**West Midlands**

**Children and Young People’s**

**Palliative Care Toolkit**

**Chapter One**

**Documents for Discharge for End of Life Care.**

**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**



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**West midlands CYPACP printable version.**

First Produced April 2011, Last Updated April 2018

Please see the Together For Short Lives website [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk) for annually updated versions   
and replace contents of the Toolkit with the most up to date version.

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and replace the contents of the Toolkit with the most up to date version.

Please complete the table below, sign and date when updated versions have   
been inserted into the folder.

It is the responsibility of all staff using the Toolkit to ensure that information   
used is the most up to date available.

|  |  |  |
| --- | --- | --- |
| Year | Date Contents  Updated | Signature |
| 2012 |  |  |
| 2013 |  |  |
| 2014 |  |  |
| 2015 |  |  |
| 2016 |  |  |
| 2017 |  |  |
| 2018 |  |  |
| 2019 |  |  |



**Dedication**

This Toolkit is dedicated,   
with love and grateful thanks, to the very many   
children and their families, including

*Amanda, Charlie-Ann, Jack, Jacob,   
Jordan, Libby & Sharlotte*,

who have touched our lives and changed us.   
It has been a privilege to be able to be a part of your journeys.   
Your strength, courage and determination has   
moved us, inspired us, informed us, directed us and provided a   
lasting legacy to support the care of other children,   
through all that you have so generously shared with us.

*We will always remember you and be grateful to have known you.*

*Thank you*



**The West Midlands Children and Young People’s   
Palliative Care Toolkit Steering Group**

The group who developed this Toolkit sat as the Clinical Subgroup of the West Midlands Paediatric Palliative Care Network.

Its membership was drawn from all sectors involved in the delivery and support of clinical paediatric palliative care across the West Midlands.

The group consisted of:

Angela Thompson Palliative Care Lead Paediatrician, NHS Coventry

& Warwickshire, Chair of Steering Group

Fiona Reynolds Deputy Chief Medical Officer,

Birmingham Children's NHS Foundation Trust, Vice Chair of Steering Group

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Claire Thomas Consultant Paediatrician Wolverhampton City PCT

Maybelle Wallis Consultant Paediatrician, Sandwell/W Birmingham

Abbie Wood Paediatric Sister Wolverhampton

Wider consultation included that of the:

|  |  |
| --- | --- |
|  | * West Midlands Paediatric Palliative Care Network membership Children’s Community Nursing Teams West Midlands * Macmillan Nursing Teams, Birmingham Children's NHS Foundation Trust * Paediatricians, West Midlands * Policy Leads, Medicines Managers and Drugs and Therapeutic Committees from within the West Midlands. |

Thanks also go especially to:

* Adam Field, Senior Graphic Designer, Design Department, Birmingham Children’s Hospital for his support in the development of the Toolkit, and to
* Martin English, Consultant Oncologist BCH for support with the Drugs and Therapeutics Committee input,
* Sir Alan Craft, Emeritus Professor, for his encouragement and Foreword
* Lizzie Chambers, Chief Executive Officer, TFSL for agreeing to host the Toolkit and its future updates at [**www.togetherforshortlives.org.uk**](http://www.togetherforshortlives.org.uk)
* The Department of Health for its funding of the Toolkit development.

Reviewed March 2018 by

Dr Mark Hunter

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Dr Sarah Thompson

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Sue Davies

Claire Mooney

Rachael Williams

Carol Farrell.

**Foreword**

This “Toolkit” marks a real step change in the delivery of palliative care to children. It should enable current best practice to be available to children, young people, and their families wherever they may be.

When I undertook a study in the 1990s to identify the problems faced by children with life limiting disease we entitled it ‘*Families of Misfortune’*. Since then there has been enormous progress in our understanding of the needs of children and young people and in how we can help all to make the best of life whilst they are living. Living well, dying well is a concept which can become a reality when the right people work together with a common understanding and a clear focus on what is best for the child.

This manual contains an absolute cornucopia of practical help to enable the best of care to be delivered. It covers all ages from newborn to young adult life and is based on symptoms and needs rather than any particular diagnoses. It has been developed by a wide variety of professionals from all care settings who have a real understanding of the issues and practical experience of delivering the best care.

It will be in every setting where it could be of value and can be used by any of the many disciplines who are vital for the successful care of these children and their families.

It is the culmination of more than a decade of developing partnership working across the West Midlands which has been led by a group of dedicated professionals who care passionately about this group of families.

It is not an end in itself and is in a format which will allow for regular updating as and when new developments need to be brought into practice.

It has been produced in the West Midlands for the families of the West Midlands but I confidently expect to see it rapidly percolating across regional boundaries.

All who will benefit from this new development are indeed fortunate as this toolkit will ensure that we really can help all to make the very best of the limited life that they have left.



Sir Alan Craft

Emeritus Professor of Child Health

Newcastle

University

February 2011

**Background to the Palliative Care Toolkit**

I am delighted to see this West Midlands Children and Young People’s Palliative Care Toolkit come together. The idea for the Toolkit grew out of the recognition that common and agreed resources, tools and documentation, around children’s palliative care, would support best practice, safe and effective, individualised and responsive care for the families and children within the West Midlands. The vision was to develop the tools and resources and to collate them into a readily available practical Toolkit, so that they could be accessed whatever the care setting or whatever the time of day or night that care was required.

In particular, its aim was to improve the experience of care for all those families within the West Midlands who find themselves in the difficult position of requiring access to children’s palliative care services.

A Clinical Subgroup was therefore established to explore the possibility of developing such a resource and the Toolkit was subsequently able to be produced as a Department of Health Funded project.

The Toolkit therefore exists to support families in their unique journeys, by equipping staff with resources that will be readily available at their fingertips to facilitate best practice, timely care. Children and their families are central to the whole Toolkit. The Toolkit is in itself a reflection of all that the families and their children have so generously shared with us over the years as we have listened to families needs and planned and delivered care together with them, for each of their individual and unique journeys, as they have loved and cared for their precious children. As one Mum shared with to me today, *‘My little boy deserved the very best’*. Thankfully, she felt that was her experience. The Toolkit aims to help this to be families experience in all settings, at all times, so that they can live their lives as fully and well as possible, and with special memories of their time with their child, even though that time is always too short.

Where available, the resources draw upon nationally recognised, researched and recommended sources. Where national guidance does not yet exist on a particular aspect of care, the guidelines support staff in collectively documenting and delivering what is currently considered best practice within the field of paediatric palliative care and paediatrics within the West Midlands.

The Steering Group included lead clinicians from within paediatric and palliative medicine, nursing, pharmacy and chaplaincy from community, hospice, local hospitals and the regional children’s hospital, spanning paediatric intensive care to community. It has been a privilege to Chair a Steering Group from such diverse clinical care settings, where all were focused upon overcoming barriers and reaching common agreement in best practice care for the good of our families and their children.

The Steering Group continues to meet and to reflect changes in knowledge around best practice and the new insight we have gained from families, within annually updated versions of the Toolkit. Annual updates of the Toolkit are available on the [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk):

*It is important to note therefore that guidance changes over time. Drugs and dosages should be carefully checked to ensure that they remain appropriate both in general and in an individual child’s specific circumstances.*

It is prescriber’s responsibility therefore to check that information is up to date and to take account of factors that will influence drugs and dosages – weight, age, other medications and their interactions, complications such as liver, renal and haematological disease in the child. Factors such as susceptibility to respiratory depression in degenerative neurological problems should be considered. Paediatric palliative care supports the care of children with a wide spectrum of conditions, necessitating careful consideration of aspects pertinent to that particular condition and its presentation in an individual child.

The information within this document will become relevant to the care of some families who have trudged a long, winding and difficult path to this point. Others will have arrived at this point shell shocked following a short and aggressive period of deterioration. All will have arrived at a place they never wished to reach. Some will have had time to make thoughtful plans that deserve our respect and time to listen to and consider with them. Others will need support to begin to consider choices and make decisions that will have far reaching implications for the family long after the palliative care team have ceased their input to the family. It is hoped that this Toolkit will go some way to improving our care of families as best practice is collectively sought, revised and agreed within the Midlands.



