 

All-Wales Paediatric Palliative Care Network

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| This pathway has been produced in partnership with Tŷ Hafan Children’s Hospice.  **Version 1. May 2019** |

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| Clinical Care Pathway |
| Neonatal Palliative Care Transfers to Hospice |
| **Rebekka Jones** Neonatal Medicine Grid Trainee  **Tim Warlow** Paediatric Palliative Care Grid Trainee |

# A. Suitable patients for a palliative care transfer

Consideration of transfer to a hospice should be given to any infant

1. who meets criteria for withdrawal of life-sustaining treatments (Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. RCPCH 2014):
2. and who is deemed stable for transport.

In addition, transfer to a hospice bed may also be arranged after the infant has passed away in hospital, so that the family can spend more time together. In this situation the parents may organise their own transport rather than using ambulance transport.

When a hospice transfer is deemed inappropriate or unsafe, the hospice can still offer support services to the family and the hospital team where appropriate and referrals are welcome if the parents wish to be referred.

# B. Referral

The following referral process is for guidance only and does not necessarily need to be followed in the suggested order (i.e. discussion with parents regarding possible hospice transfer might precede liaison with the hospice provided the parents are made aware that this is not always possible) if deemed appropriate.

1. Liaison with Tŷ Hafan regarding possibility of transfer of a baby for palliative care.

**Tŷ Hafan**

Main office telephone: 02920 532200.

Ask to speak to Clinical Nurse Specialist (CNS).

1. If hospice transfer deemed appropriate and possible, discussion with parents to explore their wishes regarding end of life care in the hospice setting.
2. Referral to Tŷ Hafan and the palliative care team if parents wish to be transferred to the hospice:

**Palliative Care team**

Dr Tim Warlow (Paediatric palliative care grid trainee): Pager 07623906243

* 1. Normal working hours:
     + **Cardiff and Vale/Aneurin Bevan/Cwm Taf Health Board**:

Dr Richard Hain (Consultant in Paediatric palliative medicine)

Tel: 02920744490 or 07976552529

* + - **Abertawe Bro Morgannwg Health Board**:

Dr Jo Griffiths (Consultant in Paediatric palliative medicine and Community child health)

Tel: 01792517837

* 1. Out of hours: Contact on-call Consultant through switchboard.

1. Tŷ Hafan +/- palliative care team to visit family in hospital the same or next day.
2. Transfer logistics to be agreed between NICU, hospice, palliative care team and family:
   1. Date and time of transfer. Aim to transfer during normal working hours as no out-of-hours resident medical cover at Tŷ Hafan.
   2. Dedicated doctor and nurse team required for transport (no other clinical duties and ideally not on transport cover).
   3. Transport options:
      * **St. John Cymru ambulance**: St. John’s ambulance service is able to provide a suitable ambulance (with driver) for neonatal palliative care transfers including transfers with transport incubators. Commissioning for palliative care transfer needs to be agreed by the referring NICU prior to transfer. Bookings should be made at the earliest opportunity (usually at least 24 hours in advance) as St. John’s are unlikely to be able to provide a service at very short notice.

For quotations and bookings contact: 02920 449631

* + - **Cymru inter-Hospital Acute Neonatal Transfer Service (CHANTS)**: CHANTS is the dedicated acute neonatal transfer service for South Wales. The service is provided by neonatal staff in Cardiff, Newport and Swansea working a 1-week-in-3 in rotation. CHANTS are unlikely to be able to support transfers of palliative patients as these should be carried out by teams knowing the patient and the family and CHANTS need to be available to provide timely emergency transfers of unwell infants. Please refer to the CHANTS Wales Neonatal Network guideline on palliative care transfers for further information.

