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| Description: Description: Description: The Hains I:Users:wmdrdh1:Dropbox:Work:Slides and pictures:WMCN logo (cropped).jpg | All-WalesPaediatric Palliative Care **Network** |

*“Emergency care planning with families of children with life-limiting conditions is possible months or years before the end of life. Advance decisions evolve over time through the development of a trusting relationship and an ethos of shared decision-making.”*

*Arch Dis Child 2010;****95****:79-82 doi:10.1136/adc.2009.160051*

Name: Tinker Bell

Date of Birth: 01/01/2014

NHS number: 111222333444

Date of this review: 01/01/2018

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| *PLEASE NOTE:*   * This document is not legally binding. It is a record of discussions about preferences for what happens in the event of a child becoming seriously unwell. * For it be effective, relevant portions must be easily identifiable by ambulance staff in an emergency. The edges of Section 5 printed in grey. Please also print a second copy of those pages on coloured paper and save it at the back of this document for ease of access. |

# **Section 1: Frequently asked questions**

*1.1. What is this document for ?*

PAC-Plan is a tool for discussing and communicating the wishes of a child, young person and/or their family. Its main aim is to explore the various things that might happen as a child’s illness progresses (particularly towards the end of life), but at a point when there is plenty of time to discuss them. The PAC-Plan has three functions:

1. It offers the child or family an opportunity to explore what might happen in the event of a sudden serious event. Some of those can be reversed, but others cannot, or could only be reversed by treatments that would be too unpleasant to bear.
2. It records that those discussions have taken place.
3. It documents what the child and/or family has expressed about each of those three potential scenarios, in a way that is easily accessible to the medical team at the time discussions about treatments need to take place (usually in a hospital ward, casualty or intensive care unit) because a sudden serious event has occurred.

PAC-Plan can include specific plans for managing (eg) pain, seizures or other symptoms, or ‘Wishes’ documents. Those plans are referred to in the PAC-Plan as modules.

*1.2. When should these discussions take place ?*

As a general rule, as early in the course of an illness as possible, because it offers the greatest opportunity to explore what might happen as the child’s illness progresses. The right time to introduce the PAC-Plan process depends on the needs of the individual child and family.

*1.3. Who can use the PAC-Plan ?*

Any member of the Healthcare Team can take the lead in the PAC-Plan process, workingin collaboration with colleagues. The child’s main consultant should usually be involved in the discussions but does not have to take the lead at all times.

*1.4. Is it legally binding ?*

No. The document records your discussions, **but it does NOT AT ALL mean you cannot discuss those issues again, or change your mind at some point in the future**. Only the section relating to permission to disseminate the information represents a form of consent. We do suggest the document is signed by both consultant and patient or family. That makes it more likely the document will be acted on, but it is not strictly necessary, and some families never feel able to sign it. There is still considerable value in the PAC-Plan discussions, and in completing the rest of the document as a record.

*1.5. Will I have a chance to discuss these issues again ?*

Yes. You can ask to have these discussions again at any time. Ideally they should be discussed every 6 – 12 months anyway, even if there have been no changes.

# **Section 2: Background to this review**

**2.1**. Date first completed: 01/01/2016 by Dr Bear.......................

Date last amended: met on 01/01/2017 by Dr. Owl

Date to be reviewed: by

(usually < 12 months)

**2.2 Additional modules**

This PAC-Plan includes the following specific modules (please circle):

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| --- | --- | --- | --- |
| Epilepsy plan | Wishes document | Ventilation support plan | Other (2) |
| Symptom control plan  √ | Organ donation  √ | Other (1) | Other (3) |

**2.3 The Plan was discussed with:**

* ~~Patient~~

√ Mother/ Father

* ~~Other family, especially grandparents~~

√ Other e.g. nurse~~/respite/key worker~~

* ~~Local authority ❑ Local authority has overriding parental responsibilty.~~

**2.3. Background information (including diagnosis, significant problems, usual level of health and well-being and reason for completing PAC-Plan at this particular time).**

