**Children and Young People’s**

**Palliative Care Toolkit**

**Chapter Three**

**Palliative Care Educational Information.**

**West Midlands Children and Young People’s   
Palliative Care Toolkit Working Party**

**On Behalf of the**

**West Midlands Paediatric Palliative Care Network**

**A Department of Health Funded Project**



**Table of Contents – Chapter 3**

**When to Use the Toolkit …………………………………………………………………… 4**

**When Should Palliative Care Be Introduced? …………………………………………. 5**

**Together For Short Lives Categories …………………………………………………… 6**

**Multi Agency Care Pathways ……………………………………………………………... 8**

**The Palliative Care Team ………………………………………………………………….. 9**

**Palliative Care Definitions and Terminology …………………………………………....10**

**Respecting Equality, Dignity and Consent to Treatment …………………………….11**

**Record Keeping ……………………………………………………………………………. 13**

**Communication in Palliative Care …………………………………………………….... 14**

**Communicating Complex Information ………………………………………………… 17**

**Communicating about Palliative Care in Learning Disability ……………………….19**

**Emotional and Psychological Needs in Palliative Care …………………………….. 20**

**The Role of Play in supporting children and young people with**

**Palliative care needs – Hospital and Hospice ………………………………………… 31**

**Using Play for Distraction ………………………………………………………………... 34**

**The work of Play Specialists …………………………………………………………….. 36**

**The Role of Play in End of life Care ……………………………………………………. 37**

**BCH Faith Matters Belief Grids …………………………………………………………. 45**

**BCH Faith Matters Pathway ……………………………………………………………… 49**

**Palliative spiritual care: Spiritual Play for Interpretive Spiritual Encounters …... 55**

**Organ and Tissue Donation ……………………………………………………………… 57**

**Verifying and Certifying Death …………………………………………………………... 60**

**What is a Post Mortem Examination? ………………………………………………….. 63**

**When to Use the Toolkit**

The West Midlands Children and Young People’s Palliative Care Toolkit is designed to support palliative care planning and provision wherever and whenever a child requires palliative care. This applies to all stages from the time of diagnosis and or recognition of the condition.

Situations when it may be helpful include when:

* Initial planning is taking place at the time of diagnosis
* A reviewing of best practice approaches to sharing difficult news would

help

* Families need written advice
* Referral to Palliative Care Services is required
* Symptom control issues arise
* Drug doses need to be confirmed
* Reviewing previously received best practice training re palliative care
* Plans around admission and discharge to HDU need to be formed
* End of life care plans need to be written and disseminated
* Informing Ambulance Control of resuscitation decisions
* Informing GP out of hours services of the clinical situation
* A Rapid Discharge from hospital is planned for terminal care at home
* Symptom control drug boxes are required
* Symptom support bags are to be provided
* Information re syringe driver use is required
* Documentation of drugs administered by nursing staff to support

symptom control in palliative care, is required

* Spiritual care needs are to be assessed
* Help is needed to know who to contact for advice re symptom control
* Clarity is required re writing controlled drug prescriptions
* Information is required to take controlled drugs abroad
* Contact details are needed for advice about organ and tissue donation
* Information would support verification and certification of death
* Families need information on what happens when their child dies

It is intended to guide nurses, medical staff (including GPs) and pharmacy staff when a child/young person requires palliative care.

It acts as a resource toolkit which can be supplemented by the owner’s local

information to enhance their access to local palliative care resources

including:

Local contact numbers of teams providing palliative care



Local respite arrangements

Local out of hours staff arrangements and accessibility

Local out of hours pharmacy arrangements

To provide a robust source of locally relevant and regionally approved information for staff to access both in and out of hours.

**When Should Palliative Care Be Introduced?**

Palliative care is often thought of as care at the very end of life. However, living with the threat that you or your child may die from a life limiting or life threatening condition turns the world upside down. These underlying conditions come from a wide spectrum of conditions with differing progressions in both time and manner. Many families find they need support in some aspects by palliative care services at times from the diagnosis onwards. This may be psychological support, symptom control etc. Palliative care offers an active and total approach to the child and families care. It is on this basis that Children’s Palliative Care Services are considered to have significant contributions to offer families with children with life limiting or life threatening conditions, from the time of diagnosis or recognition of the condition.

During the child’s palliative care journey, there are likely to be many challenges, with difficult ethical decisions to resolve and symptom control issues to face, for example. It is helpful for the family if they have had the opportunity to form a relationship of trust with their ‘palliative care team’, before such difficult decisions have to be made. Working through difficulties together in the earlier stages will pave the way for mutual respect in the latter stages, assuring the family that the team have their child’s best interest at the centre of all they advise and offer. It will also provide the opportunity to form a partnership of working together in a manner that enables the family to feel that they will be listened to and respected. Where teams, from different care settings work together well from the beginning, the family are more likely to feel supported by their ‘virtual team’.

Referral to Palliative Care Services can therefore be made at any stage from the time of diagnosis or recognition of the potentially life limiting/life threatening condition. It may be helpful to contact the lead Paediatrician for Palliative Care and the Lead Nurse for Palliative Care within the child’s home location, to discuss what might be able to be offered. Including them in early discussions with the family, pre discharge, will help options to be explored that may benefit the family. Many children benefit from attention to symptom control at a local level and help with practical and nursing care, alongside the active treatment being progressed by their Specialist team. The child’s Specialist in their condition will continue to lead the child’s care, but the shared care with the local palliative care team will offer opportunities for additional, complementary, supportive care closer to home.

***If you are think that palliative care services may be able to help in some way, please contact the lead Palliative Care Paediatrician and or Palliative Care Nurse in your area.***

**Together for Short Lives   
4 Categories of Life Limiting and Life Threatening Conditions**

Together for Short Lives has described the conditions that result in life limiting/life threatening conditions within four broad groups. However, categorisation is not easy and the examples used are not exclusive. Diagnosis is only part of the process, the spectrum of disease, severity of disease and subsequent complications and the impact on the child and family also need to be taken into account. They are useful to ensure that service provision encompasses all families who may require palliative care support. They outline which conditions might be included, and which therefore excluded from palliative care services. Those that are not encompassed by the categories may be better met through provision via other pathways.

The TFSL categories are as follows: **Category 1**

This group includes life-threatening conditions for which curative treatment may be feasible but can fail. Here access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.

Examples: Cancer, irreversible organ failures of heart, liver, kidney.

**Category 2**

This group includes conditions where premature death is inevitable, but where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.

Examples: Cystic fibrosis, Duchenne muscular dystrophy.

**Category 3**

Here progressive conditions without curative treatment options are included, where treatment is exclusively palliative and may commonly extend over many years.

Examples: Batten disease, mucopolysaccharidoses.

**Category 4**

This group includes irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and the possibility of premature death.

Examples: Severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs with a high risk of an unpredictable life-threatening event or episode.

**Integrated Multiagency   
Paediatric Palliative Care Pathways**

Together for Short Lives (previously ACT) has developed a Core Care Pathway for Children with Life-limiting and Life-threatening Conditions (<http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/core_care_pathway>), revised from ACT’s Integrated Multi-agency Care Pathways for Children with Life-limiting and Life-threatening Conditions.  
  
The updated pathway sits alongside Together For Short Lives Perinatal pathway and transitional pathways, to support integrated provision throughout the child’s palliative care journey. These pathways can be accessed at:

www.togetherforshortlives.org.uk.

Each pathway is divided into three stages supporting planning at:

* Stage 1, Diagnosis or Recognition of the condition or of need to move on
* Stage 2, Living with the condition, and
* Stage 3, End of life care phase

The pathways provide a framework from which to plan together with families and teams to provide care appropriate to the assessed needs of the child and family. Whereas the Together for Short Lives categories outline which conditions will be included and excluded from palliative care services, the Pathways outline what issues need to be addressed and which services may need to be provide at any given stage.

Each of the pathways is reproduced on the following pages in their three stages. These can then be applied both locally to a population and also and particularly, specifically to individual children and their families.

Together for Short Lives has also produced a Care Pathway to Support Extubation within a Children’s Palliative Care Framework, in 2011, available on their website: <http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/extubation_care_pathway>

**The Palliative Care Team**

An individual child’s palliative care team will consist of members from many different teams across different care settings from acute to community. These individuals need to work together as a virtual team for the child and family to enable care to appear seamless at the point of delivery,

Access to ***24/7 Children’s Community Nursing services*** forms the bedrock of children’s community palliative care service provision, providing families with choice to be able to receive their care at home where appropriate.

It is also important that local medical support (usually a Paediatrician) is identified to support palliative care provision to an individual child and also to the local population of children and families with palliative care needs.

**Community Based Medical Support to Children’s Palliative Care:**

* Community based medical support, usually a Paediatrician, should be identified to take the lead for palliative care in each locality, whether that be in a geographical locality or a hospice based locality. They will work alongside the child’s specialist and local paediatrician’s, children’s nursing teams, GP, multidisciplinary teams and family to support safe and effective delivery of palliative care in an anticipatory manner.
* It is important that cover arrangements are clear when the lead medical support for palliative care is not available out of hours or during leave. This will involve both a local agreement for access to paediatric medical advice out of hours during leave and also specific plans for individual children within their terminal phase.
* The latter is likely to draw upon support from the child’s specialist teams, local paediatrician’s, General Practitioner, and at times, adult palliative care colleagues.
* It is important that Out of Hours information is logged with Out of Hours primary care services in the terminal phase.

**The Responsibility for Agreeing Home Terminal care:**

The responsibility for recognizing the latter stages of the end of life phase and that a move towards the terminal phase of the condition has been reached lies with the lead consultant for the child. On occasion the lead consultant may not have seen the child recently. At these times the professional visiting the child at home should discuss the case fully with the lead consultant. It is essential that communication with the parents (and child if appropriate) regarding the terminal phase and its management in the home/community will already have been addressed at an earlier stage. Ideally, an Advance Care Plan will have been completed. However a discussion between parents, child (if appropriate) and professional must occur to ensure that all parties remain in agreement.

The following guidelines within the Toolkit are provided therefore to support sound decision making, symptom and medicines management of the highest standard in the home/community. It is essential that users confirm guidelines are up to date and appropriate for the individual child’s situation.

