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Photo

Endorsed by NICE

Plans can begin antenatally and are suitable for infants, children and young people

FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES

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

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Name:  (Baby, infant, child or young person) |  | | EDD (if relevant): | |  |
| DOB: | |  |
| Known as (if different): |  | | Gender (optional): | |  |
| Address: |  | | | | |
|  | | | | |
|  | | Post code: |  | |
| NHS No: |  | Hospital No: |  | | |

If ANTENATAL this document is found / filed in Mothers notes (with relevant birthing plans):

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Mother’s Name: |  | Mother’s NHS: |  | Mother’s DOB: |  |

|  |  |
| --- | --- |
| **Date of plan:** |  |

|  |  |
| --- | --- |
| **In Emergency Call:** |  |
| **Other situations:** |  |

**For Child/Young Person or Carers Use – Who to call in emergency (e.g. 999 or 111, or Hospice etc)**

**See also Emergency contacts on last page**

This document is a tool for discussing, care preferences and communicating wishes / shared decision-making between families and clinicians. ***Not every page/section needs to be completed.***

**Irrespective of the ‘Date of plan’ it is good practice to check this still reflects current decisions / views**.

It is good practice to regularly review the plan, especially if changes have occurred. However, an old / expired date does not necessarily negate this document.

For electronic copies of this form, information leaflets and guidance, see <http://cypacp.uk/>

Version 5

http://cypacp.uk/

# Decision making (Additional to the capacity and involvement summary at the back)

|  |  |  |  |
| --- | --- | --- | --- |
| First Language |  | Interpreter needed? |  |

|  |
| --- |
| **Information to help improve communication / support capacity:** |
|  |
| **Information relating to Mental Capacity Assessment (if relevant)**  Note where further information can be found, e.g. ‘Mental capacity Assessment completed on dd/mm/yy found in …’  Please record additional information relating to capacity relevant to the completion of this form.  Further information and Mental Capacity templates can be found on the CYPACP website. See also last page. |
|  |
| **Additional Comments (e.g. details of those involved if looked after child, details of significant decision making meeting and those involved, other key family members /carers to involve in important decisions, how do child / family wish to be involved in decision-making. Type of decision maker** E.g. do they prefer to be ultimate decision maker, shared decision maker or non-decision maker? (Caveat: not possible for medical teams to support decisions they do not endorse**).** |
|  |

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

# Distribution list / Key Contacts

|  |  |
| --- | --- |
| Responsibility for changes / distribution of CYPACP (please contact if you believe this version to be inaccurate) | |
| Name and Role/Department/Organisation) | Contact Details |
|  |  |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | | Name and contact details |  |  | Name and contact details |
|  | Is there a regional central database (if so upload and note where this is found) |  |  | Respite / Short Break Care provider |  |
|  | Ambulance Service |  |  | School Nurse / Head Teacher |  |
|  | Lead Paediatrician/Obstetrician |  |  | Social Services |  |
|  | Palliative Team (please include out of hours number if available) |  |  | Midwife |  |
|  | Hospice (please include out of hours number if available) |  |  | Health Visitor |  |
|  | GP |  |  | Other (e.g. Hospital Specialists ) |  |
|  | GP Out of Hours (if different) |  |  | Other |  |
|  | Children’s Community Nursing |  |  | Other |  |
|  | Hospital (ward /assessment unit) |  |  | Other |  |
|  | Local Emergency Department |  |  | Other |  |

**It is good practice to keep a copy of the care plan with the infant/child/young person at all times**

**Note: Emergency contacts can be found on last page**

# Medical Background

|  |
| --- |
| **Summary diagnoses / current situation:** |
|  |
| **Medical problems and background information (incl Antenatal scans):** Medical History, key moments in journey, family tree if helpful, previous pregnancy losses/neonatal/infant deaths (especially if antenatal plan) |
|  |

# Personal Background

|  |
| --- |
| **Personality / Baseline / Quality of life when well:** May help others recognise deterioration, targets for recovery. May also wish to document concerns about your / your child’s health, now and for the future? |
|  |
| **Tips to make infant/child/young person/yourself more comfortable:** E.g. communication methods, particular likes, music, stories, massage or they may prefer not to be touched etc. [Please note where to find more detailed separate care plans if relevant]. |
|  |
| **Social / Psychological / Spiritual / Educational Support:** (if felt to be helpful) |
|  |
| **Family details:** Please include details of siblings, other important family / friends / carers |
|  |