Dr Angela Thompson, Chair of the Steering Group

Palliative Care Lead Paediatrician Coventry & Warwickshire

**Discharge For End of Life Care.**.

**End of Life Care Drug Box Contents Guide – Oncology Conditions:**

When a child is to receive their end of life care in the community, it is important that the appropriate drugs that may be required to support that child’s symptom control are readily available if needed, both in and out of hours. These drugs are prescribed in quantities to cover commencement over a weekend (+/- bank holiday) if needed, and are then replenished in the community as needed. They are known as the contents of the ‘Drug box’ or ‘Blue box’, and often as their ‘just in case medicines’. Children will not require all the following as contents of their drug boxes. However, the drugs that they may require in end of life care in oncology conditions are more likely to be drawn from within the following list. It can be used as a template to agree appropriate drugs to prescribe for an individual child, according to their presenting and anticipated symptoms.

|  |  |  |  |
| --- | --- | --- | --- |
| **Drug approved name** | **Generic name** | **Strength** | **Quantity** |
|  | Eurax |  | 1 x 30g. |
|  | Valoid | 50mg. in 1ml. | 1 x 5 |
|  |  | 25mg. | 1 x 12 |
|  |  | **10mg.** | **1 x 5** |
|  |  | **30mg.** | **1 x 5** |
|  | Stesolid Rectal Tubes | 2.5mg. | 1 x 5 |
|  | Stesolid Rectal Tubes | 5mg. | 1 x 5 |
|  |  | 1g. (Infant) | 1 x 12 |
| Glycerin suppositories |  | 2g. (Child) | 1 x 12 |
| Haloperidol |  | 5mg. in 1ml. | 1 x 10 |
| Heparin | Canusal | 100 units in 1ml | 1 x 10 |
| Hyoscine patch |  | 1.5mg. | 1 x 2 |
| Lidocaine | EMLA | 2.5% cream | 3 x 5g |
| Levomepromazine | Nozinan | 25mg. in 1ml. | 1 x 10 |
| Midazolam, injection | Hypnovel | 10mg. in 2ml. | 1 x 10 |
| Midazolam, buccal |  | 10mg in 1ml | 1 x 5ml |
| Morphine oral solution | Oramorph | 10mg/5ml | 1x 100ml |
| Ondansetron | Zofran | 4mg. in 2ml. | 1 x 5 |
| Relaxit enema |  |  | 4 |
| Sodium Chloride |  | 0.9% | 4 x 10ml. |
| Tetracaine | Ametop | 4% cream | 3 x 5g |
| Urokinase | Syner-kinase | 10,000 units | 1 |
| Water for Injection |  |  | 4 x 10ml. |

In addition, Tranexamic acid should be considered, along with hyoscine for

|  |
| --- |
| Crotamiton Cream |
| Cyclizine |
| Cyclizine suppositories |
| **Diamorphine.** |
| **Diamorphine.** |
| Diazepam. |
| Diazepam. |
| Glycerin suppositories |

infusion or glycopyrronium.

**End of Life Care Drug Box Contents Guide – Non oncology Conditions:**

When a child is to receive their end of life care in the community, it is important that the appropriate drugs that may be required to support that child’s symptom control are readily available if needed, both in and out of hours. These drugs are prescribed in quantities to cover commencement over a weekend (+/- bank holiday) if needed, and are then replenished in the community as needed. They are known as the contents of the ‘Drug box’ or ‘Blue box’, and often as their ‘just in case medicines’. Children will not require all the following as contents of their drug boxes. However, the drugs that they may require in end of life care in non-oncology conditions are more likely to be drawn from within the following list. It can be used as a template to agree appropriate drugs to prescribe for an individual child, according to their presenting and anticipated symptoms.

|  |  |  |  |
| --- | --- | --- | --- |
| **Drug approved name** | **Generic name** | **Strength** | **Quantity** |
| **Diamorphine.** |  | **10mg.** | **1 x 5** |
| **Diamorphine.** |  | **30mg.** | **1 x 5** |
| Diazepam. | Stesolid Rectal Tubes | 2.5mg. | 1 x 5 |
| Diazepam. | Stesolid Rectal Tubes | 5mg. | 1 x 5 |
| Glycerin suppositories |  | 1g. (Infant) | 1 x 12 |
| Glycerin suppositories |  | 2g. (Child) | 1 x 12 |
| Hyoscine injection |  | 400 [microgram.in](http://microgram.in) 1ml. | 1 x 10 |
| Hyoscine patch |  | 1.5mg. | 1 x 2 |
| Lidocaine | EMLA | 2.5% cream | 3 x 5g |
| Levomepromazine | Nozinan | 25mg. in 1ml. | 1 x 10 |
| Midazolam, injection | Hypnovel | 10mg. in 2ml. | 1 x 10 |
| Midazolam, buccal |  | 10mg in 1ml | 1 x 5ml |
| Morphine oral solution | Oramorph | 10mg/5ml | 1x 100ml |
| Relaxit enema |  |  | 4 |
| Sodium Chloride |  | 0.9% | 4 x 10ml. |
| Tetracaine | Ametop | 4% cream | 3 x 5g |
| Water for Injection |  |  | 4 x 10ml. |

In addition, glycopyrronium and phenobarbitone should be considered.

Where the child is a **neonate** please consider access to drug concentrations (eg morphine) and formulations (eg, omeprazole) that may be required as special orders. Where possible the neonate should be discharged from the neonatal units with the relevant concentrations. In particular, consider making available oral morphine sulphate solution 2mg in 5ml.

**Symptom Care Flow Sheet Aide-mémoire**

Name : NHS Number: Date/time:

|  |  |  |
| --- | --- | --- |
| Appearance:  Distress:  Pain:  Sleep Pattern:  Communication:  Conscious Level:  Convulsions:  Breathing:  Colour:  Cough:  Secretions:  Feeding:  Appetite:  Vomiting:  Mouth:  Abdominal Pain:  Bowels:  Urinary Output:  Posture/Movement:  Sensation:  Skin: | Same Better Worse Well Unwell Ill  Nil Mild Moderate Severe  Controlled Some Breakthrough Uncontrolled  Normal Changed  Normal Fluctuating Deteriorating  Normal Reduced  N/A Controlled Uncontrolled  Normal Abnormal  Normal Pale Mottled Cyanosed Flushed  Nil Occasional Frequent Unable to cough  Normal Productive  Nil Orally Oral Tube Fed  Normal Increased Decreased  Nil Nausea Occasional Frequent  Moist Dry Sore  Nil Occasional Frequent Distention  <1 2 3 4 >5  Continent Incontinent Dysuria Retention Catheter  Good Volume < than usual >than usual  Normal Reduced Spasm  Reduced Normal Hypersensitive  Dry Normal Sore Itchy Oedema  Intact / Broken Risk Assessment Yes/No |  |

**The ‘Core 4’ Group of Symptoms and Drugs in Terminal Care**

A range of drugs are available to support symptom control in the final days of life. However it is likely that only a small number will be required to control the most common symptoms as the last days of life approach. These symptoms and drugs can be thought of as the ‘Core 4’ group. It is wise to become very familiar with all aspects of the use of the most commonly used drugs, moving to use other drugs where indicated in the individual child as needed. If the use of these additional drugs is not as familiar to you, then advice on their use should be sought immediately. Where discharging a child, it is wise to check on the receiving teams’ usual practice in symptom control.

**What are the ‘Core 4’ Group of Symptoms & Drugs?**

The child’s drug management will often have been rationalised and reduced in the final days. Symptoms most commonly requiring support will include Pain, Nausea and Vomiting, Terminal Agitation/Seizures and Secretions. As the end of life approaches, medication may need to be given as a 24 hour continuous infusion by syringe driver, although the need for this should always be assessed and patients only transferred from existing treatment if clinically indicated. Often, only one or two drugs will be required in the syringe driver although more may be used as necessary provided that in-solution compatibility permits. The drugs discussed below may be given in combination in solution via syringe driver, although it should be recognised that compatibility should always be confirmed, and may be limited as the number of drugs and their concentration in solution increases. Hyoscine, is usually given transdermally, rather than via syringe driver.

