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FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES

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

|  |  |  |  |
| --- | --- | --- | --- |
| Name (baby, infant, child or young person): |  | EDD (if relevant): |  |
| Known as (if different): |  | DOB: |  |
| Address including postcode: |  | | |
| NHS no: |  | Gender (optional) |  |

**If ANTENATAL this document is filed in mother’s notes (with relevant birthing plan):**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Mother’s name:** |  | **Mother’s NHS no:** |  | **Mother’s DOB:** |  |

|  |
| --- |
| Allergies: |

|  |  |
| --- | --- |
| **In emergency call:** |  |
| **Other situations:** |  |

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

**See also Emergency Contacts on last page**

This document is in accordance with NICE guideline NG61 and is a tool for discussing care preferences and communicating wishes. It is intended to enable clinicians and families to make good decisions together.

***Not every page/section needs to be completed.***

|  |  |
| --- | --- |
| **Date of Plan/Last review** |  |

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

**Decision-making (additional to the ReSPECT document at the back)**

|  |  |  |  |
| --- | --- | --- | --- |
| First language |  | Interpreter required? | Yes  No |
| **Information to help improve communication / support capacity:** | | | |
|  | | | |
| **Decision-making details/preferences:** For example - details of those involved if “looked after” child; others involved key family members/carers; how do child/family wish to be involved in decision-making? | | | |
|  | | | |
| **Important information relating to capacity and where further information can be found.**  Further guidance will be available on the CYPACP website. See also last page | | | |
|  | | | |

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

**Distribution list / Key contacts (\*where available, please include out of hours numbers)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Responsibility for changes / distribution of CYPACP** (please contact if you believe this version to be inaccurate) | | | | | |
| **Name/Role/Department/Organisation and contact details:** | | | | | |
|  |  | **Name and contact details** |  |  | **Name and contact details** |
|  | Is there a regional central database? | Upload and note where this can be found: |  | Respite/Short Break Care provider |  |
|  | Ambulance service |  |  | School Nurse/Head Teacher |  |
|  | Lead Paediatrician/  Obstetrician |  |  | Social Services |  |
|  | Palliative Team\* |  |  | Midwife |  |
|  | Hospice\* |  |  | Health Visitor |  |
|  | GP |  |  | Other (eg 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**

|  |
| --- |
| **Medical Background** |
| **Summary diagnoses / current situation:** |
|  |
| **Medical problems and background information (inc antenatal scans):** Medical history, key moments in journey; previous pregnancy losses/neonatal/infant deaths (especially if antenatal plan) |
|  |
| **Personal Background** |
| **Personality/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:** eg communication methods; particular likes; music; stories; play, etc. Please note where to find more detailed, separate care plans if relevant |
|  |
| **Social/Psychological/Spiritual/Education support:** (if felt to be helpful) |
|  |
| **Family details:** please include details of siblings, include family tree if helpful; 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, eg place of care; spiritual wishes; goal-directed outcomes; what I most value/wish to avoid; legacy and memory-making during life |
|  |
| **Family (including siblings) wishes:** Consider how you as a family wish to be supported to achieve everyday quality of life as well as any special goals, eg where you want to be as a family; who to involve; sibling support and needs (eg 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?

|  |
| --- |
| **Priorities for care, including preferred place of care at the end of life and after death:** Specify if preferred place of care at end of life is different to place of care after death. |
|  |
| **Organ and 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 0300 020 30 40/ General advice line: 0300 123 2323  Organ and tissue donation may be possible, but it depends on several factors. Specialists can guide on specifics should this option be considered |
|  |
| **Spiritual and cultural wishes around death and dying:** to include faith, beliefs and personal wishes such as music, family traditions and rituals |
|  |
| **Memory and legacy making wishes (include family/siblings/friends if relevant)**  Consider how you/your child wish/es to be remembered which may include wishes for possessions and/or digital legacy. |
|  |
| **Preparation/communication of process for management after death: 1.** Consider required referrals (including sudden death and automatic Coroner referrals (eg HIE (hypoxic ischaemic encephalopathy); **2**. Need for regular medical review; **3.**  Consider discussion and explanation of SUDIC process; **4.**. In-dwelling devices and removal |
|  |
| **Funeral preferences and bereavement support and other family preferences:** eg preferred timing for removal of equipment from home. 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**

