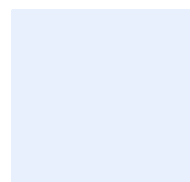
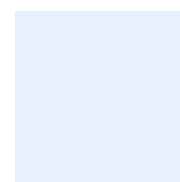




Child and
Young Person's
Advance Care Plan



ID photo



QR code

FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES

Plans can begin antenatally (using ante-natal version of this document) and are suitable for infants, children and young people

Name (baby, infant, child or young person):	Rowan	EDD (if relevant):	
Known as (if different):		DOB:	01.01.2022
Address including postcode:			
NHS no:	123 456 7890	Gender (optional)	Male

ALLERGIES:

No Known Drug Allergies

For Child/Young Person or Carers' Use – Who to call in emergency (eg 999 or 111, or Hospice, etc)

In emergency call:	999 / APLS Hospice
Other situations:	

See also Emergency Contacts on last page

This document is in accordance with NICE guideline NG61 and is a tool for discussing care preferences and communicating wishes. It is intended to enable clinicians and families to make good decisions together.

Not every page/section needs to be completed.

Date of Plan/Last review	01.01.2025
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Irrespective of the 'Date of plan' it is good practice to check this still reflects current decisions / views, and to regularly review the plan, especially if changes have occurred. However, an old / expired date does not necessarily negate this document.

For electronic copies of this form, information leaflets and guidance, see <http://cypacp.uk/>



<http://cypacp.uk/>
<https://www.respectprocess.org.uk/>

Version 5
Incorporating ReSPECT

Decision-making (additional to the ReSPECT document at the back)

First language	English	Interpreter required?	Yes ☐	No ☒
Information to help improve communication / support capacity:				
Decision-making details/preferences: For example - details of those involved if “looked after” child; others involved key family members/carers; how do child/family wish to be involved in decision-making?				
Both parents have parental responsibility. They both wish to be fully involved in decision making. Rowan is not old enough to make his own decisions.				
Important information relating to capacity and where further information can be found.				
Further guidance will be available on the CYPACP website. See also last page				
APLS Hospice can be contact to help with symptom management if required – 01234 567 890				

Clinicians have a duty to act in a patient’s best interests at all times

Distribution list / Key contacts (*where available, please include out of hours numbers)

Responsibility for changes / distribution of CYPACP (please contact if you believe this version to be inaccurate)					
Name/Role/Department/Organisation and contact details:					
APLS Hospice – 01234 567 890					
		Name and contact details			Name and contact details
☐	Is there a regional central database?	Upload and note where this can be found:	☐	Respite/Short Break Care provider	
☐	Ambulance service	The Ambulance Service have a copy	☐	School Nurse/Head Teacher	
☐	Lead Paediatrician/Obstetrician	Dr I Care	☐	Social Services	
☐	Palliative Team*	See below	☐	Midwife	
☐	Hospice*	APLS Hospice – 01234 567 890	☐	Health Visitor	
☐	GP	Dr G P	☐	Other (eg Hospital Specialists)	Dr Heart – Paediatric Cardiac Consultant
☐	GP out of hours (if different)		☐	Other	Paediatric Cardiac Specialist Nurses -
☐	Children’s Community Nursing*	Local CCNT ...	☐	Other	
☐	Hospital (ward/Assessment unit)		☐	Other	
☐	Local Emergency Department	Local Hospital ...	☐	Other	

It is good practice to keep a copy of the Care Plan with the infant/child/young person at all times

Medical Background

Summary diagnoses / current situation:

Complex Cardiac Disease (Hypoplastic Left Heart Syndrome)

Medical problems and background information (inc antenatal scans):

Medical history, key moments in journey; previous pregnancy losses/neonatal/infant deaths (especially if antenatal plan)

Rowan was born with Complex Cardiac Condition (Hypoplastic Left Heart Syndrome (HLHS)), meaning that the left side of the heart has not developed properly.

Rowan had surgery (Norwood and Glenn), however, sadly there are no further surgical options available to him.

Personal Background

Personality/Quality of life when well:

May help others recognise deterioration, targets for recovery. May also wish to document concerns about your/your child/s health now and for the future?

When well Rowan is an extremely happy and sociable young man.
However, when unwell, he can become very breathless.

Tips to make infant/child/young person/yourself more comfortable:

eg communication methods; particular likes; music; stories; play, etc. Please note where to find more detailed, separate care plans if relevant

Parents know Rowan the best, please listen to them to help ensure Rowan is comfortable.

Social/Psychological/Spiritual/Education support: (if felt to be helpful)

The family do not have any specific religious or spiritual beliefs.

Family details:

please include details of siblings, include family tree if helpful; other important family/friends/carers

Rowan does not have any siblings and are parents first child.

Priorities/Goals/Values

Baby/infant/child/young person's wishes:

Consider support to achieve everyday quality of life as well as special goals, eg place of care; spiritual wishes; goal-directed outcomes; what I most value/wish to avoid; legacy and memory-making during life

Family (including siblings) wishes:

Consider how you as a family wish to be supported to achieve everyday quality of life as well as any special goals, eg where you want to be as a family; who to involve; sibling support and needs (eg medical, spiritual or cultural backgrounds); legacy and memory-making during life; what is most valued/wish to avoid.

Parents understand that Rowan is therefore sadly 'palliative' in that there will come a time when Rowan's heart function is insufficient to sustain his life. At this time they would like to focus on Rowan's comfort.