**Pain**

*Diamorphine* is indicated for opiate-responsive pain. Due to its solubility it will be the opiate of choice for administration via syringe driver for children whose pain has previously been well managed with oral, rectal, transdermal or sublingual opiate preparations.

The dose via syringe pump should be based on that previously delivered by other drugs and routes, taking account of the effect of relative potency of both the drugs and routes of administration. Ensure that any increased doses are assessed as being necessary and appropriate.

Breakthrough analgesia should be prescribed. It should be available in the most appropriate formulation and at a dose that reflects the dose delivered via the syringe driver and the potency of the ‘breakthrough opiate’ relative to that of Diamorphine.

Remember to still consider using non-opioid drugs such as paracetamol, or, eg, NSAID for their beneficial combined effect with opiates in neuropathic pain or adjuvant non-opioid analgesics such as anticonvulsants where appropriate and not contraindicated.

See APPM Drug Formulary (Chapter 1) and Algorithms sections (Chapter 2) of the West Midlands Children and Young Peoples’ Palliative Care Toolkit and the BNF for Children.

**Nausea and Vomiting**

*Levomepromazine* is a very useful second line antiemetic when first line treatment has been ineffective. It is however, often considered as *first* choice rather than cyclizine in the terminal care setting. This is due to its broad spectrum of action, allowing it to be effective for nausea and vomiting resulting from all common triggers. This makes it particularly useful when the nausea and vomiting may have several, or unidentified, triggers in what is often complex morbidity in the final days.

Its potential sedative and anticholinergic effects must be considered.

Doses and indications are outlined in the drug doses and algorithms sections (Chapter 2) of the West Midlands Children and Young Peoples’ Palliative Care Toolkit and BNF for Children.

**Terminal Agitation and Seizures**

*Midazolam* is well recognised as being helpful in managing seizures. It will often be selected to add to the syringe pump when a child has required two doses of buccal midazolam within 24 hours for unremitting seizures, and those doses have had good effect.

It is also helpful in persistent agitation in the terminal stages. In such situations its dose range is lower than for the management of seizures.

Its potential to cause sedation must be considered, both alone and in the light of the other drugs the child is receiving.

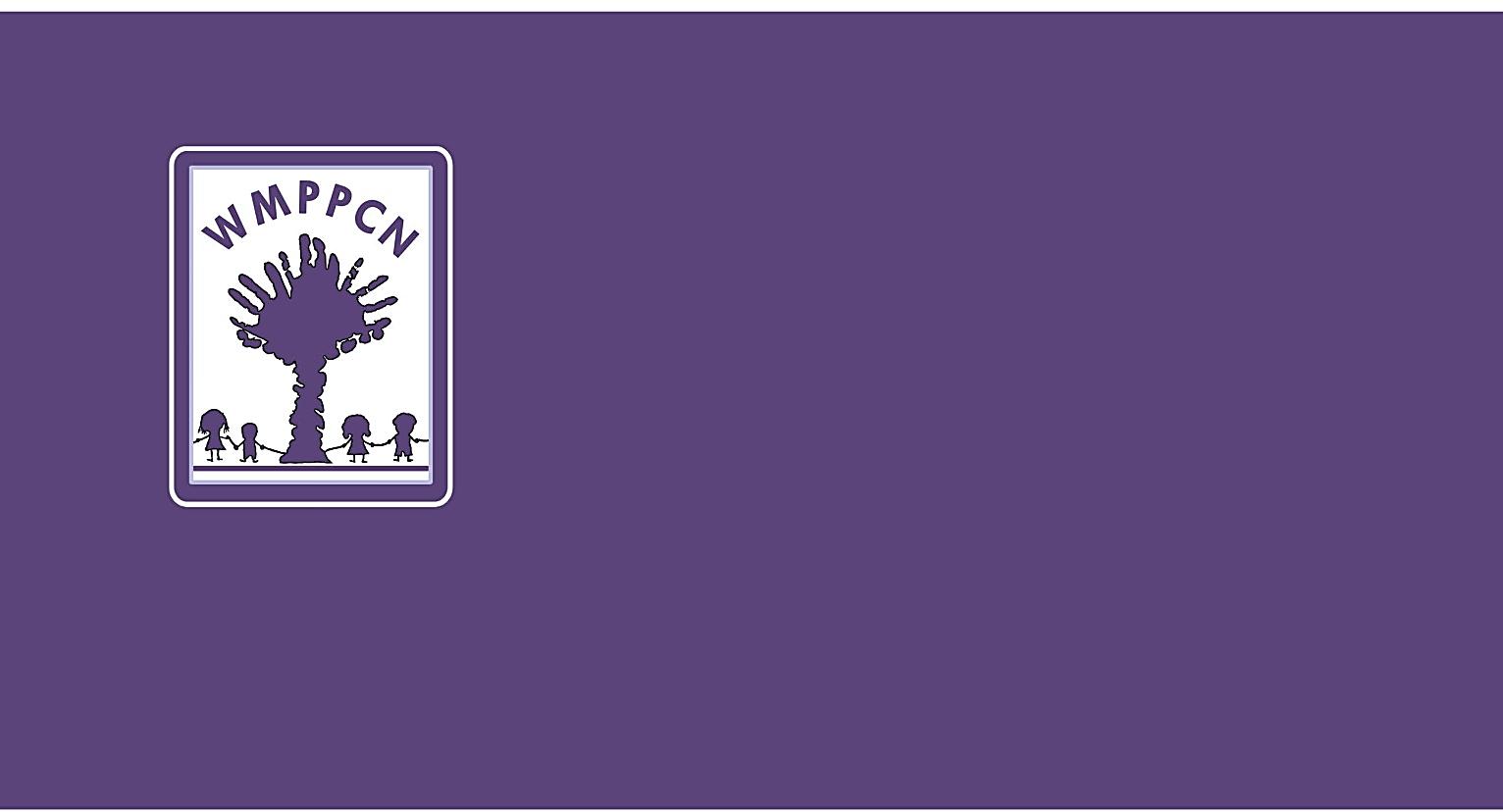
Doses and indications are outlined in the drug doses and algorithms sections of the West Midlands Children and Young Peoples’ Palliative Care Toolkit and BNF for Children.

Please refer to the APPM 2017 for up to date dosages. This can be accessed at www.togetherforshortlives.org.uk.

**Rapid Discharge Check List**

Tick Box

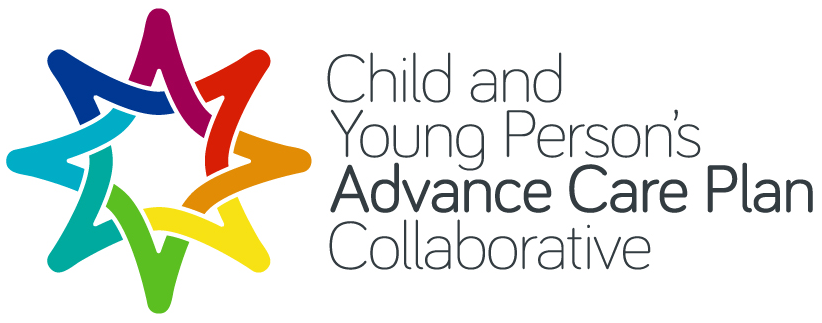
|  |  |
| --- | --- |
| Has a referral to service been actioned? |  |
| Risk assessment of address/Safeguarding issues? |  |
| Registered with GP |  |
| Home visit arrange GP for day discharged |  |
| Discussion with GP regarding management to request they inform out of hours and complete special notes document |  |
| Meet parents child/young person to discuss service and ensure choice is given around place of care |  |
| Families wishes around sharing information with extended family, extended family support |  |
| Meeting with lead consultant/staff facility discharge |  |
| Anticipatory medications / TTOS or just incase box |  |
| Anticipatory medications prescriptions to administer with incremental doses and indications |  |
| Understanding of symptom management issues, such as what is expected to happen on disease pathway document. |  |
| Has feeding been considered/absorption |  |
| Routine medication plan |  |
| Completion of Rapid discharge or advance care plan (ACP) |  |
| Who to contact in emergency (if nurses require advice out of hours) named lead consultant |  |
| Completion of basic assessment and oncall information |  |
| Appropriate equipment/oxygen obtained |  |
| Any necessary teaching actioned for patient/staff |  |
| Consider who will provide death certificate plan in place if not GP |  |
| Safe transportation to chosen address, action needed if death in transit occurs |  |
| Other siblings needs – liaison with schools informing them of current situation |  |
| Emotion needs of the family |  |
| Written and verbal guidelines on contacting service in and out of hours |  |
| **Completed by:** |  |