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| Tinker has the following conditions.   * Rare condition not progressive * Multiple and serious congenital anomalies - life threatening and not amenable to surgical correction. * Upper airways obstruction, tachypnoea and possibility of central hypoventilation. * Scoliosis. * Variable muscle tone. * Pain. * Gastro-oesophageal reflux. * Excessive drooling.   Tinker is a delightful, happy young lady who enjoys interactions with others and demonstrates this with sounds and full smiles. Tinker lives with her parents and older sister. Tinker is reliant on her parents for all care needs. Tinker enjoys multisensory play.  Tinker until recently attended school but following the admission to the Paediatric Intensive Care Unit as been too fragile to attend. Tinker is thought to have some degree of background discomfort/pain which could be gastric or bony in origin. When pain is more severe, Tinker will express this through cries, otherwise it is difficult to assess her pain.  Tinker’s family have discussed with the team their thoughts about the appropriateness of escalation of care in relation to the use of invasive ventilation. Their thoughts are that Tinker should still receive other interventions such as planned surgery or treatment of acute infection (including intravenous antibiotics). If Tinker was to have a cardiopulmonary arrest her family do not think it would be in her interest to provide resuscitation and invasive ventilation.  Tinker’s family do not want her to die in the hospital, they would like to go home if there were services they could call at anytime. They would also like to know about organ donation.  ***Using the above information discuss as a group and complete the Paediatric Care Plan.*** |

# **Section 3: About other people in the family**

**3.1 Whom to call.**

This should be the name of the professional the child or family would want to be contacted first if there were a sudden and severe deterioration.

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| **Name of person to call** | **Contact number** |
| Parents - Mrs Polly Bell &  Mr Rupert Bell | 01234567891 & 01987654321 |

**3.2. Parents/ Main Carers (these should be the people who usually care for the patient).**

|  |  |  |  |
| --- | --- | --- | --- |
| **Name** | **Relationship to child** | **Parental responsibility?**  **Y/N** | **Contact telephone number** |
| Polly Bell | Mother | Yes | 0111 222333/  01234567891 |
| Rupert Bell | Father | Yes | 0111 222333  /01987654321 |
| Noddy Bell | Grandfather | No | 0222 333444 |
| Dolly Bell | Grandmother | No | 0222 333444 |

**3.3 Who can give consent.**

The patient to whom this PAC-Plan refers is:

* ~~A child who is ‘Gillick competent’ and can give consent on his/her own behalf.~~

√ A child whose parents or guardian have parental responsibility and can give consent on his/her behalf.

* ~~Someone with capacity under the 2005 Mental Capacity Act (MCA), who can give consent on his/her own behalf.~~
* ~~Someone who lacks capacity under the MCA in whom best interests must be decided according to the MCA.~~
* ~~Subject to other legal protection e.g. care order, court decision.~~

# **Section 4: Planning ahead**

Life-limiting conditions in childhood often cause a slow deterioration over many months or even years. Sometimes, however, there can be sudden illnesses that are serious enough to pose an immediate threat to life. Often these involve the breathing. Some can be reversed with the help of medical interventions. Others can’t, or else can only be reversed by treatments that would be too unpleasant to bear. The purpose of this section is to explore the most appropriate treatment for each of those possibilities.

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| **BRIEF detail of medical condition (please note that Section 5 of the PAC-Plan is all that is seen by police and ambulance crew. Information in this box should summarise box 2.4)**  Tinker has the following conditions.   * Multiple and serious congenital anomalies - life threatening and not amenable to surgical correction. * Upper airways obstruction and possibility of central hypoventilation   Tinker should have assessment for any treatment of reversible causes. Cardiopulmonary resuscitation and initiation of intensive care and intubation should not be attempted and is not in Tinker’s best interests. This has been discussed by the multidisciplinary team and Tinker’s parents on several occasions and this is the current agreement between professionals and parents. |

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| **4.1: Management of a sudden, severe deterioration caused by something that can be reversed:**  This might include a problem during anaesthesia or an episode of choking in which there are medical interventions that can resolve the problem without being unbearable for the patient.  **√** Under these circumstances, all appropriate measures should be taken to reverse the problem. |

