

Name  
DOB  
Hosp no

# Neonatal Comfort Care Plan

This Neonatal Comfort Care Plan (NCCP) is a multidisciplinary document to aid communication between professionals and agencies. In particular it is designed for use when changing settings of care (community or hospice) for any infant who has been diagnosed with a life-limiting illness but is not necessarily dying. Use in conjunction with Checklist 4 of the Neonatal care bundle. It is parent-held and when discontinued it should be filed in the hospital medical notes.

**Date and time Care Plan commenced**..... **Reason (RCPCH criteria 1-5)<sup>1</sup>**.....

**Consultant** .....**Signature** .....**GMC**.....

**Named Consultant** .....**Signature** .....**GMC**.....

**Consider a full reassessment and review if there is:**

- Improved conscious level, functional ability, oral fluid tolerance
- Concerns expressed regarding management plan from parent/carer or team member
- At least every 5 days irrespective of the above to ensure continuing this NCCP is appropriate to the baby's needs

**If the Care Plan is discontinued:** Date and time discontinued.....

Reasons for discontinuation: .....

Confirm that the decision to discontinue the Care Plan was shared with the parent/carer Yes

Is the current location the parent/carer's preferred place of care for their baby? Yes  No

If not where would they prefer their baby to be.....  
(Discuss availability of other options for before and/or after death – see supplementary section for resources)

Parent name	Contact details	Relationship	Parental responsibility?

Key worker name	Position	Contact details

**"Key workers" above may include GP, Health Visitor or other professionals involved in the care and needing to use this NCCP**

**In the event of emergency, contact:**

<sup>1</sup> "Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework For Practice" (Second Edition), RCPCH, 2004. [http://www.bapm.org/publications/documents/guidelines/Withholding&withdrawing\\_treatment.pdf](http://www.bapm.org/publications/documents/guidelines/Withholding&withdrawing_treatment.pdf)

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## Medical Care Summary

### Section 1 - Diagnosis

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### Section 2 - Resuscitation status

DNACPR? **YES/NO**                      EHCP? **YES/NO**

### Section 3 - Comfort plans

Environment  
 Monitoring  
 Feeding  
 Minimising interventions, medications

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### Section 4 - Symptom control

Plan and prescribe for specific symptoms as appropriate

Plans for parents 'just in case'  
 - in the event of specific symptoms  
 - in the event of acute deterioration

Is a community prescription chart needed?

### Section 5 - Parallel planning

Consider making plans for the possibility of the baby surviving beyond expectations:

- Applying for Fast track Continuing Health Care provision
- Referral to Hospice for respite or palliative support
- Referral to social services for support

access to all financial benefits

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### Section 6 - Plans for ongoing review

Detail plans with GP, HV, Children's community nurse, Paediatrician (as appropriate)

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**Sign on completion of Medical Summary:**

**Doctor** ..... **Signature** ..... **GMC**.....

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## Multidisciplinary assessment and review

Use a new copy of this page to document a review, progress and document plans. E.g. Home visit by GP / CCN / HV

<b>Date of review:</b>	
<p><b>ASSESS</b>            Parent concerns:            - Events            - Changes in symptoms            - Changes in feed tolerance</p> <p>Examine:            - Mouth, skin integrity            - Is there any pain, distress, airway secretions, breathlessness, seizures or spasms?</p> <p><b>CHECK</b>  <b>Has there been a significant deterioration or improvement in condition?</b>            Is there a potentially reversible cause for the baby's condition e.g. renal failure, infection?</p> <p><b>MANAGEMENT</b>            - Changes in care at this complex, uncertain time are made in the best interest of the patient and will need to be reviewed regularly. Does the current management plan need to change?            - Do any drug doses or routes require adjustment?            - Is more specialist palliative review required?</p> <p><b>SETTING</b>            - Are there any spiritual care needs?            Consider wishes, feelings, faith, beliefs, values as well as specific religious and cultural needs.            Consider music, art, poetry photographs, something that is important to them or their well-being            -Are there specific needs at the time of death?</p> <p>- Is the baby in the parents' preferred place of care?            - Holistic needs of the family            - Are parents' needs addressed?            - Is more support needed?</p> <p>- Do parents' have any specific priorities?            - Can these be facilitated?            - Are there siblings? Is more support, help or information needed?</p> <p><b>COMMUNICATION</b>            - What do parents want to know about what is happening?            - Do they have any questions or concerns?            - Have you handed over any key information to other team members?</p>	<p style="text-align: center;"><u><b>Clinical Assessment, Communication and Plan</b></u></p>

**Person completing assessment:**

Name .....Signature .....