****

|  |  |
| --- | --- |
| NHS Organisation: |  |

|  |
| --- |
| **ALLERGIES** |
|  |

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Name |  | | | | DOB: | |  |
| Address |  | | | | | | |
|  | | | | | | |
|  | | | Post code: | | |  |
| Hospital No. |  | NHS No. |  | | | Date: |  |





Collaborators: Alder Hey Children’s Hospital, Dorset County Hospital, Gloucestershire Hospitals NHS Foundation Trust, Helen & Douglas House Hospices, Kent & Medway C&YP Palliative Care Network, Naomi House & Jacksplace, North Hampshire NHS Trust, North West Children’s Palliative Care Network, Oxford University Hospitals NHS Trust, Poole Hospital, Portsmouth Hospitals NHS Trust, Royal Berkshire NHS Foundation Trust, Royal Manchester Children’s Hospital, Solent NHS Trust, Southampton Children’s Hospital, St Mary’s Hospital Isle of Wight, Together for Short Lives, West Midlands Paediatric Palliative Care Network

**Child and Young Person’s Advance Care Plan**

This document is a tool for discussing and communicating the wishes of a child, young person, parent(s) and/or their family. The plan is also designed to record the wishes of families for their baby (neonate or infant).

In addition to recording a concise record of the advance plans it is designed to provide a rapid overview, of key decisions, to the attending carers, should an emergency situation arise when the individual cannot give informed consent for themselves and / or next of kin / parent(s) cannot be contacted.

It is a collaborative document with representation including the South Central and Wessex, West Midlands, North West, Kent and the South West for shared decision making between families and clinicians.

Child & Young Person’s Advance Care Plan (CYPACP)

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**Contacts**

|  |  |  |  |
| --- | --- | --- | --- |
| Name |  | Date of Birth |  |
| Known as |  | Interpreter needed |  |
| First Language |  | Interpreter contact |  |
| Home Address |  | | |
|  | | |
|  | Postcode: |  |
| Telephone Numbers: |  | | |

|  |  |  |
| --- | --- | --- |
| **Family Tree** | | |
|  | | |
| **Name of person/people with parental responsibility (and address if different from above):** | | |
|  | | |
| **Emergency contact number for person/s with parental responsibility:** | | |
|  | | |
| Other emergency contact No. |  | |
| **Others** (e.g. family and friends) | | |
| Name | Relationship | Telephone numbers |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
| ­­**Emergency contact for professional who knows child:** | | |
|  | | |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **For use** please tick [x] | Everywhere | Home | School | Hospital |

|  |  |  |  |
| --- | --- | --- | --- |
| **Date Plan Initiated** |  | **Date Review due** |  |

|  |  |  |
| --- | --- | --- |
| Date reviewed/ amended: | Name & title of lead reviewer | Expected review date (if appropriate) |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

**Wishes during Life**

|  |
| --- |
| **WISHES DURING LIFE** |
| **Child’s / Young Person’s wishes** e.g. Place of care, symptom management, people to be involved (professional/non-professional), activities to be continued (spiritual and cultural). |
|  |
| **Family wishes** e.g. Where you want to be as a family, who you would like to be involved  (e.g. medical, spiritual or cultural backgrounds). |
|  |
| **Others’ wishes** (e.g. school friends, siblings) |
|  |

|  |  |
| --- | --- |
| This page discussed by: |  |
| **Child /Young Person / Parent / Carer**  Professional (full name and job title/ initials)  (Initials only may be used if this page is filled out by the lead clinician) |  |
| Date: |  |

**Diagnosis and Decision Making**

|  |
| --- |
| **Diagnosis** |
|  |
| **Main problems and Background information** |
|  |
| **Social issues**  (Include if Looked after Child) |
|  |

|  |  |  |
| --- | --- | --- |
| **Decision Making Process**  **Basis of discussion / decision-making?** (Tick as appropriate) [X] | | |
|  | Wishes of child/young person with capacity | |
|  | Wishes of parent(s) for child on “best interests” basis | |
|  | Best interests basis (as in Mental Capacity Act 2005) | |
|  | Other (please state) |  |
| **Comment** | | |
|  | | |

**Specific Treatment Plans**

**(Prompt: allergies recorded on Front Cover)**

|  |  |  |  |
| --- | --- | --- | --- |
| **Management of seizures** *(Please select one option only)* | | **Date of Weight** | **Weight (Kg)** |
|  |  |  |  |
|  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **Personalised Seizure plan:** (drug name, dose and route) please add patient weight used to calculate drug doses | | | |
| First Line |  | after | mins |
| Second Line |  | after further | mins |
| Third Line |  | after further | mins |

|  |  |  |
| --- | --- | --- |
| Call **999** for emergency transfer to hospital? | |  |
| If yes, at what stage |  | |
| Description of usual seizure pattern/ types |  | |
| Other instructions for seizures |  | |

|  |
| --- |
| **Management of infection**  This section is for community use and may involve instructions to transfer to hospital.  Contact specialist team and microbiology  Please record if likely to be neutropaenic or have an immune deficiency  Preferred antibiotic or regime for recurrent infections – drug dose, route, duration: |
|  |
| **Instructions for other specific circumstances** |
|  |

|  |  |  |  |
| --- | --- | --- | --- |
| Name | Signature | Professional Role | Date |
|  |  |  |  |

**Management of a Life Threatening Event**

**Prompt: allergies recorded on Front Cover**

|  |
| --- |
| **Symptoms and signs to expect** (NB Information about diagnosis is on p6) |
|  |

|  |
| --- |
| In the event of a likely *reversible* cause for acute life-threatening deterioration such as **choking, tracheostomy blockage or anaphylaxis please intervene and treat actively.** Please also treat the following possible problems actively e.g. bleeding **(please state):** |
|  |
| A life threatening event may lead to a cardiac or respiratory arrest (cardiorespiratory arrest). If p15 has not been completed, decisions about resuscitation would normally be made on a ‘best interests’ basis. The presumption would normally be for attempted resuscitation initially unless this seemed futile, unlikely to be successful, not in best interests, or otherwise directed. |

|  |  |  |
| --- | --- | --- |
| **In the event of life threatening event** (Add comments to clarify wishes) | | |
| **🗸** | Support transfer to preferred place of care if possible |  |
| **🗸** | Maintain comfort and symptom management, and support child / young person and family |  |
| **🗸** | Clear upper airway / mouthcare |  |

|  |  |
| --- | --- |
|  | |
|  | Facemask oxygen if available. |
|  | Bag and mask ventilation. |
|  | Emergency transfer to hospital if considered appropriate. |
|  | Intravenous access or Intraosseous access. |
|  | Non-invasive ventilation. |
|  | Intubation. |
| **Comments about feeds and fluids** | |
|  | |
| **Other (please state):** (e.g. may include specific information if a life threatening emergency happens at school) | |
|  | |

|  |  |  |  |
| --- | --- | --- | --- |
| Name | Signature | Professional Role | Date |
|  |  |  |  |