**Palliative Care Definitions and Terminology**

**Palliative Care:**

Together for Short Lives defines palliative care for children and young people with life limiting conditions as an active and total approach to care, from the point of diagnosis or recognition throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Palliative care is underpinned by a philosophy of total, holistic approaches to care.

It is often best applied early in the course of illness in conjunction with other therapies to prolong life (such as chemotherapy and radiotherapy), including investigations to better understand and manage distressing clinical complications (NICE 2004)

**End of Life Care:**

This refers to the period when a child with advanced disease lives with the condition from which they will die. It includes those with any chronic, progressive, eventually fatal illness and could be a period of weeks, months or years.

**Terminal Care:**

This refers to care provided when a child is thought to be in the dying phase and usually refers to the last days or hours of life.

**Respecting Equality, Dignity and Consent to Treatment**

**Equality:**

All public bodies have a statutory duty under the Race Relation (Amendment) Act 2000 to “set out arrangements to assess and consult on how their policies and functions impact on race equality.” This obligation has been increased to include equality and human rights with regard to disability, age and gender.







Individual localities should endeavour to challenge discrimination, promote equality and respect human rights, and aim to design and implement services, guidelines and measures that meet the diverse needs of the service, population and workforce, ensuring that none are placed at a disadvantage over others.

All staff are expected to deliver services and provide care in a manner which respects the individuality of each child/young person and their carers and treats them and members of the workforce fairly and respectfully, regardless of age, gender, race, ethnicity, religion / belief, disability and sexual orientation.

**Dignity:**

|  |  |
| --- | --- |
|  | All staff are expected to ensure that each child and their carers benefit from care that is focused upon respect for the individual. In order to achieve this, the seven factors of best practice from the Essence of Care\* benchmark for privacy and dignity need to be taken into account.  \*The Essence of Care: Patient-focused benchmarking for health care practitioners, Department of Health, 2003 |

**Consent to Examination, Care or Treatment:**

Before beginning an examination, providing care or treatment, staff must ensure that they obtain the consent of the person they are examining, caring for or treating. For consent to be valid, the person must:



Be competent to take the particular decision – it is presumed that adults have capacity to consent unless it is shown otherwise. The Mental Capacity Act 2005 provides a test for assessing whether a person lacks capacity to take a particular decision at a particular time and the steps to be taken if the person lacks capacity. Young people aged 16 and 17 are presumed to have the competence to give consent for themselves. Younger children who understand fully what is involved in the proposed procedure can also give consent (although their parents will ideally be involved). In other cases, someone with parental responsibility must give consent on the child’s behalf.



* Have received sufficient information to make it – this will include information about the benefits and risks, including side effects, of the proposed course of action, the implications of not receiving the examination, care or treatment and alternatives.
* Not be acting under duress – there is a need to balance ensuring that all the child/young person’s concerns are fully identified and addressed whilst not persisting in discussions to such an extent that the person feels harassed. Staff must also be aware of the possibility of undue influence from family or friends.

If the child/young person does not have capacity to consent, decisions must be made in their best interests. The Mental Capacity Act 2005 provides structured and specific tests for capacity and a list of issues to be taken into account when determining what is in a person’s best interests.

For further information, see:

Individual Trust’s policies, procedures and guidelines on consent and the Mental Capacity Act.

Guidance within the Advance Care Plan leaflet for professionals, within the Toolkit.

**Record Keeping**

* Record keeping must comply with individual Trust requirements for record keeping.
* Advance care planning discussions with the child and family and with other professionals must be recorded in the nursing records held in the family home and in a locked cabinet at base.
* All records must be recorded legibly, signed and dated with a print name next to an example signature.

The Palliative Care Toolkit supports best practice documentation. It provides tools to support the documentation at times when:

* Plans around admission to or discharge from HDU are being formulated
* End of life care wishes are discussed and recorded Ambulance Services need informing of resuscitation decisions
* GP Out Of hours services require up to date information Rapid discharge plans and agreements are recorded
* Drugs for nursing administration are prescribed, instructed and reviewed, including as just in case medicines.
* Specific information around the completion of the documents accompanies the main tools, e.g. the Advance Care Plan and are accessible within the Palliative Care Toolkit.

**Communication in Palliative Care**

Communication underpins every element of care. The success of palliative care in every day practice will primarily be determined by the ability to give and receive information and to respond appropriately.

This section cannot equip for every type of conversation that will occur, but aims to outline suggested strategies to follow to help structure the way a situation might be approached.

1. **Breaking Bad News**

Bad news is bad news. You cannot soften the impact, but you can help the person’s adjustment by the way you deliver it. The key is to slow down the speed of transition, for example, for a family hearing that their child has Duchenne Muscular Dystrophy, taking them through from a perception of wellness to the realisation of a life threatening illness

Preparation:

- have all the information you need to hand

- plan enough time/privacy

- involve relative/friend if appropriate

Delivering bad news:

- find out what they already know

- find out what they want to know

- give a warning signal

- break the news using simple/clear language

- pause and wait for response

- assess and focus on their feelings

- encourage them to express their concerns

- check their understanding

- make a plan of action including practical support

Give written information appropriately

**2. Handling Difficult Questions**

There are several strategies to use when families or children ask difficult

questions such as:

* “Is it cancer?”
* “Are they dying?”
* “What is going to happen to me?”

Key actions:

* Find out their perceptions that lead them to ask the question. For example: “What makes you feel it may be cancer or that they are dying?”
* after obtaining a response, repeat the question if necessary by asking if there are any other reasons for them feeling this way if they give no other reason or changes the subject, you might say: “You asked about the diagnosis, is that something you would like to talk about?” if they say “no”, leave it there; they are probably not ready to have the truth confirmed
* if they give other reasons, confirm their thoughts if correct (special consideration will need to be given if this is a child and parents have not yet consented to them having knowledge).Invite them to express their emotions and provide support if appropriate pause to see if they spontaneously raise any concerns. If none are raised then invite them to voice concerns
* address only the concerns the patient raises. Answer realistically and avoid rushing in with premature or false reassurances. Iinvite further questions
* offer to provide information (written or verbal) that may be relevant assure them of continuity of care.

1. **Dealing with Collusion**

Collusion may occur when, for example, parents put pressure on a healthcare professional to withhold medical information from the child or young person.

Key actions:

Initially focus on the parent’s: - feelings

-reasons for not wanting to be truthful

Then acknowledge the:

* parent’s motives, for example wishing to protect the child from distress strain placed on the parent/child relationship by not being truthful parent’s perception of the child understanding.

Then:

* identify any evidence that the child might already suspect the truth.

Then:

* offer to assess the child’s understanding of their illness directly

1. **Dealing with Anger**

Angry parents are difficult to manage. The following strategies help to diffuse anger.

If at any point you feel threatened however you must remove yourself from the situation and refer the incident to your line management.

Key actions:

* acknowledge the anger: “You seem to be very angry”
* invite the parent to explain the cause of the anger: “Can you help me understand what is making you so angry?”

Then:

* listen to their story to get as much information as possible focus on the individual’s stress/feelings
* if appropriate

Then:

|  |  |
| --- | --- |
|  | * clarify the situation if appropriate: “It must be very difficult for you to see your child going through this” * if possible negotiate a mutually acceptable solution. |

Further information on communication in learning difficulties can be found in a toolkit to specifically support these issues, as referred to next in this Palliative Care Toolkit

**Communicating Complex Information**

Giving information is a vital part of the healthcare professional’s role. To ensure that children and families can both absorb and understand complex information it must be tailored to their specific needs. For example:

• Identify and stay with their agenda

• Be logical and organised

• Signpost where the interview is going (warning shot)

• Put complex information into simple language (without being patronising)

• Chunk information into manageable blocks

• Check understanding

• Pick up and explore verbal and non-verbal cues (empathise)

• Acknowledge the impact the information has on them by exploring facts and

feelings

• Give appropriate but not false reassurance

• Summarise and check if they have some further questions

• Arrange appropriate follow up.

**Exploring feelings**

The following techniques can be used to explore feelings such as anxiety:

• Recognition: Non-verbal/verbal evidence

• Acknowledgement: “I can see you are anxious”

• Permission: “It’s OK to be anxious”

• Understanding: “I want to find out what is making you anxious”

• Empathic acceptance: “You are anxious because…”

• Assessment of the severity and effects of anxiety

• Alteration (if appropriate) by removing of stress, cognitive challenge, boosting coping strategies, medication.

For more information in the strategies please contact Nicki Fitzmaurice [nicola.fitzmaurice@bch.nhs.uk](mailto:nicola.fitzmaurice@bch.nhs.uk)

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**Communicating about Palliative Care in Learning Disability**

A toolkit to support children, young people and families where there is a learning disability has also been developed to support communication in palliative care. The toolkit for learning disability is able to be used alongside the West Midlands Children and Young People’s Palliative Care Toolkit to support its use.

This collaborative project (in conjunction with West Midlands Paediatric Palliative Care Network, Birmingham Children’s Hospital, Connected, the National Communication Skills Training Programme, Coventry University and Keele University, Staffordshire) aimed to develop a communication toolkit to help professionals to support children, young people and families where there

is a learning disability, throughout the palliative care journey. It brings   
together examples of existing good practice initiatives but has also developed a range of other tools to support health professionals within the communication process.

The toolkit incorporates a number of informative pamphlets, leaflets, communication assessment formats, cue cards, ‘top tips’ around communicating verbally and when writing clear written information, teaching aids, and a DVD around children young people and families to highlight the challenges but, equally important, to focus upon the potential to enhance the holistic palliative care and support provided to children, young people and families where there is a learning disability.

Ultimately, if health care professionals can work creatively to effectively communicate with this population it will help to empower children, young people and families at a time when they may feel at their most vulnerable. The learning disabilities toolkit was not developed to replace education and training around this sensitive area of area of care, but to complement existing educational opportunities. Similarly, whilst the toolkit may not provide a solution to every challenge within the palliative care setting, it is hoped that it will help professionals to realise their existing potential whilst encouraging them to further explore other possibilities when communicating with children, young people and families where there is a learning disability within this sensitive area of care.