|  |
| --- |
| **Plans for delivery** |
| **Details of birth plans:** eg where to find or further details below |
|  |
| **Specific plans for delivery:** eg planned place of delivery; mode of delivery; induction/section date; plan for fetal monitoring – continuous/intermittent/none, etc |
|  |
| **Hopes and wishes** eg 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:** eg side room, particular wishes, etc |
|  |
| **Specific teams to inform:** eg neonatal team (including community/outreach team if available and appropriate), hospice team, palliative team, etc |
|  |
| **Plans for after delivery/birth – on-going care** |
| **Discussions/decisions regarding lactation** eg 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/](http://www.milkbankatchester.org.uk/donationafterloss/) |
|  |
| **Details of wishes:** eg location of care;discharge home, hospice. May reference separate discharge plans detailing medications, equipment, etc. Please note where to find if applicable. Some wishes around end of life care may be documented in the section “Wishes around end of life”. |
|  |
| **Other details** |
|  |

**Management of baby at birth (For management beyond initial period of birth – see next pages)**

|  |  |  |  |
| --- | --- | --- | --- |
| **If baby born with adequate breathing and a good heart rate:** Considerations: assessment; cord clamping; dry and wrap; skin to skin; delivery room cuddle; people to be present at delivery (ie 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 (eg full resus/comfort care) | | | |
| Yes | No | Airway positioning | Explanation/narrative/further notes: |
| Yes | No | Airway adjuncts |
| Yes | No | Intubation |
| Yes | No | Oxygen/PEEP (mask) |
| Yes | No | Inflation breaths |
| Yes | No | Ventilation breaths |
| Yes | No | Chest compressions |
| Yes | No | Intravenous access |
| Yes | No | Cardiac drugs |
| **If baby is not (or has inadequate) breathing and heart rate is low:** Consider immediate actions. Detail level of support/stabilisation (eg full resus/limited resus/comfort care) | | | |
| Yes | No | Airway positioning | Explanation/narrative/further notes: |
| Yes | No | Airway adjuncts |
| Yes | No | Intubation |
| Yes | No | Oxygen/PEEP (mask) |
| Yes | No | Inflation breaths |
| Yes | No | Ventilation breaths |
| Yes | No | Chest compressions |
| Yes | No | Intravenous access |
| Yes | No | Cardiac drugs |
| **If baby is not breathing and heart rate is absent (no signs of life):** Consider immediate actions. Detail level of support/stabilisation (eg full resus/limited resus/comfort care) and “Wishes around end of life” section earlier in plan. | | | |
| Yes | No | Airway positioning | Explanation/narrative/further notes: |
| Yes | No | Airway adjuncts |
| Yes | No | Intubation |
| Yes | No | Oxygen/PEEP (mask) |
| Yes | No | Inflation breaths |
| Yes | No | Ventilation breaths |
| Yes | No | Chest compressions |
| Yes | No | Intravenous access |
| Yes | No | 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:** eg 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” | | | |
|  | | | |
| **Other wishes:** eg feeding; name bands; first bath; memory-making; keepsakes; family members/friends to meet baby; support for siblings; ceremonies; cultural and 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) eg symptom management plan, specialty care plan(s).

Please balance the risk (version control risk) of duplicating information already detailed in separate management plans whilst recognising this section can be very helpful for quick access in emergencies.

NOTE: For antenatal care plans – this section may be deferred (if desired) until assessment after birth.

**General Management**

|  |
| --- |
| **Current course of medical treatment:** eg 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 (also note if patent upper airway) and airway adjuncts |
|  |
| **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 discussions about subcutaneous access |
|  |
| **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 plans (eg respiratory care plans), etc |
|  |

**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”** and consider transfer to preferred place. Allergies listed at front