**Wishes during End of Life**

|  |
| --- |
| **WISHES AROUND THE END OF LIFE** |
| **Priorities of care including preferred place for care of child /young person** |
|  |
| **Spiritual and cultural wishes** |
|  |
| **Other child/ young person & family wishes, e.g. what happens to possessions?** |
|  |
| **Organ & tissue donation** (see separate guidance on web link <http://www.organdonation.nhs.uk>)  National contact number**s**. 0300 123 2323  Regional contact numbers. |
|  |
| **Funeral preferences**  Seek detailed information or further advice if needed |
|  |
|  |

|  |  |  |
| --- | --- | --- |
| This page has been discussed with child / young person/ parent/ carer: | Professional:  (full name and job title/initials) | Date |
|  |  |  |
|  | | |
| If page not completed please comment on reasons | | |
|  | | |
|  | | |

**Signature Page**

Note the signatures apply to pages 4 - 9 only

**Who has agreed and supports the plan?**

(Doctors must add GMC number after the signature)

|  |
| --- |
| **Lead Clinician** |
| Name |  | | |
| Professional Registration Number |  | Role: |  |
| Signature |  | Date: |  |

|  |  |  |
| --- | --- | --- |
| **Others included in the decision making.** (also see p 14) | | |
|  | | |
| **Young Person**  (if appropriate; optional) (to ensure their opinions have been included in the decision making) | | |
| Name | Signature | Date |
|  |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Person/ Persons with parental responsibility (see page 4)**  (to ensure their opinions have been included in the decision making) | | | | |
| Name | | Signature | Role | Date |
| 1 |  |  |  |  |
| 2 |  |  |  |  |
| 3 |  |  |  |  |
| 4 |  |  |  |  |
| Other | | | | |
| 1 |  |  |  |  |
| 2 |  |  |  |  |
| 3 |  |  |  |  |

**Clinicians have a duty to act in a patient’s best interests at all times.**

If a parent or legal guardian is present at the time of their child’s collapse, they may wish to deviate from the previously agreed plan and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child/ young person. The child/young person or parents /guardian can change their mind about any of the preferences on the care plan at any time.

|  |
| --- |
| **Additional Notes** |
|  |

|  |
| --- |
| **Additional Notes** |
|  |

**Distribution List (Key Contacts)**

|  |  |
| --- | --- |
| The co-ordinator is responsible for the distribution of the CYPACP, for bringing it to the attention of professionals, and for circulating any updates to it: | |
| Name of Co-ordinator | Contact Details |
|  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **24 hour contact number available:** (record p14) | | |  | |
| **NB: The child and family will hold a full copy of their plan**  **A full photocopy of the plan to:** (include date sent and by whom) | | | | |
|  | | Name and contact details | | Date sent and by whom |
|  | Local Emergency Department |  | |  |
|  | Children’s Community Nursing Team |  | |  |
|  | Hospice |  | |  |
|  | Lead Paediatrician  (refer to p14 for specialists involved) |  | |  |
|  | GP |  | |  |
|  | Other |  | |  |
|  | Other |  | |  |

**Other professionals who require either a full photocopy, or need to be made aware that the child has a plan (please state which):**

|  |  |  |  |
| --- | --- | --- | --- |
| Full photocopy=  Aware of plan= | FP /  A | Name and contact details | Date sent and by whom |
| Hospital (ward or assessment unit) |  |  |  |
| Respite /Short Break Care provider |  |  |  |
| GP Out of Hours |  |  |  |
| Ambulance Control |  | CAD Admin  West Midlands Ambulance Service  Waterfront Business Park, Waterfront Way, Brierley Hill, DY5 1LX  Secure Email cad.admin@nhs.net  Tel: 01384 246475 |  |
| School Nurse |  |  |  |
| School |  |  |  |
| Transition |  |  |  |
| Social Services |  |  |  |
| Other  (e.g. CDOP, Coroner, or EOL Register) |  |  |  |
| Other (e.g. Hospital Specialists see p14 for contact details; list specialties only here) |  |  |  |

**If the child / young person dies** (Urgent Contact List)

**(Please contact the following people)**

|  |  |  |  |
| --- | --- | --- | --- |
| Co-ordinator responsible for the distribution of the CYPACP and bringing to the attention of professionals that the child has a plan. | | | |
|  | | | |
| **24 hour contact number available:** |  | **Phone No.** |  |

|  |  |  |
| --- | --- | --- |
|  | | Name and contact details |
|  | Parents/Guardians |  |
|  | General Practitioner |  |
|  | Lead Paediatrician |  |
|  | Hospice |  |
|  | Organ and Tissue Donation team |  |
|  | Other (Rapid Response Team) |  |
|  | Other (ED/ Childrens Ward) |  |
|  | Other |  |
|  | Other |  |

|  |
| --- |
| **Other professionals who have either a full photocopy (FP), or are aware (A) that the child has a plan** (please see page 13 and below).  **NB Where multiple hospital specialists are involved in care it is the responsibility of the lead paediatrician/ lead clinician to inform them of the death; please list names and speciality below and name of person who will inform them.** |
|  |

**Management of Cardiorespiratory Arrest**

**(Including DNACPR)\* \*Delete if not appropriate**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Child’s Name** | |  | **NHS No.** |  |
|  | **Cardiopulmonary Resuscitation status (CPR) has not been discussed**  attempt CPR unless clearly not in the best interest of the child/ young person (Only a senior clinician may make this decision) | | | |
|  | **Cardiopulmonary Resuscitation status has been discussed and the following has been agreed:** | | | |
| Diagnosis and reason(s) for decision (also see p6) | | | | |
|  | | | | |
| Ambulance Directive | | | | |
|  | | | | |

Clearly strike through unused boxes in dark ink as appropriate (only 1 box to be active)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Attempt full Cardiopulmonary Resuscitation**  OR |  | **Attempt Cardiopulmonary Resuscitation with modifications below:**  OR | | |  | **DO NOT attempt**  **Cardiopulmonary Resuscitation DNACPR** |
|  |  |  | | |  |  |
| Attempt CPR as per Resuscitation Council (UK) guidelines.  - - - - - - - - - - - - - - |  | INTUBATION |  |  |  | **DNACPR**  Patient-specific supportive care is documented on pages 7, 8 and 9  - - - - - - -- - - - - - - - |
|  | AIRWAY AND BREATHING |  | |  |
|  | CIRCULATION |  | |  |
|  | PICU |  |  |  |
|  |  | | |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **Clinician**  (usually lead clinician) | | **2nd Clinician**  (2nd Signature may be required if lead clinician has not signed above and countersigns at a later date) | |
| Clinician Name |  | Clinician Name |  |
| Professional Role/ Grade |  | Professional Role/ Grade |  |
| GMC/ (NMC) No. |  | GMC/ (NMC) No. |  |
| Signature |  | Signature |  |
| Date |  | Date |  |

www.cypacp.nhs.uk

**Version 1.1**

**Review date: December 2018**

**Please note exceeding this date does not invalidate the information contained in this proforma.**

**However this version should not be used to record a new CYPACP after this date.**

****

Policy

Child and Young Person’s

Advance Care Plan

A unified collaborative approach

This document is intended as a template for local policy for centres using the Child and Young Person’s ACP (CYPACP) forms

In the interests of safety, portability and clarity please ensure that any deviations from the content of the template, will not have the potential to result in an unintended interpretation of the plan.

The legislation, guidance and hyperlinks are up to date at the time or writing but it is the responsibility of the user to check that the most recent legislation is being adhered to.

This information can be found on the website.

[www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

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**1. Introduction**

This document was developed from a South Central policy by a working group for the Child and Young Person’s Advance Care Plan Collaborative. The collaborative is a voluntary group of NHS & private sector organisations concerned with delivering the best possible care for children with potentially shortened lives. Members span across much of the West of England.

This template policy is intended for incorporation into local policies in order to deliver a unified approach to the care of the children and young people it concerns. The template remains valid until its review. It will be reviewed initially at three yearly intervals. Details of the timing of the next review, including information on how to submit suggestions for refinement can be found on the collaborative website.