**Emotional and Psychological Needs** **in Palliative Care**

Emotional and psychological support to families and children with palliative care needs is essential. It is often required from diagnosis, sometimes during pregnancy, throughout the child’s life, end of life and beyond into bereavement. Families benefit from being able to access such support at any stage in their child’s journey. Support may be accessed directly from those involved in their day to day care, or where needed, by referral to statutory or voluntary services that provide emotional and psychological support.

It is important that families can talk about any emotional or psychological issues they have in a safe environment. When bad news is given, families often find it difficult to absorb the information and may feel a mixture of emotions, such as anxiety, stress, self-blame, guilt, sadness, worry and helplessness. They may have anticipated the news and/or be devastated at the diagnosis. Their energy is then likely to go into keeping their child as well as possible as they focus on what medical interventions will help. Family dynamics and priorities change as families attempt to cope with juggling hospital appointments, work and caring for their other children. The news may impact on their economic, financial, social, relational, spiritual, emotional and psychological wellbeing. It also impacts significantly upon siblings and family members such as grandparents.

**The Grieving Process**

The grieving process starts as soon as bad news is given; families may experience overwhelming grief with many describing a rollercoaster of emotions. As their child’s condition deteriorates and more bad news is given, parents may become increasingly traumatised. In other cases families or individuals members may remain in denial of a child’s deterioration.

Bad news is bad news, the strategy used to deliver it however can significantly impact on a families coping. Guidance can be found in Section 2 of the Toolkit, Communicating in Palliative Care where other additional strategies are suggested for supporting children and their families.

The diagnosis of a life limited condition will change a family’s life forever.

Their experience may include:

* **Anger, shock and disbelief** at what is happening.
* **Loss of the baby/child they had and the future they had planned for that child**.
* **Frustration, anxiety and worries** around their child and the fear of the child dying. They often finding this hard to vocalise.
* **Parents may have symptoms** **of not sleeping, not eating, being low in mood, exhausted, and feeling guilty**. This in turn can sometimes exacerbate family tensions or underlying mental health issues.

**Why Support Is Important**

Having psychosocial support enables discussion relating to the impact of the illness on family members allowing individuals the opportunity to think about how they are managing their emotions and interacting with others. Exploring with questions relating to who they talk to, how much they share, how they cope, facilitates time and space to reflect and talk about emotions they cannot sometimes share with family members or each other. It may give siblings the opportunity to know that they are not alone in dealing with such a situation and to know that others outside the immediate family are there to support them. Sometimes, through group work, it enables siblings to meet with others experiencing the same problems as themselves, and to feel less isolated. For the ill child, having permission to talk with a trusted person from outside the family unit can facilitate openness about their shortened future in an environment where they need not protect others from the painfulness of considering it.

**Supporting the Family Unit Through Their Journey**

The losses that families experience are manifold and may include losses of role, responsibility and self-worth. Emotional and psychological support at such times aims to reduce isolation and to facilitate communication between partners and family. It involves recalling happy memories whilst accepting the grief experienced in the loss or anticipated loss of their precious child.

The child’s siblings also require specific support in their unique journey as the sibling of a child with a life-limiting condition who may die. The impact upon siblings can be great with emotional, psychosocial and educational consequences. However families who feel well supported often report coming through such difficult times stronger. It is important that sibling’s needs are acknowledged and addressed by generic and where needed, more specialist services in a timely way.

The needs of the young person themselves will change as their journey progresses and as they develop emotionally and cognitively. Such needs should be reviewed regularly and developmentally appropriate, sensitive support offered in a readily accessible manner. This may involve input from within their local team, for example from a play specialist, or access to specialist services. At times specialist input will be needed to manage sudden changes and devastating news. Families would benefit from services being able to respond urgently at such times.

At all times, whether working directly with the child, siblings or parents, it is important that the child’s team works together and communicates well across all care settings to deliver tailored, compassionate care to support the families unique needs. The tangible evidence of teams working together effectively to support their child’s and family’s needs can help to assure families that the very best possible care is being given to them, and that their needs are acknowledged. This can in turn support their emotional and psychological needs at such a difficult time in their lives and help to provide a foundation to support them as they try to move forwards together in their new future.

2-9

**Grieving is a normal response to loss, and families may not require sustained support or specialist intervention. However, some family members will experience abnormal grief reactions, and may require counselling support. Counselling will enable the families to talk about any emotional or psychological issues in a safe and contained environment as well as address their reactions to their complex grief.**

***BEREAVEMENT SUPPORT SERVICES***

***CHILDREN AND FAMILIES/SIBLINGS WITH PALLIATIVE CARE NEEDS***

**CAMHS Services**

CAMHS services may be available in the child’s locality or at the regional centre they attend.

**Services for Adults**

May often be accessed via the GP. This is also relevant where the child has been an only child, affecting opportunity for their parents to access paediatric based services after their death, or where the young person themselves would prefer to have access to adult services.

**Guy’s Gift – offers a service across Warwickshire**

Criteria- work with children age 5-18 years of age who have experienced bereavement.

Contact Number - 08454673035

[Info@guysgift.co.uk](mailto:Info@guysgift.co.uk)

**Footsteps – Worcestershire (Previously Guy’s Footprints)**

Criteria- work with children age 5-18years of age who have experienced bereavement.

Contact Number – 08454676065

[Info@footsteps.co.uk](mailto:Info@footsteps.co.uk)

**Acorns children Hospices- West Midlands**

Criteria; Acorns accepts referrals for children who are life limited and or life threatened and likely to die before their 18th birthday. A range of support will be offered including psychosocial to the whole family including the child, parent’s carers, siblings and extended members of the family.

Contact Numbers

Selly Oak Hospice; 0121 2484850

Walsall Hospice; 01922422500

Worcester Hospice; 01905767676

[www.acorns.org.uk](http://www.acorns.org.uk)

**Donna Louise Hospice- Stoke On Trent**

Criteria; Donna Louise accepts referrals for children who are life limited and or life threatened and likely to die before their 18th birthday in the Stoke, Staffordshire and North Staffordshire region. A range of support will be offered including psychosocial, art therapy and bereavement support to the whole family including the child, parent’s carers, siblings and extended members of the family.

Contact Number- 01782 654440

**Family Counsellor Wolverhampton, West Midlands**

Criteria: Accepts referrals for parents who have a child with life limited/life threatening conditions and palliative care needs. Confidential counselling and psychological/emotional support is offered to parents, siblings and ill child. One to one counselling and family counselling available.

The Royal Wolverhampton Trust

Community Children nursing service,

Gem Centre, Neachells Lane, Wednesfield, WV11 3PG

01902 444700/445783

**Dudley Cancer Support**

Criteria: Offers counselling to parents whose child has cancer.

Regular Bereavement Group Meetings and Counselling Services

The White House

Ednam Road

Dudley

01384 231232

**www.griefnet.org**is an online site – life threatening and end of life resources. Provides online support to those dealing with grief or loss issues on a professional and personal level.

**Kidsaid.org.uk *-*** Midlands-based Charity providing therapeutic support for children and young people who have suffered any form of trauma,ranging from illness, bereavement, domestic violence or abuse and family breakdown. Offers play therapy, art and drama therapy, protective behaviours work and child/adult relationship counselling

01604 630332

**Together for Short Lives**4th Floor  
Bridge House  
48-52 Baldwin Street  
Bristol  
BS1 1QB  
England  
Telephone (General Enquiries): + 44 (0) 117 989 7820

Fax: + 44 (0) 117 929 1999

Email: info@togetherforshortlives.org.uk

National Helpline: 0845 108 2201

[*www.togetherforshortlives.org.uk/*](http://www.togetherforshortlives.org.uk/)

***STILL BIRTHS AND NEONATAL DEATH SOCIETY (SANDS)***

**Miscarriage Association**

Criteria: Any pregnancy loss up to 24 weeks.

Helpline 01924 200799 (Monday – Friday 9.00am – 4.00pm)

General enquiries 01924 200795 (Monday – Friday 9.00am – 4.00pm)

*http//www.miscarriageassociation.org.uk*

# ARC is a national charity which provides non-directive support and information to expectant and bereaved parents throughout and after the antenatal screening and testing process. Was founded in 1988 by bereaved parents to support women and their families before, during and after the antenatal screening process and its outcomes.

ARC Helpline 0845 0772290

0207 713 7486

**BLISS**

National neonatal support group

0500 618 140, Monday – Friday 9-9

**SANDS**

Criteria: Welcome calls from relatives, grandparents, siblings, aunts, uncles, fiends, health care professionals and parents: self-referral.

National Helpline 020 7436 5881 (Monday – Friday 9.30am – 5.30pm)

Fax 020 7436 3715

[www.uk-sands.org](http://www.uk-sands.org)

**Wolverhampton**

SANDS Service in Wolverhampton

07981 704846

**Specialists Midwife Bereavement Service**

To support bereaved families by giving clear unbiased information and the opportunity for open discussion. (Not counselling)

01902 695149/ 07814249255

**Birmingham**

SANDS Group Service Manager

Shrewsbury SANDS – 01743 356109

**Neonatal Deaths Wolverhampton**

Criteria: Accepts referrals of all neonatal deaths and offers emotional support to parents on the neonatal unit when they have received bad news and/or withdrawal of medical treatment is advised/has occurred. Counselling and psychological support available for parent’s together as well as one to one support.

Family Counsellor/Psychotherapists

The Royal Wolverhampton Trust

Community Children Nursing Service

Gem Centre

01902 44700/445783

**Stafford and District Bereavement and Loss Support Service (Counsellor) SDBLSS**

Hours 10.00am – 12.00 noon

150 Weston Rd,

Stafford, ST16 3RU

01785 273768

***DEATH OF A CHILD/SIBLING/PARENT/CARER (WHATEVER THE CAUSE)***

**Beyond the Horizon**

City of Birmingham

[*www.beyondthehorizon.org.uk*](http://www.beyondthehorizon.org.uk/)

*0121 4445454*

**Child Bereavement Charity**

01494 568900

*www.childbereavement.org.uk*

**Childhood Bereavement Network (CBN)**

020 7843 6309

[*http://www.childhoodbereavementnetwork.org.uk*](http://www.childhoodbereavementnetwork.org.uk/)

**Compassionate Friends Helpline**

0345 1232304

Staffordshire and West Midlands area

**Cruse Bereavement Care**

Criteria: Counselling to anyone that has been bereaved

Day by Day helpline 0844 477 9400

Website developed by cruse Bereavement Care’s Youth Involvement Project – which aims to support young people after the death of someone close to them.