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| **4.2: Management of slow, life-threatening deterioration:**  NB Comfort and support of child and family, and attention to management of symptoms (see symptom control module where appropriate) are part of routine care in all patients.  This would require further discussion with medical staff to ensure that treatment for a potentially reversible cause is appropriate. If this was not possible then preferred place of care would be decided at the time as parents would prefer home.  √ Transfer to **Star Town Hospital Paediatric Assessment Unit** (preferred place  of care).  √Transfer to high dependency unit.  √ Use of high flow oxygen in the first instance **if it will help maintain comfort**.  √  ~~Use of invasive intubation and ventilation (ie transfer to intensive care unit environment).~~ |

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| **4.3:Management of a sudden, severe deterioration that cannot be reversed, or could only be reversed by treatments that are unpleasant for the patient:**  **Tinker should have assessment for any treatment of reversible causes. Cardiopulmonary resuscitation and initiation of intensive care and intubation should not be attempted and is not in Tinker’s best interests. This has been discussed by the multidisciplinary team and Tinker’s parents on several occasions and this is the current agreement between professionals and parents.**  NB Comfort and support of child and family, and attention to management of symptoms (see symptom control module where appropriate) are part of routine care in all patients. In addition to comfort measures as above: **If Tinker has a heart beat:-**  ~~Comfort measures only; no medical attempt to reverse the problem.~~  √Suction upper airway and other airway clearance techniques.  √Oxygen via face mask or nasal cannulae, if it helps symptoms.  √Airway management including oral / nasopharyngeal airway **if it will help maintain comfort**.  √Mouth to mouth (or bag-and-mask) for five inflation breaths.  √Call 999 and transfer to **Star Town Hospital Paediatric Assessment Unit**  √Give fluids and drugs intravenously if possible. Otherwise use enteral route.  √~~If that is not possible, give fluids and drugs via an intraosseous needle (i.e. one that goes into the bone).~~  √Consider transferring to high-dependency in Star Town Hospital ~~or intensive care~~  ~~environment.~~  √Use of high flow oxygen in the first instance **if it will help maintain comfort**.  √ Consider non-invasive ventilation via Continuous Positive Airway Pressure (CPAP)  following discussion with senior medical staff and parents **if it will help maintain comfort**.  ~~❑ Consider putting a tube into airway and attaching it to a ventilator. That would mean~~  ~~transferring to intensive care.~~   * ~~If the heart stops, consider attempts to get it started again using chest compressions or an electric defibrillator. That would also mean endotracheal tube and intensive care as above.~~   **If Tinker is found without a heartbeat and with no respiratory effort, please allow her to stay with her family and experience comfort and a dignified death without attempts to restart her heart.** |

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| The PAC-Plan document provides a guide in providing care for this child in the event of a deterioration at the end of life. It is compiled in detailed discussions with the family and, where possible, the child. But those discussions cannot predict all eventualities. Notwithstanding the preferences recorded in this document, individual professionals are obliged to use their professional judgment to act in the best interests of the child, and to instigate further discussions regarding treatment if situations change. |

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| **5.: Organ donation**  Although organ donation is not always possible for children who have life-limiting conditions, all families should be offered the opportunity to discuss it with the local organ donation lead nurse.   * We have discussed this, and are not planning to take it any further.   √ We have discussed this, and will contact the lead nurse on 0777 777777 (contact number). Please see organ donation module. |

# **Section 6: Agreement with discussions**

**6.1 PAC-Plan lead (person leading on discussions e.g. specialist nurse)**

Signature: Designation:

Name (PRINT): Date:

**6.2 Senior Clinician’s agreement**

I support this Paediatric Advance Care Plan.