# Priorities / Goals / Values

|  |
| --- |
| **Baby / Infant / Child / Young Person’s wishes:** Consider support to achieve everyday quality of life as well as special goals. e.g. Place of care, spiritual wishes, goal-directed outcomes, what I most value / wish to avoid.  Legacy and memory making during life. |
|  |
| **Family (incl siblings) wishes:** Consider how Family wish to be supported to achieve everyday quality of life as well as any special goals. e.g. Where you want to be as a family, who to involve, sibling support and needs (e.g medical, spiritual or cultural backgrounds). Legacy and memory making during life, what is most valued / wish to avoid. |
|  |
| **Others’ wishes**: (wider family, school friends, carers) |
|  |

# Wishes around End of Life

If it is recognised that your child/young person is nearing the end of their life, is there anything that would be important for us to know to provide the best care possible.

|  |
| --- |
| **Organ & tissue donation** (see separate guidance on web link <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/>  National contact numbers. Referral line 03000 20 30 40 / General advice 0300 123 2323  Organ and tissue donation maybe possible but it depends on several factors, it is best to speak to a specialist nurse should they wish for this option to be considered who can guide on the specifics. |
|  |
| **Priorities for care, including preferred place of care at end of life and after death**  **Specify if preferred place of care at end of life is different to place of care after death** |
|  |
| **Spiritual and cultural wishes around death and dying**  Not just religious but important personal wishes such as music, family traditions and rituals |
|  |
| **Memory and legacy making wishes (include family/sibling/friends if relevant)**  Consider how you / your child wish/es to be remembered |
|  |
| **Requirements after death (Coroner / Post Mortem) and families thoughts around this**  For full details of processes after death see separate guides. However, opportunity to note if coroner needs to be informed (e.g. in HIE, unable to write cause of death), discuss need to see within 28 days etc  Include information on indwelling devices and removal after death if known  Also include other family preferences e.g. preferred timing for removal of equipment from house |
|  |
| **Funeral preferences and bereavement support** Seek detailed information or further advice if needed |
|  |
| **If not discussed, it may be helpful to put specific reasons / context of why not**  Note: No need to explain, but record if helpful to be aware of certain situations / circumstances |
|  |

**Perinatal Details / Management**

**Note it may be appropriate to have / refer to separate birthing plan**

**Plan for Delivery**

|  |
| --- |
| **Details of birth plans:** e.g. where to find or further details below |
|  |
| **Specific plans for delivery:** e.g. planned place of delivery, mode of delivery, Induction / section date, plan for fetal monitoring – continuous / intermittent /none etc. |
|  |
| **Hopes and wishes** (e.g. around antenatal assessments, assessments at birth, surgery etc) – see also ‘Priorities / Goals / Values’ section earlier in this care plan. |
|  |

**Plans for admission (for before and during delivery) (see also above section)**

|  |
| --- |
| **Specific Requests** (Side room, particular wishes etc) |
|  |
| **Specific Teams to inform** *(e.g. Neonatal team(including community/outreach team ifavailable and appropriate), hospice team, Palliative Team etc)* |
|  |

**Plans for after delivery / birth – Ongoing care**

|  |
| --- |
| **Discussions/decisions regarding lactation** (e.g. plans for lactation suppression, initiation, continuation, breastmilk donation)   * British Association of Perinatal Medicine (BAPM) 'Lactation and Loss' https://www.bapm.org/resources/lactation-and-loss-management-of-lactation-following-the-death-of-a-baby * Memory Milk Gift, Donation after Loss www.milkbankatchester.org.uk/donationafterloss/ |
|  |
| **Detail of wishes** (e.g. **location of care**, discharge home, hospice) – May reference separate discharge plan, detailing medications, equipment etc. Please note where to find - if applicable. |
|  |
| **Other details** |
|  |

**Management of baby at birth**

|  |  |  |
| --- | --- | --- |
| **If baby born with adequate breathing and a good heart rate** (Considerations: Assessment, cord clamping, dry and wrap, skin to skin, delivery room cuddle, personnel present at delivery [i.e. number and who], transfer to NICU or stay on Labour Ward etc). | | |
| Explanation / Narrative / Further notes: | | |
| **If baby is not (or has inadequate) breathing but has a good heart rate** *(Consider immediate actions (detail level of support /stabilisation [e.g. full resus / limited resus /comfort care])* | | |
|  | Airway Positioning | Explanation / Narrative / Further notes: |
|  | Airway Adjuncts |
|  | Intubation |
|  | Oxygen / PEEP (Mask) |
|  | Inflation Breaths |
|  | Ventilation Breaths |
|  | Chest compressions |
|  | Intravenous Access |
|  | Cardiac Drugs |
| **If baby is not (or has inadequate) breathing and heart rate is low** *(Consider immediate actions (detail level of support /stabilisation [e.g. full resus / limited resus /comfort care]))* | | |
|  | Airway Positioning | Explanation / Narrative / Further notes: |
|  | Airway Adjuncts |
|  | Intubation |
|  | Oxygen / PEEP (Mask) |
|  | Inflation Breaths |
|  | Ventilation Breaths |
|  | Chest compressions |
|  | Intravenous Access |
|  | Cardiac Drugs |
| **If baby is not breathing and heart rate is absent (No signs of life)** *(Consider immediate actions (detail level of support /stabilisation [e.g. full resus / limited resus /comfort care]) and ‘Wishes around end of life’ section earlier in plan.* | | |
|  | Airway Positioning | Explanation / Narrative / Further notes: |
|  | Airway Adjuncts |
|  | Intubation |
|  | Oxygen / PEEP (Mask) |
|  | Inflation Breaths |
|  | Ventilation Breaths |
|  | Chest compressions |
|  | Intravenous Access |
|  | Cardiac Drugs |
| **Other details** *(Consider photographs / memory making / place of care / cultural wishes / family traditions / rituals – See also other sections of Care plan)* | | |
|  | | |