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## Summary of plans when death occurs

<b>Section 1 - Immediate actions</b>	
<p>Who should parents call to confirm death?            Who will write the death certificate?            Are further diagnostic investigations needed?</p> <p>The local Coroner must be informed about all deaths - is any further action needed?</p> <p>Inform the local Child death overview coordinator</p>	<p>If the Coroner is satisfied, parents/staff can remove NG tube and dressings. Keep a nappy on and dress baby as parents wish. Keep baby in a cool room.</p>

<b>Section 2 - Within 24 hours</b>	
<p>Parents may like to consider the option of tissue donation (see additional information)</p> <p>Contact the Funeral director.</p>	

<b>Section 3 - Within 5 days</b>	
<p>Register the death (and birth) at the Registrar office.</p> <p>Families may start thinking about the funeral service.</p> <p>Would they like a burial or cremation?</p>	<p>Phone no:            (Usually operate an appointment system)</p>

<b>Section 4 - Family support</b>	
<p>What support systems are available to the family?</p> <p>Signpost to local and national agencies.</p>	

<b>Section 6 - Plans for ongoing review</b>	
<p>Further hospital appointments may help a family - consider NICU follow up, also Genetics or specialist (e.g. cardiology, neurology) as appropriate.</p>	

**Sign on completion of Summary:**

Doctor ..... Signature ..... GMC.....

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## TO FACILITATE TRANSFER OF A CHILD TO ANOTHER COUNTRY

- If the parents wish their baby to be buried in their country of origin, they will need to inform the Registrar of this when they register the baby or child's death
- Instead of the usual certificate of disposal, the Registrar will make a copy of the death certificate for the family to give to the funeral director. The funeral director will then apply to the Coroner for an out of England order, which takes one to two days. (If a post mortem suggests death was not by natural causes, an out of England order will not be issued until the legal process is complete).
- The funeral director will also arrange all the travel and transport and supply the relevant airline with the following:
  - A freedom from infection certificate (which he will obtain from the doctor who signed the death certificate)
  - A zinc lined coffin which must be hermetically sealed (it can be opened once the destination is reached)
  - A certificate to prove the body has been embalmed
  - A consular seal from the relevant embassy (only required for some countries)

### Useful contact numbers/resources

#### Local Network Hospitals

#### Telephone (Switchboard)

Royal Victoria Infirmary, Newcastle	0191 233 6161
James Cook University Hospital, Middlesbrough	01642 850 850
Sunderland Royal Hospital	0191 565 6256
University Hospital North Tees	01642 617 617
Wansbeck Hospital, Ashington	0844 811 8111
Queen Elizabeth Hospital, Gateshead	0191 482 0000
South Tyneside District Hospital	0191 404 1000
University Hospital, North Durham	0191 333 2333
Darlington Memorial Hospital	01325 380 100
Friarage Hospital, Northallerton	01609 779 911
Cumberland Infirmary, Carlisle	01228 523 444
West Cumberland Hospital, Whitehaven	01946 693 181

#### Regional Children's Hospices

St Oswald's Children's Hospice, Newcastle	0191 285 0063
Butterwick Children's Hospice, Stockton	01642 607 742
Zoe's Place, Middlesbrough	01642 457 985
Martin House Hospice, Wetherby	01937 845 045

#### Support/Counselling Services/Resources & Helplines

BLISS ("For babies born too small, too soon")	<a href="http://www.bliss.org.uk">www.bliss.org.uk</a>	0500 618 140
SANDS (Stillbirth & Neonatal Death Charity)	<a href="http://www.uk-sands.org">www.uk-sands.org</a>	020 7436 5881
Child Bereavement UK	<a href="http://www.childbereavement.org.uk">www.childbereavement.org.uk</a>	01494 568 900
Together for Short Lives	<a href="http://www.togetherforshortlives.org.uk">www.togetherforshortlives.org.uk</a>	0845 108 2201
The Rainbow Trust	<a href="http://www.rainbowtrust.org.uk">www.rainbowtrust.org.uk</a>	0191 386 4400
Saying Goodbye	<a href="http://www.sayinggoodbye.org">www.sayinggoodbye.org</a>	0845 293 8027

#### Adult Hospices offering bereavement support to siblings and families

Teesside Hospice, Middlesbrough	01642 811 063
St Theresa's Hospice, Darlington	01325 254 321
Butterwick Hospice, Bishop Auckland	01388 603 003

#### Clinical guidance

North East Paediatric Palliative Care Helpline 0191 246 9122  
[www.togetherforshortlives.org.uk/professionals/resources/2434\\_basic\\_symptom\\_control\\_in\\_paediatric\\_palliative\\_care\\_2011](http://www.togetherforshortlives.org.uk/professionals/resources/2434_basic_symptom_control_in_paediatric_palliative_care_2011)