

	<b>GREEN</b>	<b>YELLOW</b>	<b>AMBER</b>	<b>RED</b>
<b>Prognostic guide</b>	Diagnosis of malignancy, full treatment expected & delivered, in the hope of cure/long term survival.	Diagnosis of malignancy, full treatment expected & delivered, in the hope of cure. Outcome less certain due to poor prognosis, unstable clinical condition, or challenging social circumstances resulting in increased vulnerability of child.	Diagnosis of malignancy, recognised by family to lead to premature death of child. Child may be very well in the short/medium term but not likely to survive long-term. Treatment options aimed at maximising quality of life.	End of life care. Death expected v soon, clear/rapid deterioration in health. (old terminology = “terminal care”) Treatment aimed at controlling symptoms, maximising quality of life, and maximal family support.
<b>Oncological Intervention</b>	Standard treatment regimes, full supportive care provided as required for child and family. Aim = cure.	Standard or aggressive/high-risk or experimental treatment regimes, with full supportive care as required for inter-current complications, and additional emotional/psychological support for child & family. Aim = cure.	Palliative interventions, including chemotherapy, surgery or radiotherapy, but with no expectation of cure. Aim = control of disease symptoms for as long as poss	Not appropriate in these circumstances
<b>Discussion guide for oncology team. How to explore a family's Wants / Wishes / Hopes / Fears</b>	Team and parents -not expecting to discuss any details of palliative care or end of life issues at this stage / with this diagnosis, except to respond to concerns raised by child or parents	Possibility of life threatening situation recognised by clinical team or by child/family. Explore how to provide appropriate support, how to balance hope with realism, and how to live with increasing degree of uncertainty about future.	Clarify child and family's priorities about how/where to spend their remaining time together. Explore hopes and fears about any family concerns re disease progression and care before death, at the time of death, and after death. Document conclusions, and share.	Rapid and realistic appraisal of current situation with child/family, and choices that may be possible under these circumstances.  Comfort care paramount.

	<b>GREEN</b>	<b>YELLOW</b>	<b>AMBER</b>	<b>RED</b>
<b>Resuscitation plan needed?</b>	Full resuscitation would be attempted in the event of complication/collapse. No specific need to document this, would be assumed as “standard care” in these circumstances.	Full resuscitation would be attempted in the event of a collapse.  It would be useful to have this documented in notes.	Yes, and should clarify to what extent any aggressive or invasive procedures (eg IV antibiotics, intubation, ventilation, PICU support) should be pursued to extend life, in light of family’s recognition that their child will die prematurely from malignancy.	Yes, and should clarify that heroic measures (specify which) should not be pursued to extend life. Allow natural death to occur.
<b>Management Plan for any complications</b>	Full supportive care for intercurrent infections, nutrition, organ failure etc, including admission to hospital wards and PICU if relevant.	Full supportive care for intercurrent infections, nutrition, organ failure etc, including admission to hospital wards and PICU if relevant. More detailed discussion with family required re potential complications in high-risk or experimental treatment, and how to recognise when it is time to review risks/benefits of Rx.	Full supportive care, with active palliation of symptoms. May need individualised management plans for likely complications eg febrile neutropaenia, fits, nutrition and fluid balance etc, incorporating wishes for place of care, and practical issues re equipment / staffing/ access to medicines.	Pro-active prescribing for likely complications as death approaches, (eg pain management, nausea/vomiting, fits, bleeding etc) to allow prompt, safe and effective symptom management in the place of choice.
<b>Preferred Place for End of Life Care</b>	Record any expressed preferences if these are volunteered by child/family, (but no need to actively explore this question at this stage.)	Record any expressed preferences if these are volunteered by child/family	Discuss options with child & family, make arrangements to accommodate their wishes where possible.	Rapid realistic appraisal of what is possible given the child/young person’s current circumstances.

## Paediatric Oncology COLOURS OF LIFE - A USER'S GUIDE

Background: the Colours of Life tool is a mechanism for paediatric oncology staff to classify the care given by the team to children and families on their caseload.

The categories are defined as follows:

- **Green:**
  - Definition: standard paediatric oncology support for child and family, where there has been a diagnosis of a malignancy but the child is currently stable. Life expectancy may be uncertain, but death is not expected imminently.
  - Holistic Care: would include nursing, medical, social work support, +/- additional advice from dietetics, psychology, physio & OT, education and play, and spiritual support as appropriate.
  - Resus/emergency management: If unwell, full assessment and treatment would be expected, including emergency admission to hospital if required.
  - Staffing implications: standard paediatric oncology arrangements
  - Outcome measures: Good quality care for children and families in the green category will empower families to regain control in their lives, and live life to their full capacities, whilst recognising the challenges of living with treatment and preparing for a future off treatment
  - Evaluation of outcomes: survival rates, compliance with treatment regimes, educational performance, time off school/work.
- **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 intensive medical support or technology, or because the family may have challenges in their personal or social circumstances in addition to the demands of caring for a child receiving treatment for cancer.
  - Holistic Care: would include nursing, medical, social work support, +/- additional advice from dietetics, psychology, physio & OT, education and play, and spiritual support as appropriate.
  - Resus/emergency management: These children are also likely to receive full intervention in the case of emergencies, including emergency admission to hospital if required.
  - Staffing implications: Families are likely to require increased support from the team when in hospital, and increased contact time and support when out of hospital.
  - Outcome measures: The outcomes of effective care for children and families in the yellow category will be improved chances of survival, improved symptom management, and effective psychological support for the demands of uncertain or unpredictable care needs, all of which should result in improved quality of life for the child and family.

- Evaluation of outcomes: survival rates, compliance with treatment regimes, educational performance, adequate nutritional status.
- **Amber:**
  - Definitions: the child is living with a malignancy which is not curable, and 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 that the burden of further curative attempts at treatment would exceed the likely benefits, and an emphasis on quality of life as opposed to its duration.
  - Holistic Care: would include nursing, medical, social work support, +/- additional advice from dietetics, psychology, physio & OT, education and play, and spiritual support as appropriate. This will include particular attention to siblings, extended family, and the local community to proactively support them through anticipated bereavement in the not-too-distant future.
  - Resus/emergency management: 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. Individual discussions would be needed regarding the extent of resuscitation that would be appropriate in the event of major illness.
  - 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 team.
  - 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.
  - Evaluation of outcomes: Evidence of end-of-life plans in place; families able to discuss and consider choices for the care of their child; child and family able to address their wishes for preferred place of care, activities, or special time whilst child remains well. Family feedback.
- **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.
  - Holistic Care: would include nursing, medical, social work support, and spiritual support as appropriate. Active input from dietetics, psychology, physio & OT, education and play may no longer be possible.
  - 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 would require additional nursing time and medical on-call support above standard levels, and families would have additional input from their professional 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.
- Evaluation of outcomes: death in the place of choice; quality of symptom control at the end of life; family feedback
- **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.

Used with permission from Dr Nicky Harris, Medical Director, Children's Hospice South West.

For development or modification of this tool, please contact [nicky.harris@chsw.org.uk](mailto:nicky.harris@chsw.org.uk)

### **Green – a guide to discussions with families about palliative care issues**

Although statistically many children newly diagnosed with cancer are likely to be long-term survivors, the word "cancer" is still associated with death, and often means that families suddenly confront issues about facing the death of their child. Paediatric oncology teams will generally endeavour to reassure families about their child's likely survival, but it may still be appropriate to explore a child and family's particular wishes, or fears, and support them as they review the priorities in their lives. Focus on living life to the full despite limitations of illness, disability, or the constraints of life on treatment. There may or may not be an awareness of the prognosis of cancer, so be led in discussions by the child or young adult and allow them to approach these subjects at their own pace.

### **Yellow – a guide to discussions with families about palliative care issues**

A child in the yellow category may have either a poor oncological prognosis, or unpredictable health care needs due to concurrent additional illness or complications of treatment. Teams will need clear instructions about how to manage any emergencies that may arise, in conjunction with the child's usual health care team. Repeated hospital admissions may mean that children/young people have clear ideas about what they would like, or not like, to happen to them (in terms of admissions and intensive interventions) – please explore these and document in the notes. However, treat symptoms and complications as if for any other child, including emergency admission to hospital if necessary, and follow any emergency management plans that are available. Children, young adults and their families may need plenty of time and information to understand the complexities of benefits and risks of some treatment decisions, and to revisit these regularly, in order to gain a fully informed consensus with health care teams about appropriate decisions for the management of their health in the future.

The yellow category also identifies families under increased strain for personal or social reasons, over and above the emotional strain associated with caring for a child with cancer. In addition to discussions with the family as outlined in the green section above, consider sensitive exploration of the family's particular issues with a view to providing emotional, practical and psychological support where possible.

## Amber – a guide to end of life planning

End of life planning will require a sensitive and dignified approach to discussions, and protected time to allow full exploration of the child & family's wishes, concerns, and expectations of the future. This can be a lengthy process over many weeks, but however long it takes it should result in a clear understanding of the actions to be taken by staff in case of a child's gradual deterioration, (based on the likely scenarios to be encountered with that child's illness), and in case of an acute event resulting in cardio-pulmonary arrest.

In addition to health-related issues, include discussions about the child and family's wishes about how to spend their time before death (eg special visits or activities), the child and family wishes about where they would like to be and who would they like present when dying, and any thoughts about care after death (such as cremation/burial, funeral plans or memorial services, distribution of belongings, etc). Not all families will be ready for all of this at this point, but some will.

Health-related topics to be discussed include:

- Management of common illnesses eg intercurrent infections
- Management of any predictable or foreseeable complications eg fits, pain, nausea and vomiting, spinal cord compression etc
- Sudden collapse with apparent death.

Treatment options include:

oxygen and suction for respiratory compromise

Oral antibiotics

Parenteral antibiotics\*

NG or gastrostomy fluids or feeding

IV fluids or TPN feeding\*

Bag and mask ventilatory support in the community

Non-invasive ventilation (CPAP, BiPAP)\*

Intubation and ventilation in hospital\*\*

PICU admission\*\*

Peritoneal dialysis\* or haemodialysis\*\*

Transfusion support\*

Transfer to hospice or hospital\*

Comfort care and pain relief are never optional!

\* may be possible in hospice or community setting but not always

\*\* not possible in community or hospice setting

Process:

1. ensure that the discussion is taking place with the appropriate people:
  - a. child if appropriate; young adults should be included unless they expressly wish not to. Young adults who are mentally competent > 18 years must take part in discussions for these to be legally valid.
  - b. Those with parental responsibility (ideally, all of them, though this is not always possible. If not, please try to ensure consensus between all relevant individuals whenever possible. In the case of children under local authority care, involve the relevant social workers etc in discussions from the start.)
  - c. Experienced staff - usually senior nursing or medical staff - who are able to have an informed discussion about likely options, choices, and outcomes.
2. arrange an appropriate time and place
  - a. private, quiet, without telephones/pagers for interruption. If young children or siblings are not included in the discussion, make arrangements for appropriate supervision for them.
  - b. comfortable, safe, with an easy exit for anyone who finds that they need to take a quick break
  - c. box of tissues or cup of tea often useful.
3. document decisions contemporaneously, and share this record with the individuals involved to ensure that all agree on outcomes. Good practice, if time is available, is to revisit any difficult discussions the next day after allowing people to "sleep on it", to confirm that all are happy with decisions.
4. ideally, type, sign and date the conclusions on headed notepaper. The "Child and Family Wishes document" is also suitable for this purpose.
5. identify whom to share the conclusions of the document with, and how this distribution will be done (eg copies to parents for distribution, or by post to other agencies, etc)



## Red - a guide to end of life planning

As above, though there may be more pressure of time if there have not been previous end-of-life discussions. The focus should be on clarifying the management of any likely complications, with the recognition that the child/young person is likely to die in the very near future (probably days), and on care around death and after death.

Discuss options listed above, though if transfer to another location (be it hospital, hospice or home) is requested for end of life care, this must be arranged without so much delay that it becomes impossible. If remaining in the hospice or at home, some options\* are limited and others \*\* are impossible.