16 – 25 year old Male/Female

[*www.cruse.org.uk*](http://www.cruse.org.uk/)

[*www.crusebereavmentcare.org.uk*](http://www.crusebereavmentcare.org.uk)

**Wolverhampton Cruse**

01902 420055

**Dudley Cruse**

01902 420055

**Edward Trust**

Offers counselling to children and parents who are bereaved

43a Calthorpe Road

Edgbaston

Birmingham

B15 1TS

Edward House / 0121 454 1705

[*www.edwardtrust.org.uk*](http://www.edwardtrust.org.uk/)

**RD4U/Youth Bereavement Services (Excellent Website for children)**

Cruse Bereavement Care

PB Box 800

Richmond

Surrey

TW9 1RG

Free phone helpline 0808 808 1677 Monday – Friday 9.30am – 5.00pm

[*info@rd4u.org.uk*](mailto:info@rd4u.org.uk)

[*www.crusecare.org.uk*](http://www.crusecare.org.uk)

**SWINGS**

*Walsall bereavement support service*

*Globe House*

*3 Bradford Place*

*WS1 1PL*

01922 645035 (children referral)

01922 724841 (adult referral)

[*children@wbss.org.uk*](mailto:children@wbss.org.uk)

[*www.wbss.org.uk*](http://www.wbss.org.uk)

**Solihull Bereavement Counselling Service**

Criteria: Charity, Age 6 upwards, referral, one to one counselling, children in school, adults at the centre. £3.00 for assessment if unemployed. £5.00 for assessment if working.

Ullswater House

Solihull Hospital

Lode Lane

Solihull

West Midlands

B91 2JL

Contact: 0121 424 5103

*www.solihullbereavement.org*

**Seasaw grief support for the young in Oxford**

Working with learning disabilities (Children who are bereaved)

General enquiries 01865 744768

[*www.seesaw.org.uk*](http://www.seesaw.org.uk/)

**Winston’s wish**

Charity for bereaved children

Offer practical support and guidance to families, professionals and anyone who is concerned about a grieving child.

National Helpline 08452 030405

[*www.winstonswish.org.uk*](http://www.winstonswish.org.uk)

The Role of Play in supporting children and young people with Palliative care needs. – Hospital and Hospice

So what is Play and why is it important?

“Deprived of play a child is a prisoner, shut off from all that makes life real and

meaningful” (Harvey 1972)

This quote sums up the value of play to me and how important it is to have play facilities on offer in hospitals and other healthcare settings in order to maintain the emotional wellbeing of a child or young person. Most people would define play as children engaging in enjoyable activities. There are lots of definitions as to what play is but it is the predominant occupation of children. Children learn so much from play they develop social, physical, emotional, intellectual and communication skills. Play is an essential part of every child’s development and is even more important for children who experience regular contact with healthcare environments.

An unoccupied child (in hospital) is less likely to be happy than one with interesting things to do. Where play can be organized under skilled supervision it is particularly useful: (Platt 1959, p.25).

Play is central to a child’s development. There are many influential theories concerning play including work by Jean Piaget (1896-1980) and Lev Vygotsky (1896-1934). However, I feel that the most important aspect of play is what’s referred to as ‘normalising’ and ‘child led’ play. This kind of play **anyone can do,** whether you’re a qualified nurse, consultant, general practitioner or student.(Hewitt-Taylor,2008) commented that children with complex and continuing health needs have the same right to pleasure, play and development opportunities and to choose the activities they want to engage in as other children.

Normalising play helps to create a ‘normal’ experience for a child in an abnormal environment. It can help to reduce stress and anxiety and can provide opportunities to release feelings. One of the most important aspects of this kind of play is that it can help to boost a child or young person’s confidence and trust in staff and provides children and young people (yp) with a variety of unstructured play experiences which help to keep them occupied, distracted and both physical and mentally healthy.

So what is normalising play in a hospital, hospice or health care setting?

This is giving poorly children access to familiar activities in an abnormal or strange and sometimes scary environment where anxieties are heightened and where children experience lots of new faces and endure invasive treatments and where they discover strange or unpleasant sights, sounds and smells. The presence of play in these environments helps children to develop coping strategies and allows them to explore and make sense of what is happening around them.

Types of normalising play and suggestions of what to offer?

**Construction play**- building creating models, scenes, towers.

**Board games and games with rules**- monopoly, scrabble, cranium etc.

**Role play and fantasy play**- Hospital play, dressing up, and home corner

**Messy play**- Gloop (mixture of corn flour and water), play dough, sand, water, shaving foam.

**Small world play**- Avengers, Ben 10, monster high, Spiderman, dolls house, dinosaurs.

**Arts and crafts**- Colouring, gluing and sticking, painting, printing, glittering,

**Outdoor play**- physical play, outdoor toys and games, parachute play

**Jigsaw puzzles**-

**Books**- Top gear, teenage magazines, Bliss, Seventeen, Story sacks, tactile books, where’s Wally.

**Sensory play**- TAC PAC’S (tactile approach to communication Pac’s) [www.tacpac.co.uk](http://www.tacpac.co.uk)

Light and sound toys, cause and effect toys, fibre optics, mirrors, bubble tubes, UV play.

**Computer Play**- Ipads, Xbox, PlayStation, DS consoles

Child led play is where the child follows their own play urges and explores, engages and initiates play on their own. The role of the adult in this type of play is to enable and support the child in exploring toys safely and to observe and assess. Observing this type of play it allows the adult to gauge the child’s likes and play preferences and to undertake development assessments and observations where needed for clinical or education contributions.

How to assist the child or young person in playful activities.

The first thing to remember is that the parents and carers are the experts and are a great resource when getting to know their child. They can help you to build a relationship with their child and can give you valuable information with regard to their likes and dislikes and this can be of the upmost importance if their child has limited communication abilities. Another important point to consider is the age and stage of development for the children and yp this will ensure that the activities you offer meet their individual needs. I have included in this section examples of play assessments that we use at the Donna Louise Trust. They are really simple to use and are designed so that anyone can fill them in. They may need to be adapted if you would like to use something similar in a hospital or other health care setting.

A few points to remember:

Take into account the correct positioning of the child which will help to combat any frustrations and will aid their enjoyment. Remember children can play in whatever position they are comfortable in.

Try to ensure that the child or yp feels secure- he/she needs to see friendly faces and hear friendly voices.

Develop any activities that are known to them, music, singing, their favourite toys, favourite TV programmes- this can help immensely when distraction is needed for assisting with pain management or for procedures. You may want to ask how they like to spend their free time or what are their likes and dislikes.

Aim to provide a wide range of sensory activities, bubble tubes, Tac Pac’s, cause and effect toys, switch toys, music, fibre optics- these don’t have to be expensive!!

Consider the child’s or yp’s abilities- assistance to hold items, vision and hearing impairments. Involvement in activities.

Communication- do they use communication aids, P.E.C’s, Makaton, BSL, Switches. However, your communication is very important so ensure that you don’t use jargon and that you consider the language that you use in order to minimise any distress or confusion.

By remembering this information too it can help with any future procedures and can demonstrate care and interest on your behalf.

Using Play for Distraction

One of the most important aspects of a play specialist’s role is distraction; distraction is a simple but powerful technique. Alongside preparing children and yp for procedures, treatments, surgery or possibly end of life, distraction is one of the most successful ways of supporting these children in stressful and sometimes painful situations. The main aim for distraction is to displace pain from the focus of the child or yp’s attention and to replace it with a more pleasurable experience. There are some points to remember and these are

* The value and benefit of distraction lies in it being used appropriately and by no means as a last resort.
* That whatever distraction tool you use it should engage their attention throughout the procedure or until medicinal relief is achieved.
* The timing is also very important because too early and you may run out of steam or lose the child’s attention and started to late it will be of none or very little benefit.
* The general principal behind the techniques are that the more relaxed the child or yp the more the anxiety and sensation of pain is reduced. There are lots of techniques but it is essential to fit the technique to the child or yp, and one thing to remember especially when working with yp is that confidence can be a coping mechanism and that just because they say that they are alright doesn’t mean they will be so always have something prepared just in case.

I would **always** recommend that a qualified play specialist carried out the distraction as they are very skilled members of the team who have a vast knowledge of supporting children and yp in stressful situations. Play specialists can also be excellent at providing guided visualisation for children and yp. This is a skill which requires practise and that the adult needs to be confident in doing this but when done correctly has amazing benefits and is a valuable skill to possess.

If for any reason a play specialist is not present then please **don’t just do nothing**. A familiar face and a reassuring voice can emotionally support the child, but if you feel confident enough here are some suggestions which may help a member of staff to offer distraction support.

Ideas and Techniques

Singing- this is great, try to discover their favourite songs or nursery rhymes.

Jokes- Tell each other jokes and see who can keep their face straight for the longest during the punch line.

Play Games- Eye spy, counting games- these are great as they require a certain degree of concentration especially for younger children who are just learning to count. You can even use things in the room to count, lights, art work, ceiling tiles etc.

Story telling- Story sacks are great especially for children with additional needs. Tactile books for younger children and the ever useful “search for” books, “where’s wally”- lots of others on the internet.

Puppets- You can use disposable gloves, wooden spoons, tongue depressors, whatever you can find. This is a great activity to create a story or to perform a show with for the child during any treatment.

Bubbles- bubbles are great for children especially if you can get them to blow the bubble themselves as it can help to control breathing as well as offer a distraction for counting them or popping them.

Now older children or yp may engage in conversations around their favourite pop stars, music, bands, football teams, pets, hobbies etc. but also having some magazines to hand can also help, top gear, Bliss, wrestling etc.

Sensory equipment is amazing for aiding relaxation and creating calming environments. I would strongly recommend that every health care setting invests in a portable sensory trolley with bubble tubes, fibre optics, projectors, cause and effect toys and music systems because these can be of great benefit for children with more complex health care needs.

