Suffolk Safeguarding Children Board

# CDOP

# Child and Family Hopes and Wishes Management Plan

SCB Adopted: July 2010

Version Number: 1

Advance care planning for children with life-threatening and life-limiting conditions and their families is possible months or years before the end of life. Advance decisions evolve over time through the development of trusting relationships and an ethos of shared decision making.*

This document is offered as a *guide,* in response to family needs and requests. These are difficult but necessary discussions and this guidance is offered to support the process. Staff should not feel under pressure to complete every aspect of the form by a certain time or at one sitting, but be **led by the needs of the family** as to which parts need to be discussed or reviewed – with whom, where and at what time.

Health staff should aim to offer all families an opportunity to talk about end of life issues such as their concerns, hopes or wishes, but with the awareness that in some cases, families will not want to take this up, or may need more time before they are ready to do so.

**Begin by asking yourself the following questions:**

- Would you be surprised if this child died within a year?
- Would you be surprised if this child died during this episode of care?
- Do you know what the child's and family's hopes and wishes are for the end of life?

**If the answer to any of the above questions is "No", this guidance is relevant.**

**The next steps are to:**

- Find out who else is involved in the care of the child and family, e.g. is there a CCN service? Who is the Lead Professional? Specialist Practitioner? Consultant Paediatrician?
- Find out if the child and family have already discussed an End of Life and/or resuscitation plan.

(Prompt to family: *'has anyone had a discussion with you about what you would like to happen if your child becomes seriously ill?*')

If the family already has a plan, you may wish to review it with them, to ensure that it is still relevant or to update it if required. If there is no plan, you can use **any or all** of the following 5 sections to document the discussions using the templates, and the suggestions in the table below, as a guide.

Pages 4 and 5 can be used as a 'stand alone' document to confirm with the child's lead medical practitioner what treatment options are required should the child become unwell or during an acute life-threatening event.

* *Ref: L. Brook et al (2008) A Plan for Living and a Plan for Dying: Advanced Care Planning for Children; Arch Dis Child 2008; 93 (suppl): A61-A66*

| | Child | Family | Significant Others e.g. school friends |
|---|---|---|---|
| 1. Hopes and wishes during life | e.g. Special holiday, having a make-over, visit to the sea-side | e.g. Family Holiday | |
| 2. Plans for when your child becomes unwell | e.g. treatment options | e.g. what happens, place of care, what is not wanted | e.g. visiting, or wish for home schooling |
| 3. Plans for care during acute life-threatening event | e.g. preferred place of care | e.g. treatment options | |
| 4. Hopes and wishes around the time of death | e.g. preferred place of death | e.g. preferred place and care at death | |
| 5. Care after death | e.g. funeral wishes | e.g. spiritual and cultural wishes, bereavement support planning | |

**After discussion with the family, please ensure that a copy of the plan is included in the care records and record that a copy is given to the family, the child's GP and all other relevant services.**

**Index of Sections**

| SECTION 1 | HOPES AND WISHES DURING LIFE |
|---|---|

| **Name:** | **Date of Birth:** |
|---|---|

| **Child's or Young Person's hopes and wishes during life:** |
|---|
| **Family (including siblings) hopes and wishes during life:** |
| **Others' hopes and wishes during life:** (e.g. school friends) |

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| SECTION 2 | PLANS FOR WHEN CHILD BECOMES MORE UNWELL |
|---|---|

| **Name:** | **Date of Birth:** |
|---|---|

**What may happen?**
e.g. deteriorating mobility, feeding, cognitive function, worsening seizures

**Preferred place for care:**

**Preferred treatment options:** (indicate if not applicable or inappropriate)

- **Antibiotics - e.g. Oral / IV / 'Portacath'** ☐ Not Applicable ☐ Inappropriate
- **Feeding - e.g. NG tube / gastrostomy** ☐ Not Applicable ☐ Inappropriate
- **Fluids Management – e.g. IV / SC** ☐ Not Applicable ☐ Inappropriate
- **Respiratory Support - e.g. mask ventilation** ☐ Not Applicable ☐ Inappropriate
- **Seizure Management Plan** ☐ Not Applicable ☐ Inappropriate

**If child deteriorates further, preference(s) for place of death and persons present:**

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| SECTION 3 | PLANS FOR CARE DURING AN ACUTE LIFE THREATENING EVENT |
|---|---|

| Name: | Date of Birth: |
|---|---|

| | YES | NO |
|---|---|---|
| Oxygen via face mask/nasal cannulae | ☐ | ☐ |
| Airway management using oral/nasopharyngeal airway and suction | ☐ | ☐ |
| Bag and mask ventilation | ☐ | ☐ |
| Endotracheal tube and ventilation | ☐ | ☐ |
| External cardiac compressions | ☐ | ☐ |
| Defibrillation and adrenaline | ☐ | ☐ |
| Advanced life support requiring PICU admission (including inotropic drugs and advanced renal replacement therapy) | ☐ | ☐ |

| **Please give further details if required:** |
|---|
| **Other issues discussed:** |

**If child deteriorates further, preference(s) for place of death and persons present:**

Signature (Lead Medical Practitioner):

Name:

Date:

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## SECTION 4 AROUND THE TIME OF DEATH

## SECTION 4.1 FAMILY HOPES AND WISHES

| **Name:** | **Date of Birth:** |
|---|---|

**Information needs**

What is the preferred place of care for end of life care?

Where would the family like the body to be cared for after death?

**Practical Support on Day of Death**

During end of life care

Support for the family on the day of death

Support needs up to the funeral

**Memories/Keepsakes**

**Organ Donation**

**Contact numbers for Support Agencies**

(Continued on next page)

## SECTION 4.1 FAMILY HOPES AND WISHES (Continued)

| **Name:** | **Date of Birth:** |
|---|---|

**Spiritual/Cultural wishes**

**Funeral Plans** (Seek detailed information or further advice is needed)

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| SECTION 4.2 CHILD/YOUNG PERSON'S HOPES AND WISHES |
|---|

| Name: | Date of Birth: |
|---|---|

| What are your hopes and wishes for care at the time of death? |
|---|
| What is your preferred place of care? |
| Memories/keepsakes |
| Organ donation |
| Spiritual/Cultural issues |
| Funeral Plans |
| Special Friends to be included |

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## SECTION 4.2 CHILD/YOUNG PERSON HOPES AND WISHES (Cont)

| |
|---|
| **What are the CYP's main health and symptom care needs?**<br><br>*Review nursing care plans or end of life care (48hrs) as applicable.* |
| **Who will prescribe medication?** |
| **How will drugs be available out of hours?** |
| **Will the GP/Medical Practitioner/Lead Health Professional visit regularly? How often?** |
| **What clinical management plans are needed?** |

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## SECTION 4.3 EQUIPMENT NEEDS

| Name: | Date of Birth: |
|---|---|

| Equipment Needs | Professional or Agency Responsible | Date Delivered/Received |
|---|---|---|
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## SECTION 4.4 END OF LIFE CARE TEAM

| Name: | Date of Birth: |
|---|---|

| Role | Name and contact details |
|---|---|
| Lead Professional (co-ordination) | |
| Nursing support – M-F 9-5 | |
| Nursing support – out of hours | |
| Medical advice – M-F 9-5 | |
| Medical advice – out of hours | |
| Specialist symptom control link | |
| Psychological Support | |
| Spiritual Support | |
| Equipment – aids | |
| Short break care – at home | |
| Short break care – residential | |
| Other Agencies/Organisations able to provide support | |
| | |
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## SECTION 4.5 SHARING INFORMATION WITH OTHER SERVICES

| **Name:** | **Date of Birth:** |
|---|---|

| Service | Name and contact details | Date contacted |
|---|---|---|
| Ambulance | | |
| A&E and Acute Paediatric Team | | |
| CCN Team | | |
| GP out of hours | | |
| Child's own GP | | |
| Health Visitor | | |
| School | | |
| Social Worker | | |
| District Nurse | | |
| Local Pharmacist | | |
| Designated Pediatrician for sudden death | | |
| Coroner's Office | | |
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Please list other services which should have information about CYP's condition.

| SECTION 5 | CARE AFTER DEATH |
|---|---|

| Name: | Date of Birth: |
|---|---|

| |
|---|
| Choice of place of care (Re confirm choice of place of care (e.g. hospice, home, funeral parlour)) |
| Family wishes for room preparation |
| Is an air conditioning unit required? |
| Arrangements for laying out of the body (e.g. where, who, position, clothes to wear, possessions) |
| Certification of death – is an application for cremation form required? (If so a confirmatory medical certificate is also required) |
| Arrangements for visitors and visiting |
| Family members resident at the Hospice |
| Confirmation of funeral date and plans |
| Changes to body discussed with family (outline what and to whom) |
| Organ/tissue donation (if applicable) |

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| SECTION 5.1 | CHECKLIST FOR PREPARING THE ROOM FOR CARE OF THE BODY AFTER DEATH |
|---|---|

| Name: | Date of Birth: |
|---|---|

| Task | Date | Signature when completed |
|---|---|---|
| Close windows | | |
| Ensure fly screens are fully closed | | |
| Draw curtains<br>(in summer or when the sun will warm the room) | | |
| Turn radiator/heating system off | | |
| Put air conditioning on – lowest temperature | | |
| Put the known sign/symbol in the hospice entrance | | |
| Offer to parents e.g.:<br>• Placing fresh flowers<br>• Soft toy – age appropriate<br>• CD player<br>• Moses basket | | |
| Family requests (please list): | | |
| Comfortable chairs | | |
| Box of tissues | | |

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## SECTION 5.2 CHECKLIST FOR MEMORY MAKING

| **Name:** | **Date of Birth:** |
|---|---|

| Activity Requested (tick) | Completed (date and sign) | Given to: |
|---|---|---|
| Memory box ☐ | | |
| Hand prints ☐ | | |
| Foot prints ☐ | | |
| Lock of hair ☐ | | |
| Plaster casts ☐ | | |
| Photographs ☐ | | |
| Others – please list | | |
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