Signature: Designation:

Name (PRINT): Date:

*A consentee’s signature supports that this document is an accurate representation of discussions held with named professionals to date. It is not binding. Discussions within the PAC-Plan can be revisited at any time and should be reviewed regularly.*

**6.3 Child or young person’s agreement**

I have discussed the treatment and care outlined in this PAC-Plan with the appropriate professionals. I confirm that the Plan accurately represents the wishes I have for care and treatment for me………………………………… ( name of child/young person)

I understand that before any of the treatment commences I will be asked (wherever possible)

whether I still consent to it.

Child/ young person signature: Date:

**6.4. Parent or Guardian’s agreement**

I/We have discussed the treatment and care outlined in this PAC-Plan with the

appropriate professionals . I/We confirm that the Plan accurately represent the wishes

I /we have for care and treatment for …………………………( name of child/ young person)

I/we understand that before any of the treatment commences I / we will be asked whether

I /we still consent (s) to it.

Name & signature: Date:

Name & signature: Date:

**6.5. Statement of interpreter** (where appropriate)

I have interpreted the information above to the child/young person/parent to the best of my ability and in a way in which I believe the child/young person/parent can understand.

Name & signature: Date:

# **Section 7: Permission to share information with others**

**7.1 We will send copies of this Plan to:**

|  |  |  |
| --- | --- | --- |
|  | Yes/No  and initial added by Consentee |  |
| Local PAC-Plan coordinator (responsible for dissemination) | **Yes** | **Alice Wonderland Palliative Care Nurse Star Town Hospital** |
| Parents/Guardians | **Yes** | **Polly Bell & Rupert Bell** |
| Hospital notes | **Yes** | **Star Town Hospital** |
| Local Hospital paediatrician(s) | **Yes** | **Dr Rabbit Star Town Hospital** |
| Community paediatrician | **Yes** | **Dr Bear Star Town Hospital** |
| GP | **Yes** | **Dr Mouse Cloud Surgery Star Town** |
| GP out of hours service | **Yes** | **Star Town Hospital** |
| Other Hospital departments  Children’s Assessment Unit | **Yes** | **Paediatric Assessment Unit c** |
| Community Nurses including Clinical nurse specialists | **Yes** | **Cloud Surgery Star Town** |
| (Audit file)  (With child/young person/ parental consent) | **Yes** | **Dr Owl Star Town Hospital** |
| School health nursing team |  |  |
| Social Worker or Special Needs Health Visitor | **Yes** | **Mrs Bo Peep Cloud Surgery Star Town** |
| Children’s Hospice |  |  |
| School/ College Head teacher (with consent to share with school staff) |  |  |
| Other e.g Social Care, short break care provider | **No** |  |
| Welsh Ambulance NHS Trust Directed to Deputy Director of Medical and Clinical Services / Consultant Paramedic and the Named Professional Safeguarding Children. | **Yes** | Plan will be sent via post, secure email or via a safe haven fax. In the first instance phone 01792 315884 to inform the Safeguarding Team that Plan is being sent and by what method |
| Police | **Yes** | Police: North Wales 01407 724469  South Wales 01656 305944  Dyfed Powys 01267 226370  Gwent 01495 745590  Out of hours: Local Public Protection Unit Tel 101  *The Police will be informed of Plan’s existence, but they will not usually receive a copy of it.* |

**7.2 Consent to Information Sharing**

I agree to the sharing of information contained within this advance and emergency care pathway with the agencies listed above (agreement confirmed by ‘yes’ and initial). I understand that withholding consent to sharing of information may limit the utility of the ECP. All the information that will be shared and the reasons why have been explained to me. I have had the opportunity to discuss any issues arising from this matter.

Signature: (Child/young person/Parent /Guardian)\*

Name (PRINT): Date:

Second signature where needed: (Parent /Guardian)\*

(eg if consentee above is a child):

Name (PRINT): Date:

\*Delete as appropriate

(Or, if patient is over sixteen years of age:

This patient has been assessed under the MCA and is considered to lack capacity. In accordance with MCA, the Lead Consultant has considered the best interests of the patient and, after appropriate consultation set out that Act considers it to be in the patient’s best interests for the information to be shared with the people/organisations set out above.

Signature: (Lead consultant)

Name (PRINT): Date: