

CATEGORISATIONS AND ABBREVIATIONS USED IN THE FORM:

ACT CLASSIFICATION

ACT = Association for Children with Life Threatening Conditions (based in the UK).

- Proposed grouping system for life limiting and life threatening illnesses of childhood that would benefit from palliative care
- Similar diseases grouped together
- Grouping is largely based on different disease trajectories (pathways) which helps with care planning

ACT I: Life threatening conditions for which curative treatments are feasible but can fail, e.g. ALL, organ failure. (Mostly level 3 RXH).

ACT II: Conditions where premature death is inevitable, but where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, e.g. HIV/AIDS on antiretrovirals cystic fibrosis. (Intervention based on QOL).

ACT III: Progressive conditions without curative treatment options, where treatment is exclusively palliative and may extend over many years, e.g. many syndromes, inborn errors of metabolism. (Intervention level based on QOL and resource availability: usually 1-2).

ACT IV: Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death, e.g. severe cerebral palsy, spinal cord insult. (intervention level based on QOL).

ACT 0: Not really palliative care patient.

QOL: Quality of life

PAIN SCALES:

Please see pain scales available in wards

SYMPTOMS OTHER THAN PAIN:

Any symptom other than pain that may be a source of distress e.g.: constipation, anxiety, dyspnoea etc.

ABBREVIATIONS:

MDT = Multidisciplinary Team Meeting needed disciplines to coordinate care and/or make decisions.

ACP = Advance Care Plan (please refer to ACP template doc)