This policy is supported by a package which consists of:

* A Child & Young Person’s Advance Care Plan pro-forma **(Appendix 1)**
* A Guide (This accompanies the pro-forma and is designed to provide the user with practical advice in how to fill out the CYPACP).
* A website that includes supporting information and a discussion forum to support education and development of the plan: <http:///www.cypacp.nhs.uk/>
* An information leaflet for parents and carers about Advance Care Plans **(Appendix 2)**
* An information leaflet for young people about Advance Care Plans

**(Appendix 3)**

The Child and Young Person’s Advance Care Plan (CYPACP) pro-forma is designed to be a holistic, summary document that facilitates the clear and concise communication of the wishes of children or young people (and their families), who have chronic and life-limiting conditions:

* It sets out an agreed plan of care to be followed when a child or young person’s condition deteriorates.
* It provides a framework for both discussing and documenting the agreed wishes of a child or young person and his or her parents, when the child or young person develops potentially life-threatening complications of his or her condition.
* It is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service.
* The CYPACP can be used as a resuscitation plan and as an end-of-life care plan.
* It remains valid when parent(s) or next of kin cannot be contacted.

It is important to note that this policy and plan are intended to support and enhance the delivery of the best possible care to the child or young person and their family. If the structure provides a barrier to this goal it should not be used. Should this situation occur, an anonymised summary of the problem should be submitted to the working group in order that the circumstance can be considered in future revisions. The group can be contacted through the website www.cypacp.nhs.uk.

**2. Definitions**

2.1 A Child and Young Person’s Advance Care Plan (CYPACP) isa document that records the advance wishes of a child or young person and/or those with parental responsibility for them. A different Advance Care Plan should normally be used in adults. **For the purposes of this document where “Advance Care Plan” or ACP is written, it should be read as referring to the “Child and Young Person’s Advance Care Plan (CYPACP)”.**  A CYPACP will include whether the cardiopulmonary resuscitation status has been discussed, and the outcome of that discussion should a cardiorespiratory arrest occur.

2.2 Cardiorespiratory Arrestis specifically the cessation of breathing and loss of cardiac output. This definition is strict and should not be extrapolated to include any other circumstances. The terminology Cardiopulmonary Arrest is also used in some documents. In children a particular arrest is sometimes documented as a respiratory arrest where there is still cardiac output but cessation of breathing or as a cardiac arrest where there is cessation of breathing and loss of cardiac output. A respiratory arrest is much more common in children than in adults.

2.3 Cardiopulmonary Resuscitation (CPR): Interventions delivered with the intention of restarting the heart and breathing. These will include chest compressions and manual ventilation via mouth, bag and mask or endotracheal tube, and may include attempted defibrillation and the administration of drugs.

2.4 Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) refers to a specific, agreed decision to refrain from making efforts to restart breathing and/or the heart following a cardiorespiratory arrest.

* 1. **Valid DNACPR:** ADNACPR is only valid if the form is appropriately completed and is signed and dated.
  2. Local Lead Clinician for Advance Care Planning: Acts as the primary link between members of his or her organisation and the Child & Young Person’s ACP Collaborative.
  3. CYPACP Co-ordinator: is responsible for ensuring that all CYPACPs in his or her area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the CYPACP. Ideally each area should appoint and fund a CYPACP co-ordinator. This role is usually undertaken by a senior clinician, an advanced nurse practitioner or a consultant nurse. If an area does not have such a post, an individual nurse or key worker can act as a CYPACP co-ordinator for individual children on their caseload.
  4. Child Death Overview Panel (CDOP): This group monitors and reviews the deaths of all children.
  5. Rapid Response team: When there is a sudden and unexpected death in childhood (SUDIC/SUDC) a Rapid Response occurs. Police and Health work together to understand why the death occurred at that time. If the death of a child with a CYPACP occurs at an unexpected time, a rapid response may be triggered.
  6. Adult: A person aged 18 years or over
  7. Young Person: A person aged 16 or 17. Anyone under this age is regarded as a baby, infant or child.

**For or the purposes of this document when the word ‘child’ is used it should be read as ‘baby, infant, child or young person’**

**3. Policy Statement**

The CYPACP is underpinned by the following assumptions:

3.1 All children are presumed to be for attempted CPR unless a valid DNACPR decision has been made.

3.2 All DNACPR decisions are based on current legislation and guidance

3.3 Standardised documentation for the Child and Young Person’s Advance Care Plan should be used where ever possible. **(See appendix 1)**

3.4 The existence of a CYPACP for a child will be communicated to all affected members of the child’s multidisciplinary team and to all relevant settings.

3.5 The CYPACP process is measured, monitored and evaluated in the context of a robust governance framework

3.6 All staff facilitating and documenting a CYPACP will ensure they are familiar and up to date with both this policy and national legislation covering this area.

3.6 Training will be available to enable staff to meet the requirements of this policy.

**4 Purpose**

4.1 This policy provides guidance for staff responsible for providing or organising health care for children within the collaborating organisations. The guide is designed more as a practical tool to help the user fill in the CYPACP.

**5 Scope**

5.1 This policy applies to all the multidisciplinary healthcare team involved in children’s care across the range of care settings within the collaborating organisations.

* 1. This policy is appropriate for all children up to 18 years of age. Once initiated the CYPACP may be extended beyond the 18th birthday, with discretion, for young adults within the special education or hospice environment.

1. **Key Legislation and Guidance**
   1. **Legislation**  
      Clinicians using the CYPACP should be familiar and act in compliance with the following legislation: (<http://www.opsi.gov.uk/acts>)

6.1.1 *Children Act* (1989 & 2004)  
Clinicians are expected to understand how the Act works in practice. The key consideration is to make decisions consistent with the best interests of the child.

* + 1. *Adoption and Children Act* (2002) (2006) addendum 2014

Clinicians are expected to understand who has parental responsibility to consent to treatment in a child

* + 1. *Mental Capacity Act* (2005)

Applicable to 16 and 17 year old patients and adults (see point 7.2)

The Mental Capacity Act (MCA) 2005 is specific to a particular decision being considered: so a person may lack capacity for a DNACPR decision but have capacity for another e.g. preferred place of care.

Clinicians facilitating a CYPACP for 16 and 17 year old young people must be familiar with, and fully comply with the MCA.

* + 1. *Working Together to Safeguard Children* (2006 & 2013) revisions Jan 2015  
       This details the responsibilities to report child deaths to the Child Death Overview Panel (CDOP) and the role of the local Rapid Response Team. <http://www.workingtogetheronline.co.uk/chapters/chapter_five.html>
    2. *Human Rights Act* (1998)   
       The following sections of the Act are relevant to this policy:
    - Failure to provide CPR could be a breach of the individual’s right to life

(article 2)

* + - To be free from inhumane or degrading treatment (article 3)
    - Respect for privacy and family life (article 8)
    - Freedom of expression, which includes the right to hold opinions and receive information (article 10)
    - To be free from discriminatory practices in respect to those rights (Article 14)
    1. *Coroners Act* (1988) new guidance updated 2012  
       Clinicians are expected to know the circumstances when a death must be discussed with the District Coroner. <http://www.medicalprotection.org/uk/resources/factsheets/england/england-factsheets/uk-eng-reporting-deaths-to-the-coroner>

<https://www.gov.uk/government/publications/update-for-coroners-on-death-certification-reforms>

* + 1. Equality Impact Assessment **(See Appendix 5)**

**6.2 Guidance**  
Additional guidance may be drawn from the following sources:

6.2.1 Resuscitation Council (UK) Guidelines

<http://www.resus.org.uk/pages/Guid.htm>

* + 1. Advanced Paediatric Life Support Group Guidelines <http://www.alsg.org/uk/apls>
    2. Royal College of Paediatrics and Child Health (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A Framework for Practice. <http://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html>
    3. Resuscitation Council (UK) Recommended standards for recording "Do not attempt resuscitation" (DNAR) decisions (2009)

<http://www.resus.org.uk/siteindx.htm>

* + 1. Decisions relating to Cardiopulmonary Resuscitation (3rd edition) Guidance from the British Medical Association (BMA), the Resuscitation Council (UK), and the Royal College of Nursing (previously known as the “Joint Statement”) Oct 2014

<https://www.resus.org.uk/pages/dnacpr.htm>

* + 1. BMA (2006) Parental Responsibility: Guidance from the BMA. <http://bma.org.uk/practical-support-at-work/ethics/children>
    2. General Medical Council (2007) 0-18 years: guidance for all doctors <http://www.gmc-uk.org/publications/standards_guidance_for_doctors.asp#0-18>
    3. DNAR decisions in the Perioperative Period; Association of Anaesthetists of Great Britain and Ireland May 2009

<http://www.aagbi.org/sites/default/files/dnar_09_0.pdf>

* + 1. Reconsideration of ACP for surgery or procedures, GOS protocol <http://www.togetherforshortlives.org.uk/assets/0000/8555/Great_Ormond_St_policy_required_reconsideration.pdf>
    2. General Medical Council (2010) Treatment and Care towards the end of life: good practice in decision making. http://www.gmc‑uk.org/static/documents/content/Treatment\_and\_care\_towards\_the\_end\_of\_life\_-\_English\_0914.pdf

**7. Legal Considerations across the age range**

This section is currently being updated and will feature as a separate section on the website. It will include advice on transition to adult services.