|  |
| --- |
| 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)** |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **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 absences of parent/carer | | | | |
|  | | | | |
| **In the event of life-threatening event, provide the following care:** add patient-specific detail below | | | | |
|  |  |  |  | **Comments** (patient-specific decisions eg duration) |
| **Basic Life Support** | **Yes** | **No** | **Airway repositioning** |  |
| **Yes** | **No** | **Airway adjuncts** |  |
| **Yes** | **No** | **Bag and mask/tracheostomy** (also note if upper airway patent)/mouth to mouth ventilation |  |
| **Yes** | **No** | **Chest compressions** |  |
| **Yes** | **No** | **Defibrillation** |  |
| **Airway** | Yes | No | Suction |  |
| Yes | No | Intubation/Supraglottic airway insertion (eg LMA) |  |
| **Breathing** | Yes | No | Supplementary oxygen if available |  |
| Yes | No | Highflow (eg Optiflow/Vapotherm) |  |
| Yes | No | Non-invasive ventilation |  |
| **Circulation** | Yes | No | Intravenous access |  |
| Yes | No | Intraosseous access |  |
| Yes | No | Cardiac/ALS drugs (usually in conjunction with chest compressions) |  |
| **Other** | Yes | No | Emergency transfer to hospital |  |
| Yes | No | Consider Intensive Care admission |  |
| **Additional comments about the above decision or relevant other decisions** | | | | |
| Please record details of implantable devices eg VNS/pacemaker/defibrillator, and management at end of life of these devices; long-term IV access; respiratory support (further details may be in separate care plans or “Anticipated Complications” page (eg may include specific information if a life-threatening emergency happens at school).  Consider revoking ACP for planned surgery, etc  Include preferences of transfer, eg local hospital or specialist centre if more suitable (**Note:** preferences may not be possible depending upon situation and local policies.  Consider how interventions will be carried out for emergency clinicians and on-going management plans | | | | |
|  | | | | |

**Summary Plan for Emergency Care and Treatment**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **1** | **Preferred name:** |  | **Date completed:** |  |
| **2** | **Shared understanding of my health and current condition:** | | | |
| **Summary** of relevant information for this plan including **diagnosis** and **relevant personal circumstances:** | | | | |
| **This is part of the Advance Care Plan for an ante-natal baby. Before the baby is born it is likely this will be stored on the mother’s records. PLEASE NOTE: THIS DOES NOT CORRESPOND TO THE MOTHER. See the rest of the care plan for appropriate plans for the ante-natal baby.**  **Signatures and contact numbers can, however, be completed on the following page.** ***(Delete this and amend accordingly once baby is born and stored in an appropriate place)*** | | | | |
| Details of other relevant planning documents and where to find them (eg Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency Plan for the carer): | | | | |
|  | | | | |
| **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** | | | | |
| **This is is part of the Advance Care Plan for an ante-natal baby. Before the baby is born it is likely this will be stored on the mother’s records. PLEASE NOTE: THIS DOES NOT CORRESPOND TO THE MOTHER. See the rest of the care plan for appropriate plans for the ante-natal baby.**  **Signatures and contact numbers can, however, be completed on the following page.** ***(Delete this and amend accordingly once baby is born and stored in an appropriate place)*** | | | | |

|  |  |  |
| --- | --- | --- |
| CPR attempts recommended  Clinician signature | For modified CPR (Children and Young People)  Clinician signature | CPR attempts **NOT** recommended  Clinician signature |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **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 ReSPECT 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 confirmation 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 clinical record): | | | | | | | | | | | | | |
| Record date, names and roles of those involved in decision-making, and where records of discussions can be found: | | | | | | | | | | | | | | |
| **6** | **Clinicians’ signatures** | | | | | | | | | | | | | |
| **Designation** (grade/specialty) | | | | | **Clinician name** | | **GMC/NMC/HCPC Number** | | | **Signature/image** | | | **Date/Time** | |
|  | | | | |  | |  | | |  | | |  | |
|  | | | | |  | |  | | |  | | |  | |
| **Senior responsible clinician:** | | | | | | | | | | | | | | |
| **Designation** (grade/specialty) | | | | | **Clinician name** | | **GMC/NMC/HCPC Number** | | | **Signature** | | | **Date/Time** | |
|  | | | | |  | |  | | |  | | |  | |
| **7** | **Emergency contacts and those involved in discussing this plan** | | | | | | | | | | | | | |
| **Emergency contact name**  **(Primary contacts in purple)** | | | | | **Role/Relationship** | | **24 hr contact**  Tick if Yes | | | **Emergency contact number** | | **Signature**  (optional) | | |
| Patient/family: | | | | |  | |  | | |  | |  | | |
| Patient/family: | | | | |  | |  | | |  | |  | | |
| Professional: | | | | |  | |  | | |  | |  | | |
| Professional: | | | | |  | |  | | |  | |  | | |
| Professional: | | | | |  | |  | | |  | |  | | |
| **8** | **Form reviewed (eg for change of care setting) and remains relevant** | | | | | | | | | | | | | |
| **Review date** | | | | **Designation** (grade/specialty) | | **Clinician name** | | | | | **GMC/NMC/HCPC Number** | | | **Signature** |
|  | | | |  | |  | | | | |  | | |  |
|  | | | |  | |  | | | | |  | | |  |