For discussion of any infants please contact the duty team on service:

Hours of Duty 8am – 8pm, 7 days a week; change over on Monday 8am;

Swansea Team 01792 285278

Cardiff Team 02920 742680

Newport Team 01633 234844

* + - **999 ambulance**: Due to the highly sensitive and emotional nature of palliative care transfers and the need for careful planning of such transfers, consideration should be given to alternative options before planning to use a 999 ambulance.
    - **Welsh End of Life Ambulance Service:** For neonates requiring transfer who DO NOT require transport in a transport incubator and/or intensive care during transport, the end of life ambulance service can provide transport to the preferred place of care. The service operates across the whole of Wales and is run by the Welsh Ambulance Service.  Crews are non-medical so neonates requiring nursing or medical support will need to be accompanied by appropriate staff. Only some ambulances have power points. There is no suction or gas supply on board.

The service operates during the following hours:

Hours of duty: Monday – Friday 09.30 – 21.30, Saturday 09.00 – 19.30, Sunday – closed;

For referral please contact 03001239210 between these hours. Bookings can be placed in advance and as this is a dedicated end of life service this is often the most flexible and reliable transport option for rapid response or pre booked transport.

1. NICU staff to arrange MDT to discuss and agree care plan. MDT should include:

Responsible Consultant

Consultant undertaking transport

Neonatal nurse

Hospice team

Palliative care team

Bereavement midwife or other NHS support staff

Pharmacist if possible

1. NICU staff to complete attached care plan (see guidance notes for completion on page 6).

1. All medications required at Tŷ Hafan to be prescribed on hospital drug chart, TTO and Tŷ Hafan drug chart as advised by the palliative care team.
   1. All infusions to be prescribed as subcutaneous infusions.
   2. All infusions to be made up in sterile H2O.
   3. All medications to be prescribed and supplied for 2 weeks.
2. Ensure all relevant medical professionals are aware of the transfer:
   1. Named neonatal Consultant, on-service Consultant and on-call Consultant.
   2. Hospice GP Dr Lewis (07764574877) or on-call GP at West Quay Medical centre.
   3. Hospice Consultant Dr Megumi Baba (07879815755) or on-call PPM Consultant Dr Richard Hain (07976552529) or Dr Jo Griffiths (01792517837) in Dr Baba’s absence.
3. Additional points for consideration:
   * Parents may wish to visit Tŷ Hafan prior to transfer if time allows.
   * Receiving Clinical Nurse Specialist (CNS) or Consultant at Ty Hafan to ensure all senior and middle managers are made aware of the transfer by emailing:

[careserviceseniormanagmentteam@tyhafan.org](mailto:careserviceseniormanagmentteam@tyhafan.org)

[careserviceteamleaders@tyhafan.org](mailto:careserviceteamleaders@tyhafan.org)

[clinicalnursespecialists@tyhafan.org](mailto:clinicalnursespecialists@tyhafan.org)

[caremiddlemanagers@tyhafan.org](mailto:caremiddlemanagers@tyhafan.org)

1. Ensure relevant health board’s paediatric palliative care CNS aware of transfer and liaise with them as required:

Pat O’Meara Aneurin Bevan 07957640530

Kath McSorley Cardiff & Vale 07970465787

Lynette Thacker ABMU 07773281621

Vera Clements Cwm Taf 07798668051

Jayne Thomas Hywel Dda 07887948909

CCN Sarah Catterall Powys 07886113088

**Guidance notes for completing the patient care plan**

The patient care plan has been adapted from the North West Perinatal/Neonatal Palliative Care Guideline.

1. The care plan should be initiated and Section 1 completed as soon as transfer to hospice has been agreed.
2. Section 2, 3 and 4a relate to the planning of transfers and should be completed when such plans have been discussed and agreed with the family.
3. Section 4b and 4c are discharge checklists to ensure a planned transfer can go ahead.
4. Section 5 is a checklist for procedures following arrival at the hospice which includes the process of extubation.
5. Section 6 includes information regarding the transfer of the baby and should be completed for all babies even if the transfer was uneventful.
6. Section 7 consists of continuation sheets to be used for documentation by the transferring team during transfer and following arrival at the hospice.
7. The completed care plan including continuation sheets should be photocopied and copies left for hospice records.
8. The original completed care plan should be taken back to the referring hospital and stored as part of the individual patient record.