The work of Play Specialists

Play specialists in health care settings work as part of a multi-disciplinary team; their work around play is second to none. Play specialist can organise daily activities in the play room or at the bedside for all ages and stages of development. They can provide one to one play sessions around helping children achieve developmental goals, coping strategies for dealing with fear and anxiety, use play to prepare children for hospital stays or for invasive procedures, they can help children to cope with pain, and provide play sessions to assist children and yp in regaining skills lost through the effects of illness or hospitalisation.

The play specialist not only supports the poorly child but can also support the siblings and family as a whole and can offer advice and support for the family on appropriate play for their sick or injured child. They also contribute to clinical judgements through documentation and through their observations. They assist with therapeutic play because in a sense all play especially in hospital is therapeutic in that it is part of the treatment protocol aimed at speedy recovery or rehabilitation. In a hospice therapeutic play is used for pain management and assisting the child or yp to express fears or anxieties.

All children staying in hospital should have daily access to a play specialist. Furthermore the use of play techniques should be used across the multidisciplinary team caring for children…with play specialists taking a lead in modelling techniques that other staff can then adopt (Department of Health 2003, p.140

Play specialists can offer preparation sessions for children and yp and this helps to relieve anxiety and worries, increase the child’s ability to cope, gives them an understanding of their illness and treatment, gives an understanding of what will happen, eliminates any fantasies, misconceptions and the fear of the unknown. It can give them confidence and can aid relaxation, help them to come to terms with their fears and help to reduce emotional trauma. The Platt report (1959) states that the risk of disturbance to the child can be reduced by proper preparation.

The Role of Play in End of life Care

“Care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition.

It enables the supportive and palliative care needs of both child/young person and the family to be identified and met”

(ACT association for children’s palliative care 2008)

There may be times when a play specialist and non-play staff are asked to be involved in the care of a child or young person who is dying. As part of the multidisciplinary team it is important to assess the child’s level of understanding around death and illness, as well as the age and stage of development of the child or young person and develop an understanding the child’s previous experience of loss. This should be done with a clinician who can meet with the child or young person if appropriate and to discuss future wishes with the parents/carers. The main role for a play specialist in this situation is to listen to the child or yp, take into consideration any social, religious cultural or relationship issues, offer reassurance, to be honest and to use play for distraction or pain management purposes. It is important for the whole family to be supported during this emotional time and that the family spend as much quality time with their child as possible. You want to do whatever is right for the child or young person and their family.

The play specialist or non-play staff can facilitate this by:

Making sure the family are as comfortable as possible, assisting them in holding, playing, and reading or touching their child.

Providing hand or foot casts or prints if needed, this is easier if possible to be done whilst the child is alive and can be done as a family group activity.

Providing particular music or DVD’s that the child likes to watch or listen to.

Offering to take family photographs or video footage or giving a camera to family member to do this for themselves.

Seeing if you can facilitate any last wishes the child or family may have.

To provide distraction for pain management or until medicinal relief is obtained.

To provide a plan of techniques and distraction ideas that the play specialist knows have worked previously so that if they are not around other staff will be able to provide continuity of care.

The other things to remember are that older children may want to participate in creating their own memories for their family and they may like to create their own memory box, the items that can be placed in their memory box are really of personal choice, they may wish to write letters, poems, photographs, video recordings, favourite cd’s, clothing, toys etc. The list is really up to the individual.

Children and their families will take many different journeys depending on their own needs and circumstances. The prime intention of the Together for Short Lives pathways is to provide a means for developing essential components that could underpin more detailed and bespoke local pathways. They focus on putting children and families at the centre of a planning process, with the aim of delivering integrated services in response to individual needs.

Together for short lives

We advocate a care pathway approach to delivering care and support to children and families throughout their journey; from diagnosis to end of life and into bereavement. We published the world’s first care pathway for life-limited and life-threatened children, A Care pathway for children with life-threatening and life-limiting conditions in 2004, followed by A Transition care pathway for young people with life-threatening and life-limiting conditions in 2007, A Neonatal Pathway for Babies with Palliative Care Needs in 2009 and A Care Pathway to Support Extubation within a Children’s Palliative Care Framework in 2011. This care pathway approach, now widely adopted across the UK, has helped to improve the family’s journey throughout their child’s life and eventual death.

Our pathways are guided by standards at each different stage of the journey. They aim to improve the provision and consistency of care and support to children and families, and will help provide a clear pathway from diagnosis or recognition, through ongoing care to the child’s end of life and into bereavement. Each standard is then supported by a series of goals, which combine to achieve the standard.

A Standards framework for children's palliative care is available here, setting out the key standards that form the back bone of all four of our care pathways, for easy reference. It also includes self-assessment audit tools relating to these standards, so you and your colleagues can map how your service currently performs and think about how to develop the areas where the standards may not be fully met.

References

Department of Health (2003) National service framework for children and young people and maternity services: standards for hospital services. London: Department of Health.

Hewitt-Taylor (2008) Children with complex and continuing health needs. Jessica Kingsley Publishers.

Platt, H. (1959) The welfare of children in hospital. London HMSO

Save the Children (1989) Hospital: A Deprived Environment for Children? The

**Palliative Play in the Community**

Traditionally children were confined within a hospital for their end of life and palliative care; however with advanced medical technology there is now the option to allow this to take place in the home or hospice. A Community Health Play Specialist is a highly skilled and valued member of a Community Children’s Nursing Team, providing provision of specialised play during the palliative and end of life stage, although not all Community Teams have this provision. Play is well recognised in many sources as a crucial part of helping a child to cope during an illness. Play allows a child’s emotional and psychological need to be addressed and is one of the most effective tools for managing stress. Following the death of a child/young person, the Play specialist will have already formed a therapeutic relationship with the family. This allows for opportunity to talk about shared memories. Stokes (2004) highlights the importance of working with memories. Likening the process to kneading bread, so that in the shared warmth, memories can gently rise to the surface and help in the grieving process.

Written by:

Ange Mckane – Community Play Specialist for Coventry. 07967693615

Liz Lawson – Community Specialised Play Nursery Nurse for Warwickshire. 07813750434

Sian Cullimore –Community Play Specialist for Warwickshire 07710723311

Siân Jackson - Community Play Specialist for Worcestershire. 07789 077 853

Tracey Lole – Community Play Specialist for Warwickshire. 07912082983

* Explore illness and subsequent treatment
* Recognise and acknowledge difficult emotions.
* Practise using coping strategies.
* In their own home
* Model distraction techniques to families
* Develop coping strategies
* Support for patient & siblings
* provide appropriate activities for children and young people, taking into consideration their developmental age & stage of grief
* building on resilience
* Continuing bonds

Community Health Play Specialist

* Safe and familiar adult
* Advocate between children/ Young People and their Parents/ Professionals
* Encouraging families to take ‘time out’ to participate in fun activities
* Encourage day to day living. E.g. extra-curricular activities siblings may normally do
* Charity wishes
* Sign posting
* Understanding children & young person’s behaviours & stages of grief
* Giving parents time to tell their story
* Supporting parents to have difficult conversations with their children
* Supporting parents to communicate about the child/young person that died

The following discusses examples of play used by Health Play Specialists in the Community. This is not an exhaustive list and can be adapted and changed to suit each family’s requirements.

**Pre & Post Bereavement:**

* Manage the patient or siblings perception around illness and treatment, using medical equipment in role play scenario desensitising them to medical equipment they may come across.
* Interactive workbooks may be used for children to record their feelings, memories, wishes or the death from their perspective
* Preparing children and young people for death and funerals, using role play which will involve use of coffins & dolls
* Many families find it helpful to continue a bond with the child or young person who has died; this can be done in a number of ways. For example, salt jars may be made. The jars represent memories using coloured salt layers, each colour relates to a memory of their choice.
* Signifying endings is a helpful way to mark a death of a loved one and/or the end of the therapeutic relationship with a Health Play Specialist. Balloon release or a goodbye letter can be meaningful and visual ways to do this. blockpage[3]

Dyregrov (2008:36) expresses “It can be useful for even young children (from three to four years of age) to go through what has happened, as a help towards making their understanding as complete as possible and as support for their memories at a later stage. This also helps children to clarify and counteract misunderstandings and prevents fantasies."

**Distraction Techniques:**

* Community Health Play Specialists use resources to divert attention away from any procedure a child or young person may find difficult/distressing
* Teaching coping strategies suitable for the child or young person allowing them to make decisions and choices about their procedure, enabling them to transfer these strategies in other medical settings.

**Normalising Play:**

* Encourages families to continue with day to day activities when life is turned upside down, this maintains routine and stability for families.
* Reduces anxiety and distracts their focus from the illness or bereavement
* Charity funding can provide ‘special trips’ giving the opportunity for families to spend time together away from appointments etc.

**Family support:**

* Sign posting
* Health Play Specialists can support families who are observing a range of different behaviours from a child during the grief process. Parents/carers report seeing their children crying and then wanting to play outside with friends shortly after, giving the appearance of forgetting/not understanding the reality of the death.
* Health Play Specialists can help families understand this is normal behaviour in children and young people.

Providing time for families to tell their story is an important part of grieving. It gives permission to openly explore and express their thoughts and feelings “Many parents try to hide their reactions from their children in order to protect them. Our experience is that children are best served with parents who put their feelings into words so that they can better understand why their mother or father is reacting the way he or she is. This also makes it easier for a child to show their feelings and to share their thoughts with their parents” (Dyregrov, 2008:32).

**Friendly face:**

* Health Play Specialists work with children and young people continuously building trust, increasing their ability to cope with procedures and their emotions
* This relationship enables children and young people to direct questions which they do not feel able to ask family members as they may be concerned about upsetting them.
* Children & young people are reassured that Health Play Specialists will not perform any medical procedures

**Illness and understanding treatment**

* Health Play Specialists support children & young people to understand their illness and treatment at an appropriate developmental stage.
* Knowledge and understanding is also provided to siblings
* Providing specialised resources to support activities, these can include adapted dolls which blood may be taken from or medication given to or even making bespoke books or drawing around a child and exploring the body.