*7.1* **Children (under 16 years of age)**

7.1.1 For these children the MCA can only provide decisions, through the Court of Protection (a body that the MCA creates) about property and finance relating to children in certain circumstances. However it has no role in resuscitation decisions.

* + Those with ‘parental responsibility’ for the child make decisions on the child’s behalf. This ‘parental responsibility’ bestows on parents the responsibility of making decisions for, and acting in the *best interests of the child*, until he or she is old enough to make their own decisions.
  + Parents hand over the responsibility for making decisions to their child when a child is old enough to make his or her own decisions affecting their care, and ultimately their life.   
    As a child develops and matures so will his or her understanding of their illness or disability. They will come to understand their condition, the reasons for their treatment, and the consequences of not having that treatment. This maturity or competence has been referred to as ‘Gillick’(or Fraser) competence. Such competence is both time and decision specific and may not apply when a child wishes to refuse lifesaving interventions and their parents disagree.
  + The child who understands the nature of his or her illness and the likely outcomes of treatment options should be involved where possible in the decision-making process.
    1. The child’s family and health care team must decide whether the child is competent to make his or her own decisions relating to resuscitation, and to what degree they will be involved in the discussions. Over the last decade the Courts have been consulted several times regarding children who have made ‘competent’ decisions that were at odds with the wishes of their health care professionals and/or those with parental responsibility for them. The current position in Common law is that a ‘child’ under 18 can consent to treatment, but if they refuse treatment then those with parental responsibility for them can override that decision, but it would be wise to seek legal advice case by case in such circumstances.
    2. The Consultant in charge of the child's care has final responsibility for resuscitation decisions. There is no legal obligation on the doctor to provide any medical treatment if it is not in the best interests of the patient.
  1. **Young Persons (16 and 17 year olds)**
     1. Although applicable to young people in many respects, the MCA does not permit 16 & 17 year olds to make arrangements to enable them, once incapacitated, to refuse life saving treatment. Thus there is no provision for them to appoint Lasting Powers of Attorney, or to make an Advance Decision to Refuse Treatment (ADRT)
     2. There is a presumption that 16 and 17 year olds have the capacity to make decisions for themselves. Young people of this age can consent to treatment and may be able to refuse treatment in some circumstances. Legal advice may be required in this situation.
     3. If a 16/17 year old is thought to lack capacity for a decision and has a parent with them who can be consulted, they fall outside of the remit of the MCA 2005, since they are not unbefriended. The parents have a right to provide consent under the normal arrangements under the Children Act.
     4. For 16/17 year olds the main effect of the MCA is to consolidate into Parliamentary law (statute) the common law that has for many years accumulated, with respect to how 16 & 17 year olds who lack capacity, have decisions made about them.

The MCA runs ‘parallel’ with the Children Act 1989 (CA), and the two statutes are drawn up in such a way as to co-exist, rather than provide contradictory advice. There will be times when it is not clear whether a clinical problem should be approached via the CA, and thus through the Family Courts, or the MCA, and thus the Court of Protection. Sometimes the distinction may be rather fine.

**7.3 Adults (18 years and older)**

7.1.2 The legal definition of an adult is anyone of 18 years or over.

Anyone of 18 years of age or above can make his or her own decisions about consenting to, or refusing treatment. He or she can also make a legally binding ‘Advance Decision’ about these issues. An ACP should not be used for this purpose.

* + 1. In the majority of circumstances the Child and Young Person’s Advance Care Plan should not therefore be initiated after the 18th birthday and the adult form should be used. However if the form is already being used it may be better for the individual and their family to continue with the Child and Young Person’s Advance Care Plan beyond the 18th birthday. There may also be occasions where it is appropriate to use this form for adults still under paediatric services or within the hospice environment.
    2. The MCA provides a test of capacity. A person lacks capacity if they have an impairment or disturbance that affects the way their mind or brain works and the impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made. This two-stage test should therefore be used if a clinician has cause to believe that the person lacks capacity. A person is deemed to be ‘unable to make a decision’ if they cannot:
  + understand information relating to the decision that has to be made
  + retain that information in their mind
  + use or weigh that information as part of the decision-making process, or
  + communicate their decision.
    1. If an adult is found to lack capacity then the decision is made on best interests. The only person who determines best interests (i.e. decides what the best interests of the person are) is the decision maker. The decision maker is usually the clinician in charge, otherwise the Court of Protection, its deputy, or someone with Lasting Power of Attorney. Everyone else including parents or Independent Mental Capacity Advocates, are not legally able to determine best interests; they merely support the decision maker by, amongst other means, providing the information to allow the decision to be made.
    2. The MCA provides clarification on decision making in adults.

**8.** **Roles and Responsibilities**

8.1 The Chief Executive of each collaborating centre is responsible to ensure that:

* + - The local version of this policy adheres to statutory requirements and professional guidance.
    - Their organisation supports the unified policy development and the implementation within other organisations
    - The policy is monitored and reviewed

8.2 National Health Service (NHS) Commissioners must ensure that commissioned services provide funding to ensure implementation and adherence to the policy and procedure and to ensure staff training. They must resource/enable funding of an ACP Co-ordinator or ensure the inclusion of this role into the job plan of an existing post.

8.3 Chief Executives of all provider organisations must ensure that provider services:

* + - Implement and adhere to the policy and procedure
    - Procure and/or provide legal support when required
    - Resource/enable funding of an ACP Co-ordinator or identify the inclusion of this role into the job plan of an existing post
    - Resource/ enable training for staff

8.4 Directors or Managers who are responsible for the delivery of care must ensure that where the policy is implemented:

* + - That staff are aware of the policy and how to access it.
* Staff understand the importance of issues regarding DNACPR/ ACPs
* Staff are trained and updated in managing DNACPR/ ACPs
* Sufficient supporting materials are available for staff and for families
* The policy is audited

8.5 Local Lead Clinician for CYPACPs is responsible for:

* Disseminating information about the ACP package to all staff in their area who are affected by it.
* Feeding back queries about the contents and application of the package to the Collaborative Working Party on behalf of the staff in their domain.
* Acting as a resource and support for clinicians.

8.6 Senior clinicians take ultimate responsibility for the completion of a CYPACP for a child in their care. They will ensure that:

* All ‘interested parties’ are involved in the initial discussions about the possibility of an ACP for a particular child.
* Information about all possible treatment options for the child, and their implications, are available to the group while discussing Advance Care Planning.
* The group discuss whether it would be appropriate to raise the issue of DNACPR with the child and his or her family
* Decisions are appropriately documented, disseminated and reviewed.

8.7 CYPACP Co-ordinator is responsible for ensuring that all CYPACPs in their area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the CYPACP.

8.8 Clinical staff delivering care must:

* + - Adhere to the policy and procedure
    - Notify line manager of any training needs
    - Check the validity of any decision – that it is in date and signed.
    - Notify other services of the existence of the DNACPR / CYPACP on the transfer of a child
    - Participate in the audit process
    - Be aware of local procedures for storing and accessing ACP information.