**Section 1: Patient details**

*Attach patient hospital ID label*

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| **To be completed by Neonatal Consultant** | |
| Date and time care plan initiated | / / \_\_\_:\_\_\_ |
| Baby’s name | Sex: Male□ Female□ |
| Diagnosis |  |
| *Free text*  ……………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………... | |
| Family details | |
| Mother’s full name | Parental responsibility: Yes□ No□ |
| Mother’s address  (if different to addressograph) |  |
| Mother’s main contact number |  |
| Partner’s full name | Parental responsibility: Yes□ No□ |
| Partner’s address  (if different to addressograph) |  |
| Partner’s main contact number |  |
| Parental relationship | Married □ Co-habiting □ Separated □ Other □ |
| Siblings’ names and ages |  |
| Other contact numbers for family |  |

**Section 2: Contact details of professionals**

*Attach patient hospital ID label*

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| **To be completed by Neonatal Team** | | |
| Professional | Name | Contact Number |
| Named Consultant |  |  |
| On-service Consultant |  |  |
| Obstetric Consultant |  |  |
| Lead Nurse |  |  |
| Transporting Consultant |  |  |
| Transporting Nurse |  |  |
| Hospice Nurse |  |  |
| Hospice Consultant | Dr Megumi Baba | 07879815755 |
| Paediatric palliative care Consultant |  |  |
| Spiritual support / Counsellor |  |  |
| Ty Hafan GP | Dr Lewis | 07764574877 |
| Family GP |  |  |
| Community Midwife |  |  |
| Health Visitor |  |  |
| Other |  |  |
| Other |  |  |
| Other |  |  |
| Other |  |  |

**Section 3: Communication**

*Attach patient hospital ID label*

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| **To be completed by Neonatal Consultant and Neonatal Nurse** |
| **Family’s hopes and wishes at the end of life, at time of death and post death** |
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| **Memory creation** |
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| **Spiritual/religious needs explored** |
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| **Tissue donation (if possible and appropriate)** |
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| **Possibility of accidental extubation during transfer** |
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| **Possibility of death during transfer** |
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| **The process of extubation and post extubation care** |
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| **Other** |
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**Section 4a: Pre-transfer Checklist**

*Attach patient hospital ID label*

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| **To be completed by Neonatal Consultant** | **Initials** |
| **Pre-transfer planning** | |
| It is agreed that the harms to this patient of continuing or instituting life-sustaining interventions are likely to outweigh their benefit |  |
| Parents aware that transfer means no prospect of re-intubation |  |
| Spiritual needs have been assessed and arrangements made for spiritual support as appropriate |  |
| Mother fit for discharge |  |
| Transfer arrangements  Mode of transport:  Doctor name: Agreed date:  Nurse name: Parents transport: own / ambulance (please circle) |  |
| Clear medication plan, including routes of administration appropriate to receiving location |  |
| Clear feeding and fluid plan communicated to receiving team |  |
| Parallel plan in case of survival post extubation □  Plan for hospital admission and resuscitation □  Plan for feeds/fluids and on-going management □ |  |
| **End of life care and resuscitation discussed with the family** | |
| Section 3 of this form completed and printed |  |
| PAC plan completed and printed or if PAC plan not completed, family agreed to limit treatment to comfort measures only (please circle) |  |
| **Practical issues** |  |
| 7-day supply of equipment provided for on-going care provided including oxygen/suction/monitoring, feeding tubes and pumps, catheters/pads, syringes/drivers |  |
| 14-day supply of regular and symptom management medications provided |  |
| EBM as available or 7-day supply of formula to be taken if appropriate  Not appropriate / EBM / Formula: (please circle and specify formula) |  |
| Hospital discharge letter completed and printed |  |
| All teams aware for the procedures following death:  Death confirmation Team responsible: Death certification Team responsible:  Discussion with/referral to coroner required yes / no Doctor name:  If coroner’s post mortem not required, do parents wish for a post mortem (usually to be discussed after the baby’s death)? yes / no / not yet discussed (please circle)  Data submission to MBRRACE-UK and WPSU Child Death Review Panel Doctor name:  Has the baby birth been registered already? yes / no  Communication with the child’s care teams including GP following death:  Team responsible: Ty Hafan □ Palliative Care CNS □ Neonatal Team □ (if death during  transfer) |  |

