CHSW COLOURS OF LIFE - A USER'S GUIDE

Background: the Colours of Life tool is a mechanism for staff at CHSW to classify the care given by the hospice team to children and families on their caseload. It is being introduced on a pilot basis in 2008 across both hospices, and will be evaluated regarding its impact on the organisation and efficient management of care provided for children over the year. The categories are defined as follows:

- Green:
  - Definition: standard CHSW support for child and family, where there has been a diagnosis of a life limiting illness but the child is currently stable. Life expectancy may be uncertain, but death is not expected imminently.
  - Resus/emergency management: If unwell, full resuscitation would be expected, including emergency transfer to hospital if required.
  - Staffing implications: standard CHSW arrangements
  - Outcome measures: Good quality care for children and families in the green category will empower families to regain control in their lives, recharge their energy levels, and live life to their full capacities, whilst recognising the challenges of living with life-limiting illness, and preparing for the future at an appropriate pace.
  - References: For further guidance see ACT Palliative Care Pathway stages 1-4
- Yellow:
  - Definition: the child and family are likely to have increased support needs compared to those in the green category because the child may have unpredictable or deteriorating health, poor symptom management or dependence on technology, or because the family may have challenges in their personal or social circumstances in addition to the demands of caring for a life-limited child.
  - Resus/emergency management: These children are also likely to receive full intervention in the case of emergencies, including emergency transfer to hospital if required.
  - Staffing implications: Families are likely to require increased support from the care team when at the hospice, and increased contact time when not resident at the hospice.
  - Outcome measures: The outcomes of effective care for children and families in the yellow category will be an improved symptom management, psychological support, and effective respite from the demands of uncertain or unpredictable care needs, all of which should result in improved quality of life for the child and family.
  - References: For further guidance see ACT Palliative Care Pathway stages 1-4

- Amber:
  - Definitions: the child has a life-limiting condition which is managed by active palliation. These children may be quite stable for lengthy periods of time and require less medical or nursing intervention than children in the "yellow" category – the significant difference is the recognition of the end of life approaching, and an emphasis on quality of life as opposed to its duration.
  - Resus/emergency management: there would be recognition that full resuscitation would be futile, and if the child became unwell transfer to hospital would not be automatically required unless requested by the child/family. Full treatment would be provided for health conditions or symptoms that can be improved, with the aim being to maximise the quality of life.
  - Staffing Implications: Family support would be tailored to the increasing emotional demands on preparing for the end of a child's life, and will require increased input from the care team and contacts, as in the yellow category.
  - Outcome measures: Good quality care for children and families in the amber category will enable proactive symptom control and appropriate family support, and timely preparation for the child's death.
  - References: For further guidance see ACT Palliative Care Pathway stages 2-5
- Red:
  - Definition: The child is likely to die very soon and is receiving end-of-life care – this category refers to the last few days of life, when this can be predicted with any confidence.
  - Resus/Emergency management: Care is directed entirely at improving the comfort and quality of remaining life for the child, and supporting the family as they prepare for their imminent loss. The child/family will have agreed that full resuscitation is not desired.
  - Staffing implications: A child in the red category resident in the hospice would require additional nursing time and medical on-call support above standard levels, and families would have additional input from their contacts during this time.
  - Outcome measures: The markers of good quality care for children and families in the red category would be enabling the child's death to be as peaceful as possible, meeting whenever possible the family's requests about the care their child received whilst dying, and supporting the family appropriately throughout this time.
  - References: For further guidance see ACT Palliative Care Pathway stage 5

- Purple:
    - Definition: The family receive bereavement support appropriate to their needs.
    - Staffing implications: Effective intervention for children and families in the purple category will include practical, financial, psychological, spiritual and emotional support.Whilst emotional support is provided throughout the child's journey, there will be additional specific input from chaplaincy, bereavement co-ordinators, and their contacts.
    - Outcomes: effective bereavement support will enable a family to feel supported immediately after their child has died, and afterwards, and empowered to cope with the ongoing effects of grief.

Procedure :

When a child is referred:

- Referral is considered at each hospice as per usual procedure.
- When medical background information is complete, the child will be allocated to a colour grouping based on the information received. This will be documented in the child's notes and on the database following the referral meeting.
- The child will be allocated to a contact pair, who will link with the family and arrange a first visit.

At first visit:

- The contacts will meet the child and family and confirm their views where possible about the desired approach to management of emergencies, or any decisions or discussions about resuscitation.
- Resus or emergency plans will be filed in the appropriate section of the child's notes
- Any concerns or lack of clarity should be shared with the team leader for that contact pair, and brought to the following week's referral meeting for a first review discussion by the senior clinical team. (HOC, MD or doc, team leaders)

First Review:

- Will take place at the referral meeting following the initial hospice visit or contact.
- Will review the category allocation based on information above.
- Will identify the need for a medical review or discussion if this has not taken place, to clarify emergency management plans.
- Will allocate the number of nights respite to the family

- Will be followed by a letter to GP/key worker/referrer and family re nights allocated, and a summary of any interventions or resus discussions if relevant.
- Database will be updated re any changes.

Booked respite stay:

- The child's COL status should be visible on the booking screen of the database
- Prior to arrival, the colour coding should be marked on the white board in the care team office by shift co-ordinator.
- During the stay, the child's status is reviewed at each handover and changed on the white board if necessary by shift co-ordinator; reasons for change documented in notes and nature and date of change marked on inside front cover by care team member looking after that child.
- When going home, any changes to colour status to be amended on database.

Whilst non-resident in hospice:

- Contact pairs are responsible for keeping in touch with family, and updating database and team leader of any significant changes in child or family situation.
- Changes in COL category to be marked in child's notes as above.

THE NEEDS OF CHILDREN AND FAMILIES VARY WITH TIME. A CATEGORY ALLOCATION FOR A CHILD / FAMILY IS NOT FIXED. THERE IS NO LIMIT TO THE NUMBER OF CHANGES OF CATEGORY THAT CAN BE MADE.

<u>Specific Responsibilities</u>

Contact Pairs

- Update database and notes regularly when child not resident in hospice; discuss any significant changes with team leaders

Team leaders:

- Responsible for overseeing contact pairs to ensure that they are effectively keeping in contact with families

Medical Staff:

- Identify children/families where further clarification of emergency management or resus status would be useful
- Arrange second-tier medical support when a child in red category is admitted.

Areas for future development:

Data management

- Identify the number of days provided for respite care, palliative care and end of life care
- Identify changes in workload over time
- Identify changes in type of workload between various CHSW units
- HOC and SMT: Use information provided to monitor skill-mix, future development of hospice etc

New referrals:

- Fast-track referrals of children likely to be in red category

Workload and resource management

- Family reviews: Tailor number of days respite offered to needs of child and family
- Team leaders: When confirming booked visits, use COL categories to ensure manageable workload on shifts, or arrange additional staff support.
- Team leaders: Prioritise emergency booking requests: red > yellow/amber > green.
- Team leaders: Should ensure that contact pairs receive an equitable distribution of children/families in each category,
- Contact pairs: When planning first visits, arrange as emergency for children in red category; arrange urgently for children in amber category; less time urgency for yellow and green categories

Education Co-ordinators:

- Look at distribution of workload on care team and identify potential training needs eg bereavement support etc and target individuals most likely to benefit

Finance/SMT:

- Identify areas and volumes of work that could be funded through statutory funding sources

Research:

- Track family journeys over time – to develop tools to predict likely levels of support in future
- Evaluate activity against desired outcome measures
- HR: to define appropriate staffing complement levels for workload