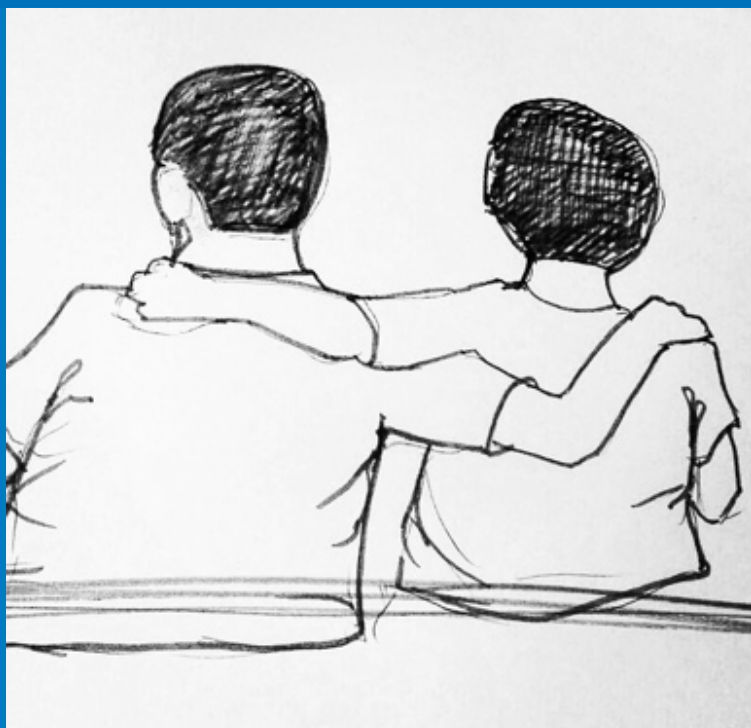




University Hospitals Bristol
NHS Foundation Trust

Staff Information
Trustwide

Supporting a child visiting a seriously ill or dying patient



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Supporting the child of a seriously ill or dying patient

This leaflet has been written for hospital staff and adults who may be supporting a child or children visiting a seriously ill or dying adult. The leaflet is designed to give some general tips and to point those affected to some expert resources.

Introduction

Explaining serious illness or death to a child can be difficult and staff may need support at such times.

Children cope with the news that a parent or someone significant in their lives is seriously ill in a variety of ways such as shock, sadness, anger, indifference or excitement. The way that children react will differ according to their age.

Aim

This leaflet is designed to give you some guidance on how to support the child of a seriously ill or dying adult in hospital.

The leaflet has been laid out using frequently asked questions with guidance and directions to further resources if required.

Should children be encouraged to visit seriously ill or dying patients in hospital?

Whether a child visits a seriously ill or dying patient is a decision for the parents or carers to make. However, ward staff are often asked by the parent or carer for their opinion.

It can be helpful for children to visit to help them to understand the situation, why this person is no longer at home and where they have gone. It may also help them to begin to understand that the person may not come back.

Staff should consider practical issues such as how the patient looks – have they undergone surgery or trauma that has left them looking very different which may be distressing for the child?

The ultimate decision about whether a child visits rests with the parent or carer. No-one can or should force a child to visit a patient.

Who should talk to the children about the patient?

The best person to talk to a child is someone they know and trust. If you are asked to speak to a child, perhaps of an older age, you should ensure they have a parent, relative or carer with them. Ensure you feel you have enough information to be able to speak with the child; you may wish to include a doctor in the conversation. Keep the conversation clear, simple and honest. Do not use euphemisms such as 'gone to sleep' as this may be confusing for the child. The child's age will alter the way you speak with them – see below.

How can I help support children of different ages?

The age of the child will alter the way you speak with them:

0-2 years:

- Serious illness/death is not understood. However, absence of an important adult or new emotional changes in those caring for them will be noticed and may lead to emotional and/or behavioural changes in a baby or child.
- A child may protest loudly at loss (temporary due to hospitalisation or permanent through death), and may search repeatedly for the person who is not present. The child will need comforting and appropriate reassurance throughout this period.

2-5 years:

- The affected child may search for the absent adult and expect them to return. If the adult has died, it may take time for

the child to realise that they are not coming back. It is best to advise keeping to routines and to provide stability and comfort.

- This age group tends to think more 'literally' so careful use of language and avoidance of euphemisms or indirect terms is important. Saying someone has 'gone to sleep' is not truthful and may make them afraid that someone else who goes to sleep may not come back.
- Children may believe that their actions have had an impact or even caused the person's illness or death. Reassurance that this is not the case is important.
- Questions should be answered as simply, honestly, and openly as possible.
- Changes in behaviour may occur such as bladder, bowel or stomach upset, being afraid of new things such as the dark, or children may suffer bouts of emotion such as anger or crying.