**Section 4b: Nursing discharge summary**

*Attach patient hospital ID label*

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| **To be completed by nursing staff** | |
| Current ventilation |  |
| Current respiratory problems (i.e. secretions) |  |
| Nutrition |  |
| Elimination (i.e. stoma) |  |
| Pain management (including route of administration) |  |
| Symptom management (i.e. vomiting, seizures) |  |
| Skin condition and care |  |
| Any known infections |  |
| Personal items for transfer with baby |  |
| Any other relevant information |  |
| Name: Designation:  Signature: Date and Time: | |

**Section 4c: Discharge checklist**

*Attach patient hospital ID label*

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| **To be completed by nursing staff** | **Initials** |
| Confirmation of cot at hospice Date: Time: |  |
| Appropriate professionals contacted on discharge |  |
| Pre-transfer care plan (Section 4a.) complete |  |
| Badger discharge summary complete |  |
| Necessary equipment supplied |  |
| Milk (EBM or formula) supplied (if appropriate) |  |
| Discharge medication dispensed and ready for transfer |  |
| Name: Designation:  Signature: Date and Time: | |

**Section 5: Post-transfer checklist**

*Attach patient hospital ID label*

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| **To be completed by Neonatal Consultant** | **Initials** |
| **On arrival at hospice** | |
| Receiving team confirms the plans for extubation, medication, symptom management, fluids and feeding |  |
| The family’s agreement for extubation confirmed |  |
| Provide the family with time and appropriate privacy to complete rituals/wishes |  |
| **Withdrawal of life-sustaining treatments discussed with the family** | |
| Process of extubation |  |
| Preferred role/participation at time of extubation |  |
| Symptoms and signs that may occur post extubation |  |
| Explain that death may not occur in the expected time frame and the child may survive longer |  |
| **Extubation process (NICU team to lead this and remain at hospice until completed)** | |
| Commence medication for symptoms as required |  |
| Discontinue monitoring if still in place and silence alarms (incl. ventilator alarms) |  |
| Suction ETT and mouth immediately prior to extubation |  |
| Remove ETT and place out of sight |  |
| Turn off ventilator |  |
| **Post extubation** | |
| Review symptoms and initiate/continue treatment as required |  |
| Review fluid/feed management plan |  |
| Ensure receiving team have a copy of the PAC plan, medical and nursing discharge summary |  |

**Section 6: Transfer feedback**

*Attach patient hospital ID label*

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| **To be completed by the transferring team and receiving hospice team** |
| **Did the baby die during transfer**: Yes □ No □ (if no skip to +)  If yes, time of death: \_\_:\_\_ Place of death:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  **Death verified by:**  Print Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Designation:\_\_\_\_\_\_\_\_\_\_\_\_ Ext:\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Signature:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_/\_\_/\_\_ Time:\_\_:\_\_  **Death certified by:**  Print Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Designation:\_\_\_\_\_\_\_\_\_\_\_\_ Ext:\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Signature:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_/\_\_/\_\_ Time:\_\_:\_\_  Time of arrival at transfer destination:\_\_:\_\_  NB. The certifying doctor needs to circle the ‘not seen’ on Option C of the Death Certificate if they were not present at the time of death.  **Datix completed:** Yes □ No □ **Datix number:** |
| +**Transfer documentation received** Yes □ No □ |
| **Any other significant events during transfer:**  **Datix completed:** Yes □ No □ **Datix number:** |
| **Is there anything that may have been useful for the baby’s transfer?** |
| Handed over by:  Print Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Designation:\_\_\_\_\_\_\_\_\_\_\_\_ Ext:\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Signature:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_/\_\_/\_\_ Time:\_\_:\_\_ |
| Handover received by:  Print Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Designation:\_\_\_\_\_\_\_\_\_\_\_\_ Ext:\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Signature:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_/\_\_/\_\_ Time:\_\_:\_\_ |

**Section 7: Transfer documentation**

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**Section 7: Transfer documentation**

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