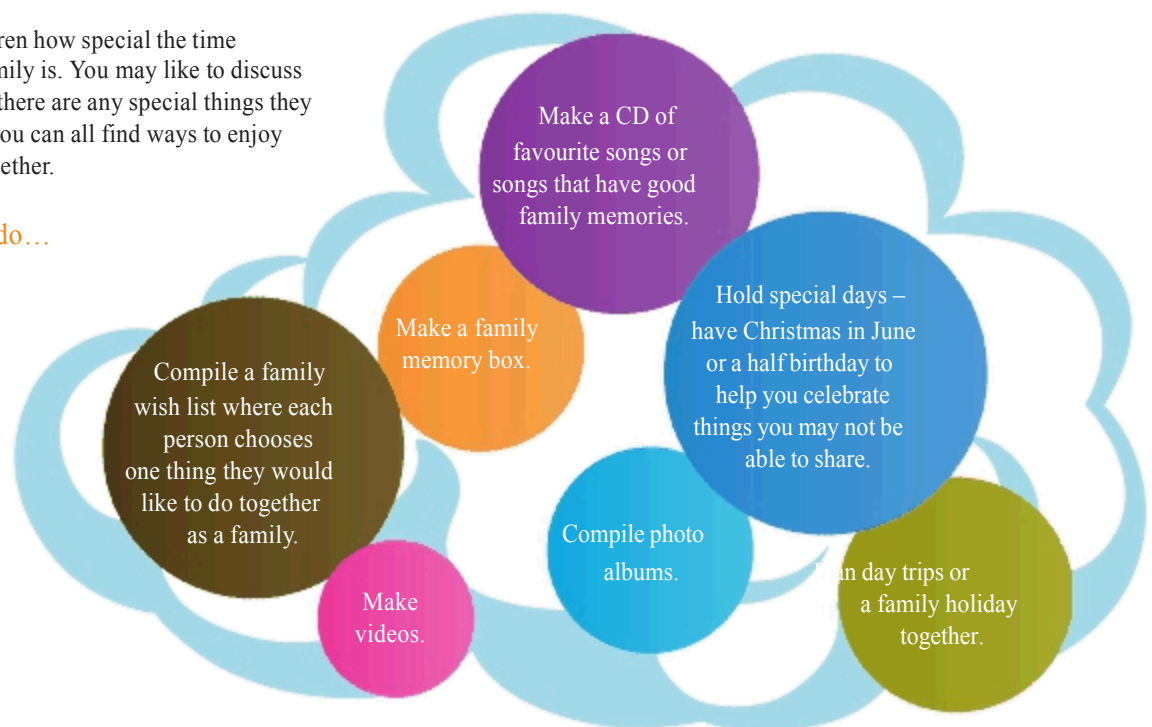


## Live for now

A terminal illness does not mean an immediate end to family life but it does mean things will change. You will not have the future you always thought you would have, but you do have the present so make the most of it. Knowing that a relative has limited time means that the time you have left together is very precious. Use the time to do things your family will enjoy and create special memories that will prove invaluable in the future.

Explain to your children how special the time they have left as a family is. You may like to discuss with your children if there are any special things they would like to do, so you can all find ways to enjoy the time you have together.

Things you could do...



## Keep it normal

Living with terminal illness often means that children have to cope with various changes in their usual routine. In the middle of such confusion and unsettledness, children generally cope better if as much of the normal routine as possible is kept. If you can keep dinnertime at the same time, ensure children still attend the same clubs and participate in the same activities, and so on. Involve family and friends to help you achieve this – as these relationships will be important to your child in the future. Try to keep family life as normal as possible so that your child doesn't have to cope with too many changes at once and disruption to family life is as small as possible.

Although your child will need time to adjust and their behaviour will undoubtedly change, it is essential that you set boundaries and enforce them in the same way you always have. Children dealing with terminal illness are going through a massive change and upheaval.

Of course allowances must be made, and their behaviour will vary, but it is essential that you do not allow them to use this as an excuse for continued unreasonable or bad behaviour.

## Saying goodbye

Generally, people suffering with terminal illness will become very ill and have to go into hospital or a hospice. It is important that children are allowed to visit so they have a chance to say “*Goodbye*” or “*I love you*”. It is not generally helpful to exclude children at this stage. They also need to be able to say goodbye in their own way.

If a child does not want to visit their special person in hospital do not force them. They may wish to say goodbye in a different way, for example, they may prefer to make a card or draw a picture, tape a message or write a poem or letter. If they seem to be struggling to find a way to say goodbye, offer them suggestions. Do not make them decide there and then. Leave them to think about the different ways they can say goodbye and let them know you will help them if they want you to.

Terminal illness can change the way someone looks. They may have lost or gained a lot of weight, their hair may have fallen out, and they may look very ill or be connected to machines. If this is the case, it is important that you let your child know in advance that their special person will look different. It is just as important that you explain that this is because of the illness and their special person is still the same person inside.

It may be useful to take toys or books to the hospital so children are not ‘forced’ to talk to their special person and the time together can be spent as naturally as possible. Taking flowers or treats may help – children like to feel useful and it will help them to know their visit has made their special person’s day very special.

Undoubtedly, saying ‘goodbye’ to those you love is one of the most difficult things a person suffering from a terminal illness will have to deal with. They should not do anything they feel uncomfortable with, however they should try and find a way to say ‘goodbye’; eg write a letter, or make a tape; as their survivors will cherish the memories forever, and it may go some way to helping them come to terms with the death in the future.

# Funerals

This is often a subject that is avoided because it is painful and difficult to deal with at this already emotionally charged time. However, by discussing it together and making arrangements it will help those left behind not only to give the person who has died the goodbye they wanted, but also to celebrate their life.



Parents/carers have very different views on whether children and young people should see the body after death or attend the funeral, however children and young people do value the opportunity to choose. For them to make the right choice for themselves, it is important that they understand what is involved.

## Why It Can Help to See the Body and Attend the Funeral

Families will have different cultural and religious beliefs about seeing the person who has died and attending the funeral, but it can help a child / young person to:

- begin to say goodbye
- begin to accept the reality and finality of the death
- begin to understand what has happened
- be less scared
- feel part of what is happening
- share with others an important last memory about the person who died

## Seeing The Body

It is a good idea to liaise with the undertaker about visiting the body. In some instances the body may be marked or disfigured, and it is important to know before visiting the body if an affected area has been covered.

Here are some points which may help the child / young person decide on whether they would like to see the person after they have died:

- Assure them that they can change their minds at any time, even at the last minute
- Check that they are happy with the choice they've made – but not too often.  
Children and young people often want to please and may say what they think you want them to say
- Let them know, clearly and in detail, what to expect. Ideally from you or someone else who has already seen the body. Eg *'Your dad is lying in the coffin. You will see all of him because the lid isn't there. He's got his eyes closed and his skin's cold. He may feel rather hard, like a statue. If you would like to touch him you can, but only if you want to. I kissed his forehead which was what I wanted to do but it seemed strange that his skin was cold. So don't be surprised if it doesn't seem to be your dad'*
- Give them choices about what they do when they enter the room – they can wait by the door, stroke a head or hand, and leave when they want to
- Children and young people often appreciate taking something with a special meaning to leave with the body, eg: a card they have made, or a shell from a favourite holiday or a picture

## What type of funeral?

There are many kinds of services available, and it is worth getting the help of a funeral director who will be able to advise and explain the different choices. If required, the funeral director can make a home visit and will not normally charge for giving advice, even if you do not choose to use them.

### Cremation

It is important to make clear any wishes about what should be done with the remains. Ashes can be scattered in a garden of remembrance or in a favourite spot (subject to the landowner's permission), buried in a churchyard or cemetery, or kept.

If no wishes have been expressed, it is the responsibility of the funeral director or crematorium staff to contact the relative before disposal.

### Burial

Most cemeteries are non-denominational and are owned by local authorities or private companies and fees vary with plots costing anything from £30 to £5,000 depending on the location. People should be aware that because of the pressure of space, particularly in bigger cities, most burial plots are now sold on a system of leasehold. Remains can therefore be moved to another part of the cemetery once the lease has expired.

Because the majority of cemeteries are non-denominational, most types of funeral service or ceremony can be conducted there. Advice will also be available from the ministers of the religion or religious organisation that the deceased may have belonged to.

If the choice is to be buried in a churchyard, the priest or minister can confirm if space is available and the right to be buried there. A burial will require the certificate for burial or cremation or if a coroner was involved, the order for burial.

### Cultural, humanistic and non-religious

More and more people are considering different sorts of funerals as an alternative to traditional religious services and cremations. Many of which are along more environmentally friendly lines such as woodland burials or burial at home if the size of the grounds allows it. In fact the choice continues to widen, with people sometimes sending their ashes into space.

One of the most popular alternatives to traditional burials and cremations is in woodland or a nature reserve burial ground. It is also perfectly possible to arrange some aspects of the burial yourself. However it requires a degree of courage, planning and determination to undertake a complete D-I-Y funeral.

A death certificate signed by a doctor and a certificate for burial from the registrar of deaths will be required if you are planning most of your own arrangements. However, if planning a private burial - which includes those not in a churchyard or cemetery - you must first register your intention to do so. It is advisable to consult both the Environment Agency and the local council environmental health department about possible pollution of water courses.

### 'Green' Funerals – Woodland or Nature Reserve Burial Grounds

'Green burials' are becoming increasingly popular and there are a number of commercial sites opening around the country, promoting eco-friendly funerals and more informal ceremonies. These are often in woodland or nature reserve burial grounds of which there are currently about 50 already open in the UK, with at least another 50 applying for planning permission.

The Natural Death Centre has researched the laws and regulations for the UK surrounding burial on farmland and in large private gardens and recent cases have confirmed that no planning permission is required for 'a limited number of unmarked and unfenced graves'.

At woodland burial grounds relatives may be able to plant a tree to mark the site either on or near the grave. At nature reserve burial grounds, which can be wild flower meadows or pastures, graves are either unmarked or may be marked by a small wooden plaque that will rot away naturally and bulbs and flowers can be planted.

For those not using undertakers, cardboard and wooden coffins are obtainable, as well as woollen shrouds. However an increasing number of undertakers will offer assistance with a woodland burial, such as providing transport of the body and cardboard coffins.

A list of woodland burial grounds is available from the Natural Death Centre:

The Natural Death Centre, 12a Blackstock Mews,  
Blackstock Road, London N4 2BT  
Helpline (10am-2pm Mon-Fri): 0871 288 2098  
Email: [ndc@alberryfoundation.org](mailto:ndc@alberryfoundation.org)  
Website: [www.naturaldeath.org.uk](http://www.naturaldeath.org.uk)

The Natural Death Centre is an educational charity dedicated to supporting those dying at home and providing a movement to parallel the natural birth movement, including acting for the consumer. It produces its own handbook, *The Natural Death Handbook (4th edition £15.50 inc p&p)* which offers advice on all areas of organising a 'green burial' as well as aspects such as living wills. It also offers a good funeral guide, listing good funeral directors and good crematoria and cemeteries.

### D-I-Y Funerals

An increasing number of undertakers will offer advice (usually at an hourly rate) about organising a D-I-Y funeral. Alternatively, see *The New Natural Death Handbook* for detailed information and advice on how to organise a completely D-I-Y funeral.

### Burial at Sea

About 20 burials take place at sea each year. Apply to the Ministry of Agriculture for a licence which is free, but there are a large number of bureaucratic guidelines to discourage it. For a licence apply to the marine licensing department at the Ministry of Agriculture, Fisheries and Food (MAFF) on 020 238 5869 or contact your local Fisheries District Inspector.

If a sea burial is planned, you should tell the registrar when registering the death, so that a 'Coroners Out of England Form' (Form 104) and the local coroner's address to which it should be sent can be obtained from the registrar.

Source: [www.ifishoulddie.co.uk](http://www.ifishoulddie.co.uk)

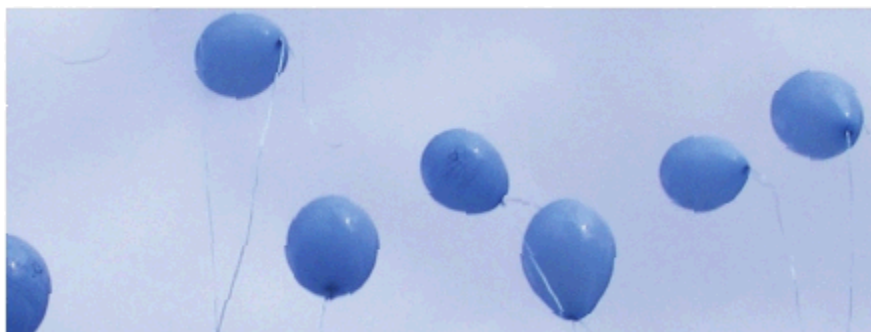




## Attending the funeral

If you are prepared to let your child make the choice of whether to attend the funeral, some things may help them decide:

- Assure them that they can change their minds – at any time
- Check that they are happy with the choice they've made – but not too often. Children / young people often want to please and may say what they think you want them to say
- Have someone available who the child / young person is close to and trusts (eg. a teacher / friend, who is not emotionally tied to the person who has died) who can be with the child / young person during the funeral. If the child / young person wishes to leave the service they can do so safely
- Provide clear and detailed information about what will happen at the funeral. This will involve explanations about the difference between, for example, burials and cremations
- Reassure them that it is all of the body of the person who has died that is being buried or cremated. Some younger children are confused and wonder what happens to the head, arms and legs



- Give reassurance that the person who has died can no longer feel anything, so they will not feel the flames nor will they be scared at being buried
- Offer clear and detailed explanations of what to expect from people at the funeral. Some children and young people can be shocked that people seem to have a party after someone has died; others are upset when people say 'How lovely to see you'. Explain that this doesn't mean that these people are happy that the person has died – they're just the sort of things that adults say. Equally, seeing adults in deep distress may alarm children but preparation beforehand will help them understand that this is a reasonable response to the huge thing that has happened
- Create opportunities to be involved. This may be in the planning of the funeral service. It may be through saying or reading or writing something about the person who has died. It may be through choosing a particular piece of music. They may wish for something special to be put in the coffin, for example, a picture or something linked to a memory
- Give plenty of reassurance that they can still be involved and participate in saying 'goodbye' even if they choose not to attend and that they won't be criticised if they don't go to the funeral

## Alternative 'Goodbyes'

If it is not possible for the child / young person to attend the funeral, for whatever reason, there are other positive ways in which they can be involved. If the funeral happened some time ago and the young person regrets that they did not attend, it is never too late to have a memorial or other ceremony that includes them saying 'goodbye'. It could be linked to an important date eg date of their death, or birthday.

- Visit the grave or other special place, for example where the ashes were scattered
- Visit a place with special memories
- Create a special place of the child's / young person's choosing
- Visit a place that you went to regularly



Some of these ideas may make the occasion special:

- Hold a small ceremony with specially chosen music, poems and tributes
- Bring a picnic of the dead person's favourite food to share
- Prepare something to leave in the 'special place' – flowers, a laminated poem, or a toy
- Release helium-filled balloons to which messages are attached on labels
- Light a candle and share special memories with each other
- Start a collection of memories from family and friends of the person who has died



# Ten things that can help you and your child

- 1 Do not protect your child from the reality of the situation – there is support available to help you do this.
  - Talk with your child – explain how you are feeling and what you think about the situation.
  - Talk about the effect of treatments eg. tiredness, hair loss.
  - Explain why and how things happen.
  - Be honest and give information in small chunks using language they will understand. You may find you need to do this more than once.
  - Avoid using confusing language eg. ‘....will go to sleep’.
  - Encourage children to ask questions.
  - Talk to other family members about how you plan to involve your child to enable a common approach to be taken.
- 2 Listen to your child
  - Encourage your child to talk about how and what they think and feel about the situation.
  - Clear up any misunderstanding and misinformation they may have.
  - Be prepared for unexpected questions.
  - Remember you may not have all the answers and it is ok to say you don’t know.
- 3 Watch your child for any unusual behavior. They may become for example withdrawn, attention seeking or demonstrate illogical fears.
  - Seek professional help.
  - Make all schools and clubs aware of the situation so that they can respond appropriately.
- 4 Keep your child’s routine as normal as possible – schools, clubs, friends to stay etc.
- 5 Continue to plan activities you all enjoy, for example trips to the cinema, the beach, picnics, football matches etc.
- 6 Warn children that the illness can sometimes make the family grumpy and upset, and that there may be times when it will seem as though they are not being listened to. Explain they may feel left out because the sick person needs time and attention. Reassure them by giving them a hug and telling them they are special, and arranging some special time together to do something you both enjoy. Have fun – that is important and OK during this difficult time.
- 7 Share memories and experiences with your child and other family members.
  - Make a story book with photographs and words to describe memories of events, for example parties, holidays, Christmas and birthdays.
  - Collecting items for a memory box.
  - Recording a CD or DVD of special times.
- 8 Look after yourself  
Your GP can help here. Talk to family and friends, and do not either refuse offers of help, or be reluctant to ask for help.
- 9 There are a number of books / leaflets available that you may find helpful – refer to the book list at the back of this booklet.
- 10 Do consider accepting help from professionals eg. GP, counselor, support groups, McMillan team, Simon Says etc.



## Making a life book

Here are some ideas on making a life book, to help a child/young person keep memories alive of someone who was important to them. It is designed to help a child/young person understand more about the person who has died and to give them information that they may find invaluable as they grow older.

The contents could include some of the following:

- Information about the person's childhood – where they were born, their family, education
- The person's hobbies and interests as a child; any special achievements
- Where they went to school and what they did when they left school
- Their jobs/careers
- Interests and hobbies as a young adult
- How they met their partner; what they enjoyed doing together
- Information about the marriage; moving in together
- The person's good points eg really good at .....
- The person's not so good points eg not very good at .....
- Information about the birth of the child(ren)
- Relationships with the child(ren)
- The person's hopes and dreams
- Things that worried the person
- Information about the illness and treatment, or details of how the person died, including where the child(ren) were when it happened
- Information about when/if the person knew they were going to die
- Information about the death and the funeral
- Information about 'us' as a family without the person
- Things missed most, now that the person has died
- Things that are remembered about the person
- Favourites – holidays, special places, foods, sports, TV, films, books, perfume/aftershave etc

These headings are simply a guide and can be altered to suit the needs of your family. It may be easier to record thoughts and ideas onto a tape/CD/DVD. A close friend or family members may be able to help collect the information together.

## How bereavement can affect behaviour

When you and your children are trying to come to terms with the death of someone important, it is hard to know how to deal with difficult behaviour.

### What is normal?

It is normal for children and young people to be particularly good and particularly difficult in the days, weeks and months before and after the death of someone who has been terminally ill and who was important to them. They may become quiet and withdrawn, or they may become extrovert and display unacceptable behaviour. They may be kind to you or they may seem furious all the time, behaving as though it is your fault. They may cling to you or they may ignore you, or, most commonly, a mixture of the two.

### What helps?

#### · Remembering that children and young people grieve too

Remember that children also experience the turmoil, pain and confusion that happens when someone important dies. Unlike adults who cannot escape from this for a second, children are able to 'puddle jump', meaning that one moment they are feeling very upset and the next they are off playing and laughing – until they encounter the next puddle.

#### · Keeping a balance

Try to keep a balance between keeping things almost as they were before – if you never let the children do 'x' or 'y', don't let them do it now (unless there is a good reason of course!). If, for example, they always had a regular bed time, then you should keep to it. However, you may need to give them extra cuddles and reassurance around bed time, but don't think you have to drop all your old rules and customs. It is important to understand that they are struggling to manage all sorts of complicated feelings and worries, so they may get distracted, short tempered, angry, or aggressive. You won't want to let them hurt themselves or anyone else, so you will want to try to contain that behaviour while showing them that you understand why it is happening.

#### · Keep explaining

Try to ensure that they understand as fully as they can what happened and what is going to happen. When children worry it often is displayed by difficult behaviour. Children and young people overhear adults and put 2 and 2 together to make 17! Check that they have an understanding of the facts; their imagination can be worse than the facts, and keep checking that they are fully aware and understand what has happened and what is happening currently.

#### · Involving them

Try to involve your children as much as possible. One of the worst feelings is that of being left out or even shut out. Helping children/young people to anticipate what will happen and preparing them for difficult or possibly upsetting events means that they can be part of them. Sharing in what happens can help them.

#### · Keep talking

Talk about the person who has died. This can be hard, particularly as time goes on, but keep mentioning the person who died in an everyday way. Telling the children/young people the family stories about the person will enable them to keep having a real picture, a real sense of the person they are missing. The person who died may not always have been a hero – or the 'bad guy' – so it is important to remember both sorts of anecdotes.

# A charter for bereaved children & young people

Although each bereavement will be unique, bereaved children and young people have key needs:

## 1 Enough Information

Bereaved children need answers to their questions. They need information that clearly explains what has happened, why it happened and what will happen now.

## 2 Being Involved

Bereaved children should be asked if they want to help with important decisions that will affect them (such as planning the funeral, remembering anniversaries)

## 3 Family Involvement

Support for the bereaved children should include their parent(s). It should respect each child's confidentiality.

## 4 Meeting Others

Bereaved children can be helped by meeting other children who have had similar experiences.

## 5 Telling the Story

Bereaved children have the right to tell their story. This may be through drawings, letters or puppets. The stories can be heard, read and seen by people important to the child.

## 6 Expressing Feelings

Bereaved children should feel comfortable showing all feelings that go with grief such as anger, sadness, guilt and anxiety. They may need help to find ways to do this.

## 7 Not to Blame

Bereaved children often feel they are to blame for the death. They may need help to understand this is not true!

## 8 Established Routines

Bereaved children should continue with interests and activities they have enjoyed if they choose.

## 9 School Response

Bereaved children can benefit from a positive response from school or college.

## 10 Remembering

Bereaved children have the right to remember the person who died for the rest of their lives. This may involve reliving memories so that the person becomes a comfortable part of the child's ongoing life story.

*“A child can live through anything provided they are told the truth and allowed to share the natural feelings people have when they are suffering”* Eda Le Shan.

## Let the school help

Inform your child's teacher what is happening. This will allow the teacher/school to help keep an eye on your child – providing additional support while your child is at school.

Teachers can be very supportive during this difficult time and some schools employ Emotional Support Workers or other staff who have had bereavement training in whom your child can confide. It can often be of great help to the child affected by bereavement if people in their class/school know and understand a little about the situation they are going through.

It may be helpful for your child to have 'special time' during the school day where they can telephone their parent(s) to be reassured that they are still there. Constant reassurance during an unsettling time like this can be of great comfort to a child of any age.



## Simon Says support groups

Following the death of someone important in a child or young person's life, attending a bereavement support group may be considered. It can be very comforting to realise that other children and young people are experiencing similar emotions and they are not the only ones to have lost someone special.

Bereaved children and young people may find it difficult to ask questions or talk to their parents/carer for fear of upsetting them.

Simon Says support groups provide a safe, supported and friendly environment for children and young people who are in various stages of grief. It can be very comforting for them to realise that other children and young people are experiencing similar emotions and they are not the only ones to have lost someone special.

### Children's Support Groups

#### Who attends?

Children up to the age of about 11yrs with a parent or guardian.

#### What goes on?

Support groups are tailored around the needs of the families in a friendly and informal atmosphere.

A typical session would run as follows:

- Arrival – welcome – registration – introductions
- Organised varied activities could include games, craftwork, colouring, drawing, face painting and puppet themed interaction
- Refreshments are offered, giving adults an opportunity to talk about how their children are dealing with their bereavement and other issues, which may have arisen
- Future events are announced

#### Past Themes

Support groups follow a theme, and past themes have included happy memories, change, relationships, guilt, anger, stress, sadness, love and hate, bullying, dreams and nightmares, fears and worries. Both children and adults are encouraged to think about any themes they would like covered and feedback is always welcome.

Please contact the office of Simon Says for dates and locations of groups.





## Young People's Support Group

### Who Attends?

Young people aged between 11yrs – 18yrs  
(young people may bring a friend/family member if it makes them feel more comfortable)

### What Goes on?:

Support groups are tailored around the needs of the young people in a friendly and informal atmosphere offering:

- Individual space and time
- Opportunity to talk and be listened to
- Support and advice
- Fun and laughter (but it's ok to be sad too)
- Various fun activities including cooking delicious food
- Time to meet other young people who have also had someone important to them die and are going through similar experiences and feelings
- A place for young people to come and relax, and to be themselves

### Themes:

Groups follow a theme and include; happy memories, change, relationships, love and hate, guilt, anger, stress, sadness, panic attacks, bullying, dreams and nightmares, fears and worries.

Young people are encouraged to think about any themes they would like covered and feedback is encouraged.

Young people say .... “No one listens”

Simon Says .... “We Will!”

Please contact the Simon Says office for dates and locations of groups.

## Simon Says is here for you and your children

Remember.....

Dealing with a terminal illness need not be done alone.

You may not know who to turn to at a time like this - do not forget that the trained volunteers for Simon Says are here to help and support you.



## Books for families when someone is seriously ill

### A Flash Of Blue

By A Worrall  
1985, Methuen  
ISBN: 0416508308

14 year old Shelley has difficulty dealing with her anger and fear when her father is dying of cancer.

### A Summer To Die

By L Lowry  
1993, Laurel Leaf Library  
ISBN: 0440219175

13 year old Meg tells the story of the death of her sister from Leukaemia.

### As Big As It Gets

By J Stokes & D Crossley  
2001, Winston's Wish  
ISBN: 0953912329

Supporting a child when someone in their family is seriously ill.

### Children Can Learn To Cope With Loss And Change

Fairview Press  
ISBN: 0962050245

Aiming to be used weekly, over a number of sessions, this workbook will help families communicate and teach children about illness and coping skills. With simple, clear writing and plenty of space for children to draw and colour, it covers areas such as change, feelings and looking after oneself. It also has suggestions for how adults can help children as well as useful addresses and additional reading.

### Flamingo Dream

By Donna Jo Napoli  
& illustrated by Cathie Felstead  
2003, Greenwillow Books  
ISBN: 0688178634

This bright and colourful book is told by a young boy whose dad is seriously ill and dies soon after a trip to Florida to see the place where he grew up. The collage style illustrations capture the things the boy collects to remind him of his dad. A sensitive but honest book, which emphasises the importance of memories.

### I Don't Know What To Say

By Dr R Buckman  
1968, Macmillan London Ltd  
and Papermac  
ISBN: 0333469839

### Loosing Uncle Tim

By Mary-Kate Jordan  
& illustrated by Judith Friedman  
1999, Albert Whitman & Company  
ISBN: 0807547581

this picture book for slightly older children explains how a young boy accepts the changes in his life when he finds out that his Uncle Tim has AIDS and is going to die. It is a serious and sensitive book that covers lots of issues and difficult feelings that can occur when someone has a serious illness.

### On Eagles' Wings

By Sue Mayfield  
A Lion Children's Book  
ISBN: 0745948901

Tony's mum is dying and there is nothing he can do about it. He can't always put on a brave face and his dad won't talk about things. Only Clare seems to understand - somehow she helps him keep it together. Then Tony finds an injured seagull, a creature he *can* nurse back to health. And, slowly, gradually, Tony begins to understand that death can sometimes bring freedom.....

### See Ya Simon

By D Hill  
1995  
ISBN: 0140363815

Told by Simon's best friend Nathan, this book manages to combine an awareness of the real tragedy of a young person with a deteriorating and fatal illness with a robust hilarity that has the reader laughing out loud. This is a very funny, moving and devastatingly honest story about the true meaning of friendship.

### Talking to Children

1993  
Cancer Link

Talking to children when an adult has cancer.

### The Secret C

By Julie A Stokes  
& illustrated by Peter Bailey  
2000, Winston's Wish  
ISBN: 0953912302

The Secret C attempts to answer some of the questions and worries a child may have about cancer, especially when it involves someone in the family. This reassuring book will help adults and children to talk about the difficult issues and feelings involved when someone is seriously ill and briefly talks about the possibility of death.

### Two Weeks With The Queen

By Morris Gleitzman  
& illustrated by Andy Bacha  
1999, Puffin Books  
ISBN: 0104130300X  
(Also available in audiocassette)

Twelve-year-old Colin, an Australian boy, is sent to stay with relatives in England when his brother becomes ill with cancer. He is determined to find a way of curing his brother, which leads him into all sorts of adventures including trying to visit the Queen! Colin finds a friend in an older man named Ted who helps him express his feelings and understand what he has to do.

### What Do I Tell The Children?

BACUP  
1996, Lithaflow Ltd. London  
ISBN: 1870403762

A guide for the parent with cancer.

### When Someone Has A Very Serious Illness

By M Heegaard  
1991, Woodland Press USA  
ISBN: 962050245

### When Your Mum Or Dad Has Cancer

By A Couldrick  
1997, Sobell  
ISBN: 095175373738

# Helpful Websites

<a href="http://simonsays.org.uk">simonsays.org.uk</a>	Child/Adolescent Bereavement Support.
<a href="http://winstonswish.org.uk">winstonswish.org.uk</a>	Help for grieving children and their families.
<a href="http://childhoodbereavementnetwork.org.uk">childhoodbereavementnetwork.org.uk</a>	Childhood bereavement.
<a href="http://mariecurie.org.uk">mariecurie.org.uk</a>	Providing resources to aid conversations with children about life threatening illness.
<a href="http://rd4u.org.uk">rd4u.org.uk</a>	Specifically for young people aged 12-18. Information and interactive.
<a href="http://crusebereavementcare.org.uk">crusebereavementcare.org.uk</a>	All aspects of bereavement. Some information for children.
<a href="http://ukselfhelp.info/careline/">ukselfhelp.info/careline/</a>	Confidential crisis telephone counselling for children, young people and adults.
<a href="http://childline.org.uk">childline.org.uk</a>	Free national telephone helpline for children and young people. Information on bereavement.
<a href="http://connexions-direct.com">connexions-direct.com</a>	Information and advice for young people.
<a href="http://griefencounter.com">griefencounter.com</a>	Helps bereaved children & young people rebuild their lives after a death.
<a href="http://noahsarkcafe.org.uk">noahsarkcafe.org.uk</a>	Offer support groups to children & teenagers who have suffered loss through death, divorce or other transitions.
<a href="http://papyrus-uk.org">papyrus-uk.org</a>	Provides resources & support for those dealing with suicide, depression or distress – particularly teenagers & young adults.
<a href="http://riprap.org.uk">riprap.org.uk</a>	Helps children who have a parent with cancer.
<a href="http://uk-sobs.org.uk">uk-sobs.org.uk</a>	Those who are left behind after a suicide can be helped by talking to others who have experienced a similar loss.
<a href="http://supportline.org.uk">supportline.org.uk</a>	Confidential emotional support for children, young people & adults.
<a href="http://teenissues.co.uk">teenissues.co.uk</a>	Internet based unique reference point for teenagers to find answers to commonly experienced issues.
<a href="http://there4me.com">there4me.com</a>	For 12-16 year olds needing advice or help with worries.
<a href="http://tcfsiblingsupport.org.uk">tcfsiblingsupport.org.uk</a>	Support and information for siblings after a death. Pen-pal link for over 16's.
<a href="http://childbereavement.org.uk">childbereavement.org.uk</a>	Support, information & training when a baby or child dies, or when a child is bereaved.
<a href="http://teachers.tv/schoolmatters">teachers.tv/schoolmatters</a>	1) Coping with bereavement 2) Life stuff: Without You
	2 videos about school coping with death.
<a href="http://seesaw.org.uk">seesaw.org.uk</a>	Grief support service for children and young people. Support for schools.
<a href="http://uk-sands.org">uk-sands.org</a>	Providing support for parents & families whose baby is stillborn or dies soon after birth

## Can you help?

Simon Says rely on the donations and goodwill of organisations and individuals.

Only with continued contributions can Simon Says carry on making a positive difference to the lives of vulnerable children and young people.

If you would like to find out how you can help, please contact Simon Says.

Help Simon Says to make a difference.

## References

Winstons Wish – [www.winstonswish.org.uk](http://www.winstonswish.org.uk)

Child Bereavement Network - [www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)

## Acknowledgements

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## If I could

If I could, I would teach each child to be positive, to smile, to love and be loved.

I would teach each child to take time. To observe some miracle of nature – the song of a bird, the beauty of a snowflake, the orange glow of a winter sunset.

I would teach each child to feel warmly about those whom the task of learning does not come easily.

I would teach each one to be kind to all living creatures and to crowd out of their lives feelings of guilt, misunderstanding and lack of compassion.

I would teach each child that it is alright to show their feelings by laughing crying, or touching someone they care about. Everyday I would have a child feel special.

And through my actions each one would know how much I really care.

Kevin Mayhew







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