**References:**

Dyregrov, A. (2008) *Grief in Young Children: a handbook for adults.* 2nd edition *London: Jessica Kingsley*

Stokes, J. (2004) *Then, now and Always*. Cheltenham*:* Portfolio Publishing

2 - 68

**BCH Faith Matters Belief Grid – 1 BCH Chaplaincy: Rev Paul Nash**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Religion Issues** | **Buddhist** | **Christianity** | **Hinduism** | **Judaism** | **Muslim** | **Sikhism** |
| **Care of the** | May not wish | Offer a Baptism | Any jewellery | May wish to hear | May wish for | The five K’s |
| **dying / End of** | sedatives. | or blessing for | and sacred | Psalm 23 read | reading before | should not be |
| **life** | Family may want wish | the child if this | threads should | and the *Shema.* | death. | removed. |
|  | to wash the body. | has not | not be removed. | The body should | Eyes and mouth | Family will read |
|  | Provide a place and space of peace and quiet. | happened. | Close eyes and  straighten body.  May wish to be | be handled as little as possible. After death close | closed, body straightened, turn head to the | Holy books, there are no priests. |
|  | Some families |  | placed on the | eyes, clothing | right and cover | Music or prayers |
|  | may wish for the |  | floor. | remain and cover | with clean sheet. | may be played. |
|  | body not to be |  | Family may | with sheet then | May wish to face | Close eyes and |
|  | touched for as |  | wish to wash | untouched for a | Mecca (S.E. | straighten body. |
|  | long as possible |  | the body and | short time | direction in UK) | Family may wish |
|  | after the death. |  | wrap it in a | (enquire about | Privacy for family | to wash and |
|  | (Time for the |  | white cloth. | washing). Family | to grieve. | dress the body. |
|  | mind to leave |  | Holy water may | may wish to | Any sacred | If the boy is over |
|  | the body) |  | be applied to | wash body. | jewellery should | 5 or puberty, he |
|  |  |  | the lips. | Some traditions may wish for same gender contact only. | not be removed. Washing has to be in accordance to Islamic faith. | will wear a turban. |
|  |  |  |  | Most traditions may wish for the child not to be left alone. | Families may wish to take the child home with them. |  |
|  |  |  |  | Separate undertakers. | Separate undertakers. |  |

**BCH Faith Matters Belief Grid -2 BCH Chaplaincy: Rev Paul Nash**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Religion Issues** | **Buddhist** | **Christianity** | **Hinduism** | **Judaism** | **Muslim** | **Sikhism** |
| **Visit from the religious leader** | Call a faith representative to facilitate peace and quiet for meditation. | Roman Catholic and some C of E require a Priest for last rites, blessing and or Baptism. | A priest may be required, reading from Holy Books. | Offer a visit from a Rabbi, but reading are normally lead by the family | Offer a visit from an Imam, but prayers are normally led by the family. | Offer a visit from a Priest or Chaplain, but reading can be led by the family |
| **Organ donation** | No religious preference as norm | No religious preference as norm | No main issues | Varied attitudes, referral to rabbi | Varied attitudes (allowed majority) | Varied attitudes, generally ok |
| **Post mortem** | No religious preference as norm | No religious preference as norm | No religious preference as norm | Varied attitudes, some families will be very against it, referral to rabbi. | Not keen | No main issues |
| **Funeral** | Cremation is preferred but will depend on tradition. | No general preference of burial or cremation. | Funeral take places ASAP after death. Children may be buried, adults are cremated. Gift of a toy in the coffin for the child to play with while they | Funeral take places ASAP after death, 24 hours. A “watcher” sits with the body within some traditions. May prefer burial in separate cemetery. | Funeral take places ASAP after death, 24 hours. Always buried. Funeral prayer will be led by the Imam Believe in Paradise or Hell (young children assured of | Always cremated, although babies without teeth maybe buried. mourners sometimes wear white.  Ashes poured into flowing water. |

**BCH Faith Matters Belief Grid -3 BCH Chaplaincy: Rev Paul Nash**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Religion Issues** | **Buddhist** | **Christianity** | **Hinduism** | **Judaism** | **Muslim** | **Sikhism** |
| Funeral cont |  |  | are in heaven awaiting rebirth. Photo candle / religious symbol at home for 12 days after funeral | Mourners do not leave the house. Mourning for a child is 30 days | Paradise and interceding for parents) |  |
| **Beliefs about suffering** | Suffering is universal and is eased by not being selfish | Varied attitudes. Can be fatalistic or angry with God. | Varied attitudes | Varied attitudes | Death is seen as the will of God. Life span of every individual was allocated at the beginning of time.  *Subr* (patience) is highly  encouraged. | Varied attitudes |
| **Belief about the after life** | Believe in rebirth. | Believe in life after death in Heaven or Hell. Infants assured of Heaven in most traditions. | Believe in rebirth. Children enter heaven first. | Believe in life after death in Heaven or Hell. Infants assured of Heaven in most traditions. | Believe in life after death in Heaven or Hell. Infants assured of Heaven and pray for family | Believe in rebirth. |

BCH Faith Matters Belief Grid - 4 BCH Chaplaincy: Rev Paul Nash

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Religion Issues** | **Buddhist** | **Christianity** | **Hinduism** | **Judaism** | **Muslim** | **Sikhism** |
| **Gender** | Adapt to local | No main | Ladies wear | The Orthodox | Segregation at | Eldest son |
|  | culture | differences | Shari at end of life.  Close female relatives only at the crematorium. Gender to gender greeting at home, using holy name of | tradition will prefer same gender care, touch etc. Some traditions do not have women in mourning prayers | the funeral | represents family. Will sit separately at funeral |
|  |  |  | God | (Kaddish) |  |  |

For further information please contact:

Rev Paul Nash Chaplaincy Birmingham Children’s Hospital[**paul.nash@bch.nhs.uk**](mailto:paul.nash@bch.nhs.uk)

Multifaith Care for Sick and Dying children and their families. A multidisciplinary guide. P Nash et al, JKP, 2015

Spiritual care with Sick Children and Young People. P Nash et al, JKP, 2015

**BCH Faith Matters Pathway**

Birmingham Children’s Hospital

Child’s Name: DoB: NHS Number:   
Child’s Faith:

Please consider and complete the relevant key points

**Part 1: Throughout the Palliative Care Journey:**

**Interpreter requirements:**

|  |
| --- |
| **Visit from religious leader request:** |

|  |
| --- |
| **Breaking bad news support:** |

|  |
| --- |
| **Conducive visual space environment:** *Including images that might be offensive and what can be put in place to ensure comfort of the child* |

**Same gender care requirements:**

|  |
| --- |
| **Modesty and clothing requests**: |

|  |
| --- |
| **Personal hygiene**: *Including keeping religious artefacts on the body (e.g. Sikh 5 K’s or Jewish Kippah)* |

|  |
| --- |
| **Diet and food:** *including comments on fasting, vegetarian diets* |

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Part 1 Continued: Faith Matters Pathway

|  |
| --- |
| **Belief about suffering, Death and Dying:** *Including views on the suffering of children and the afterlife* |

|  |
| --- |
| **Religious and spiritual needs:** *In hospital, e.g holy books and prayer (times, resources)* |

**Visitors – family requests:**

|  |
| --- |
| **Life Support – families views:** |

|  |
| --- |
| **Organ donation:** *Views on both receiving and donating* |

|  |
| --- |
| **Post mortems – families views:** |

|  |
| --- |
| **Care in the community - families wishes:** |

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Faith Matters Pathway

**Part 2: The Last 24 hours and Bereavement**

|  |
| --- |
| **Family Wishes:** |

**Preferred place of death:**

|  |
| --- |
| **Inform:** *Which family members should be informed first (religious and cultural rules)* |

**Rituals around the dying**: *End of life prayers, final blessings, last rites/rituals*

.

|  |
| --- |
| **Treatment of the body**: |

|  |
| --- |
| **Rituals, washing, and treatment of the body:** *By whom, do’s and don’ts* |

|  |
| --- |
| **Rapid release:** *In light of religious needs for funeral to take place within a certain time frame.* |

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Part 2 Continued: Faith Matters Pathway

|  |
| --- |
| **Organ and tissue donation:** |

|  |
| --- |
| **Belief about Suffering, Death and Dying:** |

**Large numbers of visitors**:

**Coroners:**

|  |
| --- |
| **Expressions of grief:** *What expressions of grief can be expected (both culturally and religiously)* |

|  |
| --- |
| **Condolences:** *What should be said (or avoided)* |

|  |
| --- |
| **Funeral:** *Where is it likely to take place, who facilitates the service, what is likely to happen* |

|  |
| --- |
| **Burial or Cremation:** *If either a religious requirement, comment here.* |

Part 2 Continued: Faith Matters Pathway

|  |
| --- |
| **Belief about death and the afterlife:** |

|  |
| --- |
| **Parents:** *How best to help parents from a faith perspective. What role does the bereaved parent play?* |

|  |
| --- |
| **Grief and mourning:** *Any religious specific mourning rituals* |

|  |
| --- |
| **Siblings:** *How to comfort a bereaved sibling, views of faith and suffering from a sibling perspective* |

|  |
| --- |
| **Ongoing relationship with the deceased:** |

|  |
| --- |
| **Counselling**: *Would counselling be appropriate? Faith specific?* |

|  |
| --- |
| **How can a person not of this faith help?** |

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**Palliative spiritual care:**

**Spiritual Play for Interpretive Spiritual Encounters:**

**What is an Interpretive Spiritual Encounter?**

At its simplest, an interpretive spiritual encounter (ISE) is an episode of care where a chaplain engages a child in an activity which is designed to function as an assessment tool to identify spiritual needs. It is the participative nature of the encounter that creates and offers time and space for the child to explore safely spiritual needs. The power lies with the child as we seek to gain ongoing consent, let them take the lead, make choices and feel in control of the process. We do this by offering activities which are appropriate to development levels, medical condition, ability and interests. We regularly used this approach in palliative care situations. Activities we most regularly use for an initial assessment are making a bead bracelet where the colours of the beads relate to different qualities; an examen lolly stick doll which the patient creates and uses it to talk about what makes them happy or sad; a blob tree picture where a patient identifies with particular blob people in the picture ([www.blobtree.com](http://www.blobtree.com)). Information on these activities can be found on the Centre for Paediatric Spiritual Care website: www.bch.nhs.uk/cpsc.

**How ISE works for new patients**

Chaplains visit with their own bag of spiritual care activities. The chaplain introduces themselves and offers an activity, usually letting the child choose which one(s) they would like to do. The child is given permission to engage with the activity how they wish including being able to stop at any time. During the activity the chaplain actively listens, watches, and with discernment and permission engages with the child. They invite them to talk about what they have done and why they have done it like that or explore other issues they want to. The chaplain makes an ongoing assessment of spiritual needs based on what is occurring and facilitates discussion around what has been shared and observed. Where appropriate an offer is made to return. Chaplains record what they have done in the patient notes (where protocol) and complete the appropriate record for the department which includes noting future interventions, referrals, concerns and further ISEs to explore.

**Benefits of ISE**

1) Having a clear objective for a visit and being prepared but not prescriptive.

2) Spiritual care is easier to explore than explain in a paediatric context and we found that while engaging in activities children made connections to what was important to them at that time. It is also easier for parents to see what a chaplain is doing.

3) ISE takes seriously personal choice and autonomy and the child is in control which is often an unusual experience in hospital.

4) ISE offers a model for assessment and ongoing assessment but is also an intervention which helps meet spiritual needs.

5) Religious care is possible with ISE as activities can be faith related, for example we have an Islamic version of the bead bracelet exercise and the religious dimension of the examen

doll exercise can be used with Christians.

Spiritual care we have found is easier to “explore than explain” and this model of assessment and intervention can be used by MDT in the care of our patients.

Rev Paul Nash, Senior Chaplain Birmingham Children’s Hospital paul.nash@bch.nhs.uk

*Exploring Spiritual Care with Sick Children and Young People* by Paul Nash, Kathryn Darby and Sally Nash published by Jessica Kingsley and presents ISE in greater detail and includes many activities which can be used in paediatric palliative spiritual care and lots of practice examples including from palliative care settings.

**Organ and Tissue Donation**

Patients and their families may want to know their choices about the donation of organs and tissues for the purpose of transplantation after death. The following information is set out to guide health care professionals when donation is raised for discussion.

Organ Donation

The Kidneys, Liver, Heart, Lungs, Pancreas and Small Bowel can be donated after death for the purpose of transplantation.

A Neonate from 36 weeks gestation, Infant, Child or young person may be able to be an organ donor after death. However, NHS Blood and Transplant (NHSBT) Advisory Groups (for each organ) alongside transplant centres have developed organ specific guidelines where the age and weight of the donor as well as the Donor’s medical history are assessed before acceptance of an organ for transplantation. The Specialist Nurse for Organ Donation (SNOD) will be able to advice on this.

|  |
| --- |
| **A Case Study** [Image result for pride of britain awards 2015](http://www.google.co.uk/url?url=http://www.mirror.co.uk/news/uk-news/pride-britain-award-hero-who-6522900&rct=j&frm=1&q=&esrc=s&sa=U&ved=0ahUKEwiQr5f0hN7KAhUFKA4KHQEbCuk4FBDBbgggMAU&usg=AFQjCNEPG_ife5tNfJKNdhuxmZyK34BtmQ)  ***Teddy Houlston was just 100 minutes old when he became the UK’s youngest organ donor after he died.***  ***Teddy’s mum Jess was just 12 weeks pregnant with twins when she and husband Mike were told that one of them was fatally ill and if born alive would only survive very briefly.***  ***Though doctors offered the couple the option of a termination, Jess said: "We thought that even if we had a moment with him, or 10 minutes, or an hour, that time was the most precious thing that we would ever experience."***  ***As they continued with the pregnancy, the couple decided that they wanted to donate their baby's organs.***  ***Jess said: "Organ donation was something I've always felt quite strongly about ever since I was a child."***  ***The success of the transplant "helped us grieve", she said, adding: "Knowing that he was able to do such good, more good than most of us will ever do in our lifetime - it is just overwhelming how proud we are of him."*** |

Only a small number of patients die in circumstances where they are able to donate their organs for transplantation. All being ventilated and cared for in an acute hospital trust and most dying as a result of a neurological injury where death has either been confirmed by Brain Stem Death Testing (Donation after Brain Stem Death, DBD) or where there has been a decision to withdraw treatment (including ventilation and supportive medication) and death is anticipated imminently following this (Donation after Circulatory Death, DCD).

Patients cannot donate their organs for transplant in the presence of an Absolute Contraindication.

|  |
| --- |
| **Absolute Contraindications to Organ Donation**   * **Age >85 years (on or after their 85th birthday)** * **Primary intra-cerebral lymphoma** * **All secondary intracerebral tumours** * **Any active cancer with evidence of spread outside affected organ within 3 years of donation \*\*** * **Melanoma (except completely excised Stage 1 cancers)** * **Active (not in remission) haematological malignancy (myeloma, lymphoma, leukaemia)** * **Definite, probable or possible case of human transmissible spongiform encephalopathy (TSE),including CJD and vCJD, individuals whose blood relatives have had familial CJD, other** * **Neurodegenerative diseases associated with infectious agents.** * **TB: active and untreated** * **West Nile Virus (WNV) infection#** * **HIV disease (but not HIV infection\*)** * **A history of infection with Ebola virus**   **\*\* The term active cancer has been agreed to identify cancers where there is a probability the cancer will be transmitted to the recipient** |

In addition, there are organ specific contraindications to donation and the SNOD will be able to discuss these with you. It is important to emphasize that a disease of condition may not exclude all organs from being donated, For example, ‘Inborn Errors of Metabolism’ are an absolute contraindication to liver donation but the patient would be able to donate other organs.

It is essential that Health Care Professionals collaborate with the SNOD when considering a patient as an organ donor. An example of good practice where collaboration works well for patients, families and staff who care for them is an early notification or ‘Trigger’ tool which is in place on the Paediatric Intensive Care Unit at Birmingham Children’s Hospital (BCH). The tool ensures consistent and appropriate identification of patients who may be able to be organ donors after their death and ensures early involvement of a SNOD to assess suitability, plan and support an approach to the family and then support the families’ decision.

The tool ensures a conversation about organ donation with a family is always done ‘By the RIGHT People, in the RIGHT Way, at the RIGHT time’

|  |
| --- |
| **BCH Trigger Tool for Referral to the SNOD**  When there is a patient …  Where Brain Stem Death is a likely diagnosis  **Or**  A patient’s active treatment is being withdrawn and death is likely to be imminent after this  **Staff should contact the on call SNOD on air page 07659 137 821** |

**Tissue Donation**

Eye tissue (corneas and sclera), heart tissue (aortic and pulmonary valves and tissue patches), skin, bone and tendons are the tissues that can be donated for transplantation

* Tissue Only donation is coordinated by a Nurse from the National Blood Service (NBS) and is very different from organ donation
* There are many more contraindications to tissue donation than organ donation and therefore it is essential that advice is sought from NBS Nurses regards Tissue donation suitability before offering the choice to a family
* The NBS Nurses do not attend the patient, the facilitation of Tissue donation (including consent) is via the telephone
* Tissues can be donated up to 48hrs hours after the patient’s death
* Tissues are donated from a patient in a clean environment, usually the hospital mortuary

It may be possible for a patient who dies outside of a hospital to donate tissue; however in almost all cases the patient would need to be moved to a hospital mortuary for tissue donation. Please seek advice from the NBS Tissue Nurse.

Contact Information  
The Midlands SNOD Team on Air Page 07659 137 821

NBS Tissue Donation Nurses on Air Page 0800 432 0559

For Contacting other Regional SNOD Teams please call NHS Blood & Transplant on 01179 75 75 75 and ask for the Duty Office

A useful website for further information is

www.odt.nhs.uk

**Verifying and Certifying Death**

When a child dies, they must be both *verified* to have died, and then *certified* as to the cause of their death.

**Verifying a Child’s Death Involves**:

Observing the child for at least 5 minutes to establish irreversible cardio respiratory arrest. This is established by a combination of:

* Confirming that there is no central pulse, eg, carotid or femoral pulse by palpation for at least one full minute
* Confirming that there are no heart sounds by auscultation for at least one full minute
* Confirming that there are no breath sounds heard by - auscultation and no rise and fall of the chest for at least one full minute
* Confirming that pupils are fixed and dilated
* Confirming that there is no response to painful stimuli

In addition:

|  |  |
| --- | --- |
|  | Give adequate time to confirm all of the above, with longer assessment where appropriate. Extra care should be particularly taken when verifying death in neonates. Be thorough!  Any additional related observations may be helpful to note, if, for example, livido reticularis or rigor mortis etc. are evident at that time.  Whilst verifying the child’s death, remember to also examine the child to confirm that there are no visible signs of concern. |

**Remember**:

* This will be a very difficult time for the family. Think how you would wish yourself and a child of yours to be treated at such a time.
* All equipment (syringe pumps, nasogastric tubes etc.) must remain in place until the child has been verified to have died and until no concerns have been raised and the case is confirmed not to need referring to the coroners.
* Explain to the parents what you need to do for legal purposes, before examining the child. It is respectful to ask their permission to do so. Their child should be treated with the utmost respect and dignity throughout the verification.
* Once you have verified that the child has died, confirm this sensitively to the family, and record your findings and time, along with the time the death was said to have occurred.
* If it is *not a coroner’s case* and you are able to complete the medical certificate of the cause of death, confirm with the parents how and when they will receive the certificate.
* All additional supportive information and materials required by the family at this stage in a non-Coroners, non-Rapid Response Enquiry Death, are outlined in the ‘When a Child Dies’ section of the toolkit.

***You must discuss the case with the Child Death Review Paediatrician, and where appropriate, other agencies (Social Care***  ***Police etc) to determine whether any further action is required (Rapid Response Enquiry) or whether the death is considered to have been ‘at the time, in the place, and in the manner’ expected, with no concerns having been identified. You must do this even when the death was expected.***



* ***See the section on ‘The Child Death Review Process’ or***
* [*www.dcsf.org.uk*](http://www.dcsf.org.uk)***.***

If it is possible that this will be a Coroners Case, see below.