8.9. Commissioners and commissioned services, for example pharmacists and dentists, should be aware of this policy and consider its implications when commissioning or providing services.

8.10 The Ambulance service staff will:

* + - Adhere to the policy and procedure
    - Notify line manager of any training needs
    - Ensure they are aware of the existence of a DNACPR/ CYPACP via the individual / relatives or the health care professional requesting assistance
    - Check the validity of any decision – that it is in date and signed.
    - Participate in the audit process
    - Be aware of local procedures for storing and accessing ACP information

8.11 Hospices will adhere to the policy and procedure, and will ensure that:

* Information regarding a DNACPR/ Child and Young Person’s Advance Care Plan is included in pre-admission documentation.
* All DNACPR/ Advance Care Plans are effectively cascaded to staff.
* Individual staff will:
* Notify line manager of any training needs
* Ensure they are aware of the existence of any DNACPR/ CYPACPs for patients in their care.
* Check the validity of any decision– that it is in date and signed.
* Participate in the audit process
* Be aware of local procedures for storing and accessing ACP information

8.12 Schools have a responsibility to ensure that:

* The CYPACP is available and followed
* In an acute event, an ambulance is called and the presence of the CYPACP highlighted to ambulance staff (follow protocol including giving home postcode)
* In an acute event, parents are immediately contacted by phone

**9 Process**

The guide to using the CYPACP (www.cypacp.nhs.uk**)** should be used when initiating an ACP. It provides guidance on the overall process as well as page-by page instruction on completing the documentation.

**10. Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)**

* 1. Whatever the prognosis and advance directives that may be in place, the child’s comfort should always be a primary consideration. Every attempt should be made to minimise distress and to fulfil the child and the families’ wishes wherever possible.
  2. Notwithstanding the above, a child with a valid DNACPR decision in place should not have any attempt made to resuscitate them in the event of a life threatening change in his or her clinical condition (excluding reversible causes such as choking or anaphylaxis, or causes specific to the individual child specified in the CYPACP).
  3. In hospital a clinical emergency (crash/2222) call will not usually be made and no active interventions will be made to assist the child’s failing respiratory or circulatory function including compressions and ventilation.
  4. If an ambulance is called then Ambulance Control must be told about the existence of a CYPACP.
  5. A DNACPR decision specifically directs the omission of CPR, it does not mean withdrawal of care.

* 1. All children are for attempted resuscitation unless there is a valid DNACPR decision in place. If there is any doubt about the validity of a DNACPR decision then resuscitation should be initiated.

* 1. A valid DNACPR decision:
* Reflects the agreed wishes of the child (where appropriate), those with parental responsibility for the child, and the health care professionals caring for the child.
* Is clearly recorded in the DNACPR section of the ACP.
* Falls within the time period specified on the form.

* 1. If the death is anticipated in the community, the GP should be called

**11. Guidance on when the CYPACP may not apply**

11.1 The CYPACP will only apply to situations described within the care plan and when it is signed by the child’s lead clinician.   
There is an opportunity on the pro-forma for both the child (if they have capacity) and their parent to endorse the plan, where dictated by local policy or considered appropriate. This does not include the DNACPR form which is validated by the signature of a senior clinician.

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11.2 The CYPACP should not normally be usually be used for the first time in an adult of 18 years or over. There may be some young adults in which this form was initiated before their 18th birthday. If the young adult is deemed competent and has signed the form, it will remain valid, and a parental signature is not required.

11.3 In all circumstances not covered by the CYPACP it must be assumed that the child should have full resuscitation measures in the event of deterioration or collapse. Clinicians retain the right to not resuscitate or to stop resuscitation if they believe it is futile.

11.4 A valid CYPACP should be followed even when the parent or legal guardian is NOT present at the time of the child’s acute deterioration or collapse.

11.5 If a parent or legal guardian is present at the time of his or her child’s collapse, and they wish to deviate from the previously agreed ACP, then their wishes should be respected provided they are thought to be in the best interests of the child.

For further guidance on how to complete the Child and Young Person’s Advance Care Plan, please see Staff Guidance leaflet available at: [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

**12 Review**

There is no fixed expiry time on a CYPACP, although this may be dictated by local procedures. Normally the review date would be specified by the senior clinician completing the form. It should be reviewed regularly. Review meetings need to be organised well ahead of time to ensure there is always a current valid plan. The local CYPACP co-ordinator is responsible for distributing the latest version of the CYPACP.

**13 Situations where there is lack of agreement**

Where the clinical decision is challenged and agreement cannot be reached, a second opinion should be sought. Mediation should be considered. If there remains disagreement, legal advice must be sought in a timely fashion.

**14 Cancellation of a DNACPR Decision**

If a decision is made to cancel or revoke the CYPACP or DNACPR decision the plan should be crossed through with 2 diagonal lines in dark ball-point ink and the word **‘CANCELLED’** written clearly between them, dated and signed by the senior clinician. The reasons for this change should be clearly documented in the child’s clinical notes.   
  
It is the responsibility of the CYPACP Co-ordinator to inform all parties and to organise an urgent review so that a new CYPACP can be completed.

**15 Exclusions from and suspension of DNACPR Decision**

15.1 A DNACPR decision does not include immediately remediable and acutely life-threatening clinical emergencies such as choking or anaphylaxis. Appropriate emergency interventions, including CPR should be attempted in such circumstances.

15.2 A valid DNACPR decision may be temporarily suspended, for example around the time of specific interventions such as anaesthesia or surgery that have an associated increased risk of cardiopulmonary arrest. If such procedures are planned then the CYPACP should be reviewed and whatever decision is made should be documented and communicated accordingly. This documentation should clearly specify the beginning and end date of the suspension (*cross reference policy* ***6.2.9 page 7***).

**16 Audit**

16.1 Collaborating organisations should monitor and evaluate compliance with this policy through audit and data collection. See Appendix 3 for a model audit form to be completed for an agreed sample of CYPACP forms.

16.2 All organisations must have clear governance arrangements in place which indicate individuals and committees who are responsible for the governance of this policy at a local level.

This includes:

* Data collection
* Ensuring that approved documentation is implemented
* Managing risk
* Sharing good practice
* Monitoring of incident reports and complaints regarding the CYPACP and DNACPR process.
* Developing action plans and ensuring that they are completed

16.3 Frequency and information.

* Compliance with the policy should be audited annually
* Local leads will decide the number of CYPACPs to be examined.

16.4 Information from audit will be used for future planning, identification of training needs and for the policy review.

16.5 It may also be useful to audit and review how the CYPACPs are used:

* how many children have a CYPACP
* whether it was used in practice
* how many children who have died had a CYPACP
* location of death for children with and without a CYPACP

**Appendix 1**

**Child and Young Person’s Advance Care Plan**

Please refer to current document on website: [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

**Appendix 2**

**Young Person’s Information Leaflet**

Please refer to current document on website: [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

**Appendix 3**

**Parents Information leaflet**

Please refer to current document on website: [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

**Appendix 3**

**CYPACP Model Audit Form**

Service………………………………………

Date………………………………………….

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Question | Yes | No | Comments |
| 1 | Is there a Child and Young Person’s Advance Care Plan? |  |  |  |
| 2 | Has the decision been recorded on approved documentation? |  |  |  |
| 3 | Has the decision been made by an appropriate clinician? |  |  |  |
| 4 | Is the record clearly dated and signed in full? |  |  |  |
| 5 | Are there clear patient identifiers? |  |  |  |
| 6 | Are all fields of the records completed? |  |  |  |
| 7 | Is there evidence that the best interests of the child have been considered? |  |  |  |
| 8 | Is there evidence of discussions with the child and/or their family? |  |  |  |
| 9 | Is there evidence that the multidisciplinary team are aware of the decision? |  |  |  |
| 10 | Is there evidence that decisions are reviewed and documented? |  |  |  |
| 11 | Is the Child and Young Person’s Advance Care Plan policy easily accessible to relevant staff? |  |  |  |
| 12 | Is there evidence that copies of the ACP have been distributed to the individuals listed on the final page of the ACP |  |  |  |

Comments: