

This document is a tool for discussing and communicating the wishes of a child/parent(s) or young person. It is particularly useful in a future emergency, when the individual cannot give informed consent for themselves and/or next of kin cannot be contacted (Adapted from the NHS, UK and Umduduzi, Durban).

PLEASE ENSURE A COPY OF THIS DOCUMENT IS AVAILABLE IN THE PATIENTS MEDICAL NOTES, A COPY IS GIVEN TO THE FAMILY, THE PRIMARY PHYSICIAN AND RELEVANT MEMBERS OF THE MULTIDISCIPLINARY TEAM

CHILD	Name	Gender	Date of birth
CAREGIVER	Name	Relationship	Cell
ADDRESS			

Date of plan		Date of review	
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ADVANCE CARE PLAN PARTICIPANTS

	NAME/DEPARTMENT	CONTACT DETAIL
Family member/Caregiver		
Family member/Caregiver		
Doctor		
Doctor		
Nurse		
Therapist		
Social worker		
Psychologist		
Other (specify)		

CLINICAL AND PSYCHOSOCIAL PROBLEM LIST

DIAGNOSES Include current management	
CURRENT SYMPTOMS, AND CONCERNS	
SOCIAL AND FINANCIAL CIRCUMSTANCES Include siblings and support systems	
SPIRITUAL ASSESSMENT	Faith:
	Importance/influence
	Community
	Address in care

Name.....

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REASONS FOR ADVANCE CARE PLANNING		
1. ACT CLASSIFICATION (Association for Children with Life-threatening Conditions)	DETAILS	
ACT 1: Life-threatening conditions for which curative treatments are feasible but can fail (e.g.: cancer, disseminated TB, organ failure when transplant is available). Mostly IL 3, at tertiary level.		
ACT 2: 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.: Cystic Fibrosis, HIV/AIDS on antiretrovirals, renal failure where dialysis is available). IL based on quality of life (QOL)		
ACT 3: Progressive conditions without curative treatment options, where treatment is exclusively palliative and may extend over many years (e.g.: Trisomy 18/13, inborn errors of metabolism, inoperable cardiac disease, renal failure – no dialysis). IL based on QOL and resources, usually 1-2		
ACT 4: Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death (e.g.: severe CP, FAS, Down syndrome, spinal cord insult). IL based on QOL		
1. ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH CATEGORIES Includes categories where withdrawal and/or with-holding of life-sustaining treatment may be ethically and legally justifiable		
REASON	KEY DETERMINANT	✓
I. Life is limited in quantity	1. Brain stem death	
	2. Imminent death with physiological deterioration despite treatment	
	3. Inevitable death with no beneficial interventions	
II. Life is limited in quality	1. Burden of treatment outweighs potential benefits	
	2. Burden of the child's underlying condition causes suffering that overcomes potential benefits	
	3. Lack of ability to benefit	
III. Informed competent refusal of treatment		

ADVANCE CARE PLAN

CARDIOPULMONARY ARREST AND RESUSCITATION STATUS		
CATEGORY	DETAILS	✓
FULL CPR		
Modified resuscitation Define: eg fluids but no compressions or artificial breaths		
Allow natural death (CPR inappropriate)		
INTERVENTION LEVELS AND GOALS OF CARE		
INTERVENTION LEVEL	CARE APPROACH	✓
1	Comfort care only, avoid painful procedures/investigations unless information gained helps to achieve goal of comfort	
2	Comfort care with specific life-supportive care (e.g. IV antibiotics, blood transfusions) but excluding mechanical ventilation	
3	Includes mechanical ventilation and all forms of life prolonging care (e.g. dialysis)	

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GOALS OF CARE Include physical, psychological, social and spiritual goals	
PREFERRED PLACE OF CARE	
CHILD AND FAMILY'S WISHES DURING LIFE Where permitted	

CASE SCENARIO MANAGEMENT PLANS FOR ANTICIPATED PROBLEMS		
Illness/acute deterioration/complications/end of life scenarios		
PROBLEM	ACTIONS Include interventions appropriate for goals of care. E.g. pain management, respiratory support	SPECIFIC LIMITATIONS Inappropriate interventions
Example: dyspnoea	Pharmacological: low dose oral morphine	Not for IPPV

MEDICATIONS Current and additional that may be required for symptom control. Based on weight:				
DRUG	DOSAGE AND FREQUENCY	ROUTE	INDICATIONS	STOP IF

CHECKLIST	Yes/No
1. Does the child have a birth certificate?	
2. Application for care-dependency grant completed?	
3. Does the caregiver need a letter for employer?	
4. Has the family had the opportunity to invite spiritual supporters to the ward?	
5. Does the child/family have relocation plans? If yes, where to?	
6. Is there a funeral policy in place?	
7. Any equipment needed?	
8. Was Reach For a Dream contacted? If yes, provide contact details.	

PLACES OF CARE AND SUPPORT		
TYPE OF SUPPORT	FACILITY/PROFESSIONAL	CONTACT DETAILS
Primary care team (GP/District Hospital)		
Access to medication		
Emergency care		
End of life care		
Specialist care		
CBO/NPO involvement		
Grief and bereavement support		

FOLLOW-UP DETAILS	
NAME OF CLINIC	FOLLOW-UP DATE