**Where a Child’s Death is A Coroners Case:**

Which deaths should be discussed with/reported to the coroner’s office?

A death would be reported to the Coroner if:

* The cause of death appears unknown
* The death occurred within 24 hours of admission to hospital, or when

the child had been brought in dead

* The doctor attending the child did not see them within the last 14 days

before death

* Death was related to injury, however remotely
* Death was not thought to be of natural cause
* Suspected suicide
* Deaths related to suspicious or criminal activity
* Deaths within 24 hours of surgery or anaesthetic, or anytime thereafter

if the death is thought to be related to either.

* Deaths related to industrial disease or poisoning
* Deaths where there is a question of self neglect or neglect by others
* Death from hypothermia, food poisoning, alcoholism, or drug abuse.
* Deaths related to medical mishap if the relatives have criticised medical

care, if related to the cause of death.

-Later deaths in children or young people with previous Birth injuries

* If in doubt, the case should be discussed with the Coroners officer.

It is possible, after discussion with the Coroner’s Office, that the doctor will be

able to complete the medical certificate of cause of death and that no further

action will be required.

*Where the case could possibly be a coroner’s one*:

* The doctor should call the coroner’s office
* Inform the family. (They are unable to refuse the referral).
* The child’s body and surrounding objects should not be touched or moved
* All equipment (syringe pump, nasogastric tube etc.) must stay in place (although the battery can be removed from the syringe driver).
* The coroner’s officers will then lead the ongoing investigation of the child’s death and the care of their body. They will discuss the case with staff and family and will arrange for the child’s body to be transported to hospital (by funeral directors) for a post mortem to be held. The decision re further investigation and issue of the medical certificate of cause of death will then lie with the coroner.

**Certifying a Child’s Death**

Once it has been confirmed that the medical certificate of cause of death can be completed, this should be done so as soon as possible to avoid unnecessary delay for the family. It is only after the medical certificate of cause of death has been issued that the funeral directors and family can proceed with the funeral arrangements.

The doctor who attended the child during the last 14 days of their life will be able to complete the death certificate. If the doctor did not attend the child in this period, then discussion with the coroner will be required first.

The medical certificate of cause of death is:

Legal evidence of the cause of death.



It also provides epidemiological data.

It is important to complete it as thoroughly as possible.

A specimen sample of a medical certificate of cause of death can be seen on the next page. Complete it as follows and indicated on the specimen:

1. Give the full name of the patient

2. Provide the date of death

3. Give the child’s age

4. Enter the place of death

5. Give the date that you last saw the patient *alive.*

6. Depending upon circumstances, circle 1, 2, 3 or 4 and a, b or c.

If a post mortem is being held by the coroner, then you will not be completing the death certificate. However, if the relatives consent to a post mortem, to gain further information about their child’s condition, (‘hospital post mortem’) then 1 or 2 will need to be ‘rung’. See also the section on ‘Post Mortems’ in the Toolkit.

7. The cause of death must be completed as thoroughly as possible. Do   
not give mode of death as a cause, eg, coma, cardiac arrest etc. An example may be:

1. Intracerebral haemorrhage
2. Cerebral metastases
3. Osteosarcoma

8. Sign the form and print your name underneath your signature and add GMC number

9. ‘Residence’ can be completed as hospital or other place of work

10. Complete the counterfoil. On this section only, abbreviations are

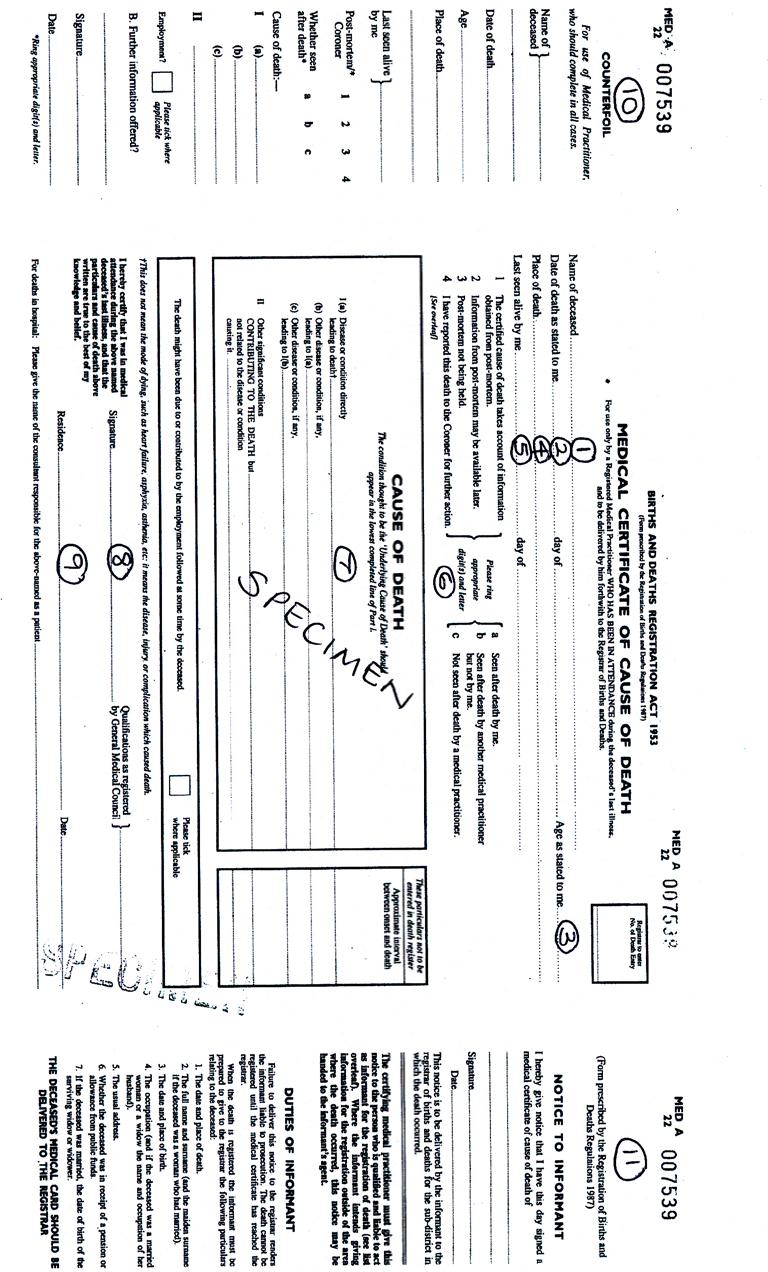
permissible.

11. The ‘Notice to Informants’ is completed and attached to the envelope   
containing the completed medical certificate of cause of death, and given to the relatives. It is important to explain to them, what has been written.

Note, this section must also be read with the section ‘Child Death Review Process’.

Up to date information can be sought at[**www.dh.gov.uk**](http://www.dh.gov.uk)

Specimen Medical Certificate of Cause of Death



**What is a Post Mortem Examination?**

A post mortem examination is an examination of a person’s body after death. An examination for a baby or child would be carried out by a consultant pathologist often at Birmingham Children’s Hospital or Birmingham Women’s Hospital if the child is a small baby or at the mortuary close to the Coroner’s Office. The purpose of the post mortem examination is to gain further information about the cause of death.

There are two types of post mortem examination:

**Consented –** This is an examination, which can be either requested by the child’s parents or by the Consultant caring for the child, in order to find more information about the child’s illness, when the cause of death is already known. This can only be done with the parents’ full permission and the parents have choices about the extent of the examination on what happens to any tissue samples.

**Coroner’s –** This is an examination ordered by HM Coroner, when the cause of death is unknown or the child’s death is unexpected, and as such becomes a legal requirement, so the parent’s consent is not required. Parents will have choices about what can happen to any tissues taken during this examination once the Coroner’s purposes are complete.

**An examination after death can do the following:** Help to confirm the cause of death

Show other diseases or conditions that may have been present but may not have been obvious at the time

Assess the effectiveness of treatment and medication given, such as radiotherapy and chemotherapy for cancer

In some cases it may help with the planning of future pregnancies

Help to answer questions about potential health problems that may run in the family

Help to answer questions that the parents may have in the future

By law the **Coroner** can order a post mortem examination to be undertaken. There are 3 main reasons why the Coroner may do this. They are:

1. If the child’s death was sudden and unexpected
2. The doctor caring for the child is unable to provide a cause death

|  |  |
| --- | --- |
|  | 1. The child’s death was the result of an accident or unusual circumstance (including deaths following a medical procedure such as surgery) |

**Consent for a Post Mortem Examination**

Consent for a consented post mortem examination can only be taken by professionals who have had specific training in taking consent for the procedure. The Laws which apply to the treatment of a child after death are contained within the **Human Tissues Act 2004.** The consent forms for a Consented Post Mortem Examination are specific forms and families must be fully informed about the nature of the post mortem examination and give full consent about how tissue samples and biopsies are treated after the examination. The Pathologist performing the examination must also be involved in the consent procedure. The consent is recorded on specific consent forms and parents must be given written information about the examination to fully explain the procedure.

**Coroner’s Post Mortem Examination**

The Coroner may order a post mortem examination without the parents’ consent. The process of informing the parents about the examination is undertaken by the Coroner’s Officer who has specific training informing families about what will happen. A Coroner’s Post Mortem examination may happen at a Hospital or at a mortuary close to the Coroner’s Offices. Once the Coroner has completed his investigation the parents can chose what happens to any tissue samples taken during the examination.

**How do Parents Get the Results of the Examination? Consented Post Mortems**

If the parents have consented to an examination, then they will be offered an appointment with the Consultant who was in charge of the child’s care, approximately six to eight weeks after the examination. The report will be available for this meeting, and the findings and any implications will be discussed with the parents and family.

**Coroner’s Post Mortems**

If the Coroner has ordered the examination, the results will be given to the family via the Coroner’s office. The parents will also be offered an appointment to discuss the findings with their Consultant as well. However the parents should be aware that the Coroner’s permission will be required for this meeting, and he may not allow the meeting to take place until after the inquest is complete.