**Plans for immediately after delivery (Management of baby)**

|  |
| --- |
| **Management** (e.g. investigations planned, place of care ), *Consider using ‘Management of Anticipated Complications / Deteriorating Health’ section* |
|  |
| **Symptom Management plan (or where to find this).** *Consider using ‘Management of Anticipated Complications / Deteriorating Health’ section or separate symptom management plan* |
|  |
| **Other wishes** *(e.g. Feeding/ name bands / first bath / memory making / keepsakes / Family members or friends to meet baby / support for siblings / ceremonies / cultural & religious wishes)* |
|  |

**For Management beyond the initial period of birth please refer to:**

**- ‘Management of Anticipated Complications / Deteriorating Health’ page/s**

**- ‘Management of an Acute Significant Deterioration / Emergency’ page/s**

**Management of Anticipated Complications / Deteriorating Health Include reference to separate documents (and where to find) e.g. symptom management plan, specialty care plan(s)**

**Note: For Antenatal care plans - this section may be deferred (if desired) until assessment after birth**

**[Balance - avoiding duplication due to risk of version control, but aim for quick help in emergencies]**

**General Management**

|  |
| --- |
| **Current course of medical treatment:** e.g. Disease directed therapy, clinical trials etc. |
|  |
| **Notes on likely deterioration (if known and relevant):** Consider likely cause(s) of deterioration including signs, symptoms and red flags |
|  |
| **Management of progressive deterioration (if different to general deterioration detailed below)**  It may be appropriate to refer to other sections such as priorities of care if end of life is recognised. |
|  |

**Systems approach to managing deterioration**

|  |
| --- |
| **Airway** (Tracheostomy and airway adjuvants) |
|  |
| **Breathing** *(Oxygen, pressure and ventilation support)* |
|  |
| **Circulation / Cardiac** (Access, diuretics, blood pressure support, Implants – what patient has, when and how to change or turn off) |
|  |
| **Neurology** (State if VP shunt or reservoir present and action if blocked; role of pulsed steroids in neurological decline; acute seizure management) |
|  |
| **Management of commonly occurring Infections** (including central line and stated temperatures for individual child) |
|  |
| **Nutrition and hydration** (including presence of, or discussion about, NG, NJ PEG and JEJ, TPN) |
|  |
| **Blood tests** (consider frequency, indication and specific tests or stop routine tests) |
|  |
| **Blood products** (consider type, frequency and indication eg blood test or clinical symptoms) |
|  |
| **IV/SC Access** (Portacath/Hickman/Midline/other and discussion about subcutaneous access) |
|  |
| **Patient specific care plans** (include date issued, where to find and service /specialty) |
|  |
| **Condition specific interventions / General** (not previously mentioned, may include when to call 999, transfer to hospital) |
|  |

**Other patient plans / where to find** (symptom management plans, specialty care plan (e.g. Respiratory care plan etc)

|  |
| --- |
|  |

**Out of Hours Support and Contact** (include all relevant specialists / services ) **Note: also add Emergency contacts on last page**

|  |
| --- |
|  |

**Emergency contacts can be found on last page**

# Management of an Acute Significant Deterioration / Emergency

* **For review with ‘Management of Anticipated Complications’ / ‘ReSPECT’**
* **If end of life recognised see ‘Wishes around End of Life’ & consider transfer to preferred place of care**
* **Allergies on Front Cover**

|  |
| --- |
| 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.**  **(Irrespective of resuscitation wishes)** |

