



Nottingham University Hospitals **NHS**
NHS Trust

Nottingham Children's Hospital

Supporting children and young people when someone is seriously ill

Information for adults

This document can be provided in different languages and formats. For more information please contact:

Child Bereavement Team
Nottingham Children's Hospital
Tel: 0115 924 9924 ext 66276

or

Hospital Palliative Care Team
Nottingham University Hospitals
Tel: 0115 993 4977 / 0115 919 4402



We are here for you

Introduction

It can be difficult to know when and how to tell children that someone close to them is seriously ill, particularly when there is a possibility the person may die.

An adult's instinct is often to protect children and delay telling them. However, children tell us that they want to be involved as soon as possible as they often already know something is wrong.

It is usually better they hear it from someone they know and trust, rather than hearing it second-hand or from someone else, for example in the playground.

Aim

This leaflet is designed to give you some helpful advice and guide you to further information and support during this difficult time.

Where do I start?

Before having a conversation with a child it is important to think about who, where, when and how this information will be given.



Who will tell - someone the child knows and trusts.

Where to tell - if possible let the child choose, but it is important that both the person telling them and the child feel safe and comfortable in the chosen place.

When to tell - as soon as possible, particularly when a child is already asking questions.

How to tell - keep things clear, simple and honest eg. it may be helpful to begin with something like 'I have something sad to tell you'.

If you have more than one child, you can tell them together or separately, but try to make sure they all find out around the same time so that no-one feels left out.

Breaking the news

Check what the child already knows. Go at the child's pace, using words they can understand.

Children will often need some information about the illness including its name and how it is being treated.

Encourage the child to ask questions and answer as truthfully as possible. Be hopeful, but don't make it seem less serious than it is and don't be afraid to say you don't know, particularly if they ask if the person is dying.

You may need to repeat information and keep checking their understanding. They may need time to take it all in.

Ongoing support

Don't be afraid to show your emotions, however, try not to let them get out of control as this may distress the child.

Children need to know there is no right or wrong way to react to sad news.

It is not unusual for children to be very upset one minute and asking what is for tea the next.

Encourage children to express feelings and emotions. This may be through quiet time, sport, art, play or talking.

Children may feel anxious and have further questions about the illness and how it affects them. Occasionally, they may blame themselves or others for the person's illness.

Try to keep a usual routine, being aware this may need to change at short notice.

Children need to be kept up to date with what is happening.

Children need to know who is there for them.

Try not to make promises to the child that you may be unable to keep.

Inform staff at the child's nursery/school and other relevant adults who may be able to offer ongoing support, where possible.

Allow time to play and have fun.

Provide choices and opportunities for the child to care for and be with the person who is ill as much or as little as they wish.

If being with the person is difficult encourage other ways of contact eg. messages, cards, drawings, text, e-mail or web cam.

Prepare children for any initial changes in appearance and ability and behaviour of the person who is ill eg. not being able to talk or play with them.



Creating memories

Where ever possible, provide opportunities to capture and create memories for the future, particularly those that include the thoughts and the feelings of the ill person themselves.

Some examples are:

- Creating a life story.
- Photo album/collage.
- Memory/journey/life box.



Involve the child in making and choosing future keepsakes.

Preparation

If you have been told that someone important to a child is dying, as hard as it may seem, it is really important to prepare and support the child for the person's death.

Provide a simple explanation about death. This may be something like; "when someone dies, they stop breathing, their body stops working and their heart no longer beats."

Again, it can be helpful to use factual words and to say, for example, that sadly the person isn't going to get better and that they are dying, rather than the temptation of saying they are 'going to sleep' or 'going away'.

However it is always important to take into account the beliefs and culture of the family and the individual.

Give time and encourage children to ask questions about dying and death and the changes they may see as the ill person's condition deteriorates.

This may include things like the person sleeping more, being unable to talk, they may no longer eat or drink, and their breathing may change.

Give the child reassurance that the person is being cared for and kept comfortable.

The child may or may not want to be with the person, offering a choice is important.

If they chose to be with them they will need support and will need to know it is okay to touch and talk to them.

They may like to sit and talk about their day and what they have been up to, share stories or just hold their hand.

Saying goodbye

Children often tell us they want a chance to say goodbye.

Some examples are:

- Visiting the person, possibly spending time together on their own.
- Writing a card or a letter.
- Giving the person something special to keep with them

Try not to ignore the situation – it implies it is not happening

Supporting and preparing a child can help them to cope now and in the future.

Resources

Local

Spiral at Family Care (Nottingham)
Tel: 0115 9603010
www.familycare-nottingham.org.uk

Child Bereavement Team
Nottingham Children's Hospital
Tel: 0115 9249924 ext 66276

Sue's Place (Newark)
Tel: 01636 551739
www.sues-place.co.uk

Laura Centre (Leicester)
Tel: 0116 254 4341
www.thelauracentre.org.uk

Treetops Hospice (Sandiacre/Derby)
Tel: 0115 949 7354 / 939 6609 (answer phone)
www.treetopshospice.org.uk

National

Childhood Bereavement Network (CBN)
Tel: 020 7843 6309
www.childhoodbereavementnetwork.org.uk

Child Bereavement Charity
Tel: 01494 568900
www.childbereavement.org.uk

Winston's Wish
Helpline: 0845 030405
General Enquiries: 01242 515157
www.winstonswish.org.uk



Cruse Bereavement Care
Helpline: 0844 477 9400
www.cruse.org.uk

Resources for young people
Tel: 0808 8081677
www.rd4u.org.uk

Useful websites

www.terminalillness.co.uk
www.mariecurie.org.uk
www.macmillan.org.uk
www.riprap.org.uk (for young people when parent has cancer)
www.whybother.org.uk (Macmillan's young person's site)

Feedback

We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):

Freephone (City Hospital Campus): 0800 052 1195

Freephone (QMC Campus): 0800 183 0204

From a mobile or abroad: 0115 924 9924 ext 65412 or 62301



Minicom: 0800 183 0204

E-mail: pals@nuh.nhs.uk

Letter: NUH NHS Trust, c/o PALS, Freepost NEA 14614,
Nottingham NG7 1BR

www.nuh.nhs.uk

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is accurate and impartial.