5-8 years:

- Children at this age have started to formulate an understanding around death and may ask questions around death and dying if a significant person in their life is seriously ill.
- The child may be preoccupied with thoughts of death and may feel that their actions have in some way contributed to this person being ill or dying.
- Questions around illness and death should be answered openly and honestly in language the child can understand.
- Children may face questions from other children at school – teachers should be informed of the situation so they can

provide support for the child.

8-12 years:

- Communication may become more difficult at this age. Children may exhibit changes in behaviour or feelings of physical pain such as a tummy ache or headache.
- At a time when children start to develop an internal drive to want to become more independent the loss of a significant person may lead them to feel helpless and to emotional instability.
- Children may want to show a 'brave face' but feel lost inside. Allow children time, space and a safe environment to speak about their feelings.
- Children may feel guilty for experiencing periods of happiness. Reassure them this is okay.
- As for younger children, hospital staff involved in any conversations should be open and honest. Resources for giving further expert support should be given where possible.

13-18 years:

- Teenagers may understand death to a greater degree but may not have the emotional maturity to deal with it. They may find it difficult to talk about it to their parents and may seek other 'trusted adults'. Listen to anything these children may wish to discuss, be honest with them around any questions and offer resources to expert guidance that can help them at this time.
- Loss (temporary or permanent) can be frightening for a teenager who is already experiencing the physical and mental changes of adolescence. Emotions can be intense. Reassure

them it is okay to be sad or to cry. They may feel they need 'permission' to express their feelings as they may feel they need to be strong for others.

- Physical activities, sport or new areas of interest may offer an alternative way for adolescents to channel emotions which should be encouraged where possible.

Please see the Barnardo's Child Bereavement booklet for further guidance:

http://www.barnardos.org.uk/child_bereavement_booklet_explaining_death.pdf

Please consider contacting the child's school also to let them know what is going on so they can help support the child while they are at school.

Making memories

Staff may wish to offer children the idea of creating some memories of the patient for example:

- A memory box which contains items that remind the child of the patient
- A collage or photo album

If well enough, the patient may wish to be involved.

Further ideas can be found within the Winston's Wishes website:
<http://www.winstonswish.org.uk/?gclid=CIK7iavpjs0CFYdAGwodCMkNow>

What about after death?

Children may request to see a loved one after they have died. The decision as to whether this is appropriate lies with the parent/carer of the child. Staff should consider any change in appearance or disfigurement in the patient that may cause increased distress. For some children, witnessing the patient after death can help them to understand and accept what has happened and provide some closure.

The viewing of the deceased patient may occur on the ward or in the hospital mortuary viewing room. An adult or carer should accompany any child/children viewing a patient who has died along with a member of staff. Staff need to consider also that the accompanying adult will need support. Further hospital guidance can be found around mortuary viewing and visiting hours here:

<http://connect/ClinicalCare/endoflifecare/Pages/Practicalissuesonward.aspx>

Resources Available in adult ICU:

The following resources are kept in ICU – please ask the nurse in charge if you need one:

- Muddles and Puddles – Work book for children aged 3-9 years approx. Provides practical and sensitive support for children.
- Out of The Blue – For older children aged 10 approx., ideas of how to remember a loved one and how to express thoughts and feelings.
- A Childs Grief – Booklet for adults who are supporting children through bereavement.
- Medi Kidz – A comic booklet endorsed by the Intensive Care Society to explain the Intensive care unit, Aged 6 approx.
- After Someone Dies leaflet – A leaflet about death, bereavement and grief for young people. Aged 12 approx.
- As Big As It Gets- A leaflet for adults to support a child when a parent is seriously ill.

The children's hospital also has information which is more focussed on care after the death of a child but also has more generic information which may be of some help: <http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/parent-support-services/when-your-child-has-died/>

Online resources:

- <http://www.winstonswish.org.uk/?gclid=CIK7iavpjs0CFYdAGwodCMkNow>
- http://www.barnardos.org.uk/child_bereavement_booklet_explaining_death.pdf
- <http://www.whatsyourgrief.com/supporting-grieving-families-tips-rns-nurses/>
- <http://www.griefencounter.org.uk/young-people/>
- <http://www.stchristophers.org.uk/candle>
- <http://www.hospicenet.org/html/parent.html>
- <https://www.mariecurie.org.uk/help/bereaved-family-friends/supporting-grieving-child>
- <http://www.childbereavementuk.org/>

Notes and queries

For access to other patient leaflets and information
please go to the following address:

**[www.uhbristol.nhs.uk/patients-and-visitors/
information-for-patients/](http://www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/)**

Hospital switchboard: 0117 923 0000

Minicom: 0117 934 9869

www.uhbristol.nhs.uk



For an interpreter or signer please contact the
telephone number on your appointment letter.



For this leaflet in large print, audio or PDF format,
please email patientleaflets@uhbristol.nhs.uk.