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|  |  |  |  |
| --- | --- | --- | --- |
| **Note any differences to plan detailed below if parents / carers are not present**  If none recorded, assumption will be made to follow plan detailed below, even in absence of parent / carer | | | |
|  | | | |
| **In the event of life threatening event provide the following care** (Add patient-specific detail below) | | | |
|  |  |  | Comments (Patient specific decisions e.g. duration) |
| **Basic Life Support** |  | **Airway Repositioning (Note: CHOKING must always be treated)** |  |
|  | **Airway Adjuncts** |  |
|  | **Bag and mask / tracheostomy /mouth to mouth ventilation** |  |
|  | **Chest compressions** |  |
|  | **Defibrillation** |  |
| **Airway** |  | Suction |  |
|  | Supraglottic airway insertion (e.g.LMA) |  |
|  | Intubation |  |
| **Breathing** |  | Supplementary Oxygen if available |  |
|  | Highflow (e.g. Optiflow / Vapotherm) |  |
|  | Non-invasive ventilation |  |
| **Circulation** |  | Intravenous access |  |
|  | Intraosseous access. |  |
|  | Cardiac/ALS drugs (usually in conjunction with chest compressions) |  |
| **Other** |  | Emergency transfer to hospital |  |
|  | Consider Intensive Care Admission |  |
| **Additional comments about the above decisions or relevant other decisions**  Please record details [and management at end of life] on implantable devices VNS/ Pacemaker / defibrillator etc. Long term IV access or respiratory support (further details may be in separate care plans and ‘Anticipated complications’ page).  (e.g. may include specific information if a life-threatening emergency happens at school)  Include preferences of transport. E.g. Local hospital or specialist centre if more suitable  Consider how interventions will be carried out for emergency clinicians and ongoing management plans. | | | |
|  | | | |

**Emergency contacts can be found on last page**

**Summary plan for Emergency Care and Treatment**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **1** | **Preferred Name:** |  | **Date completed**: |  |
| **2** | **Shared understanding of my health and current condition:** | | | |
| **Summary** (for use in emergency) of relevant information including **diagnosis** and **relevant personal circumstances**: | | | | |
| Details of other relevant planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan/s): | | | | |

|  |  |
| --- | --- |
| **3** | **Additional comments regarding management of significant deterioration / resuscitation** |
| **See also page prior, ‘Management of an Acute Significant Deterioration / Emergency’). Include:**   * **Priorities of treatment** * **Balance of intervention versus comfort** * **What I most value / wish to avoid** * **Any relation to end of life wishes** | |
|  | |

|  |  |  |
| --- | --- | --- |
|  |  |  |
| CPR attempts recommended | For modified CPR  (Child and Young Person)  (as detailed on Management of Acute Significant Deterioration page) | CPR attempts NOT recommended |
| (Clinician signature) | (Clinician signature) | (Clinician signature) |

**Emergency contacts can be found on last page**

|  |  |  |  |
| --- | --- | --- | --- |
| **4** | **Capacity and representation at time of completion** (see also ‘Decision Making’ section) | | |
| Does the person have sufficient capacity to participate in making the recommendations on this plan? | | Yes  No | If no, in what way does this person lack capacity?  If the person lacks capacity a conversation must take place with the family and/or legal welfare proxy. |
| Document the full capacity assessment in the clinical record. | | |

|  |  |  |  |
| --- | --- | --- | --- |
| **5** | **Involvement in making this plan** | | |
| The clinician(s) signing this plan is/are confirming that: (select A, B or C, OR complete section D below): | | | |
| A |  | This person has the mental capacity to participate in making these recommendations.They have been fully involved in making this plan. | |
| B |  | This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends. | |
| C |  | This person is less than 18 years old (16 in Scotland) and (please select 1 or 2, and also 3 as applicable or explain in section D below): | |
|  |  | 1 | They have sufficient maturity and understanding to participate in making this plan |
|  |  | 2 | They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account |
|  |  | 3 | Those holding parental responsibility have been fully involved in discussing and making this plan |
| D | | If no other option has been selected, valid reasons must be stated here. (Document full explanation in the clinical record). | |
| Record date, details of legal proxy, names and roles of those involved in decision making, and where records of discussions can be found: | | | |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **6** | **Clinicians’ signatures** | | | | |
| Grade /specialty /Designation  (grade/speciality) | | Clinician name | GMC/ NMC/ HCPC Number | Signature | Date & time |
|  | |  |  |  |  |
|  | |  |  |  |  |
| Senior responsible clinician: | |  |  |  |  |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **7** | **Emergency contacts and those involved in discussing this plan** | | | | |
| Emergency Contact Name (Primary Contacts in purple) | | Role and Relationship | 24 Hour contact  Tick if Yes | Emergency contact no. | Signature (optional) |
| (Patient /Family) | |  |  |  |  |
| (Patient /Family): | |  |  |  |  |
| (Professional): | |  |  |  |  |
| (Professional): | |  |  |  |  |
| (Professional): | |  |  |  |  |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **9** | **Form reviewed (e.g. for change of care setting) and remains relevant** | | | | |
| Review date | | Designation (grade/speciality) | Clinician name | GMC/ NMC/ HCPC No. | Signature |
|  | |  |  |  |  |
|  | |  |  |  |  |
|  | |  |  |  |  |