They are known to the APLS hospice.

Please discuss at the time if it is recognised that Rowan is coming to the end of his life as it is likely parents would want Rowan to go to the hospice, if possible.

Others' wishes:

Wider family, school friends, carers

Wishes around End of Life

If it is recognised that your child/young person is nearing the end of their life, is there anything that would be important for us to know to provide the best care possible?

Priorities for care, including preferred place of care at the end of life and after death: Specify if preferred place of care at end of life is different to place of care after death.

Please discuss at the time if it is recognised that Rowan is coming to the end of his life as it is likely parents would want Rowan to go to the hospice, if possible. (Please also contact the hospice as soon as possible to try and help facilitate this).

Parents are aware that Rowan can go to the hospice after death and it is likely that they would want this if possible. Please discuss at the time.

Organ and tissue donation: See separate guidance on web link:

<https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/>

National contact numbers: Referral line 0300 020 30 40 / General advice line: 0300 123 2323

Organ and tissue donation may be possible, but it depends on several factors. Specialists can guide on specifics should this option be considered

Parents do not wish for Rowan to donate his tissue or organs.

Spiritual and cultural wishes around death and dying: to include faith, beliefs and personal wishes such as music, family traditions and rituals

There are no specific religious or spiritual rituals / processes to be followed.

Memory and legacy making wishes (include family/siblings/friends if relevant)

Consider how you/your child wish/es to be remembered which may include wishes for possessions and/or digital legacy.

No specific requests.

Preparation/communication of process for management after death: 1. Consider required referrals (including sudden death and automatic Coroner referrals (eg HIE (hypoxic ischaemic encephalopathy)); 2. Need for regular medical review; 3. Consider discussion and explanation of SUDIC process; 4. In-dwelling devices and removal

Rowan is known to have a life limiting condition. There are no further surgical options and it is known that this sadly means he may die suddenly.

Usually for a child that dies in the community, national guidance indicates that 'Sudden Death' protocols may require a child to be taken to the hospital for investigations and that the police may be called by the ambulance service.

A decision will need to be taken at the time as to whether a life-threatening event is 'unexpected' or 'sudden'. However, given that at the time of writing this care plan he is known to have the potential to die suddenly the SUDIC processes MAY not be required. The palliative services can be contacted 24/7 on To help with this decision making if require, where staff are happy to discuss with any professionals (including ambulance services and / or the police).

Funeral preferences and bereavement support and other family preferences: eg preferred timing for removal of equipment from home. Seek detailed information or further advice if needed

Discuss at the time

If not discussed, it may be helpful to put specific reasons/context of why not:

Note: No need to explain, but record if helpful to be aware of certain situations/circumstances

Management of Anticipated Complications/Deteriorating Health

Include reference to separate documents (and where to find) eg symptom management plan, specialty care plan(s). Please balance the risk (version control risk) of duplicating information already detailed in separate management plans whilst recognising this section can be very helpful for quick access in emergencies.
NOTE: For antenatal care plans – this section may be deferred (if desired) until assessment after birth.

General Management

Current course of medical treatment: eg disease directed therapy; clinical trials, etc
There are no further surgical options available for Rowan. Focus should be on treating reversible conditions such as infections, and any symptoms (such as breathlessness) he may have.
Notes on likely deterioration (if known and relevant): Consider likely cause(s) of deterioration, including signs, symptoms and red flags
Sadly Rowan's cardiac function is impaired and over time (and in times of illness) he may struggle. This is likely to present with breathlessness and oedema. Please contact the cardiac team or the palliative team if needing help with any symptoms.
Management of progressive deterioration (if different to general deterioration detailed below): It may be appropriate to refer to other sections such as priorities of care if end of life is recognised
If Rowan is deteriorating gradually and recognised to be nearing the end of his life, then please communicate this to parents as they may wish to go to the hospice.

Systems approach to managing deterioration

Airway: Tracheostomy (also note if patent upper airway) and airway adjuncts
No specific issues
Breathing: Oxygen, pressure and ventilation support
Usual target saturations for Rowan are 83-87%.
Circulation/cardiac: Access; diuretics; blood pressure support; implants – what patient has, when and how to change or turn off
It is unlikely that inotropes would help Rowan and thus if needing these please instead consider transfer to the hospice.
Neurology: State if VP shunt or reservoir present and action if blocked; role of pulsed steroids in neurological decline; acute seizure management
Management of commonly occurring infections: Including central line and stated temperatures for individual child
Infections should be treated as normal. However, please be aware that Rowan's impaired cardiac function may particularly present during times of illness.
Nutrition and hydration: Including presence of, or discussion about NG, NJ PEG and JEJ, TPN
Blood tests: Consider frequency, indication and specific tests or stop routine tests
No specific tests required
Blood products: Consider type, frequency and indication eg blood test or clinical symptoms
IV/SC access: Portacath; Hickman; Midline; other; and discussions about subcutaneous access
Nothing specific of note.
Condition specific interventions/general: not previously mentioned, may include when to call 999, transfer to hospital
Other patient plans/where to find: symptom management plans; specialty care plans (eg respiratory care plans), etc
The Cardiac team and Palliative team are available for support on symptoms such as oedema or breathlessness.

Management of an Acute Significant Deterioration/Emergency

For review with "Management of Anticipated Complications"/"ReSPECT"

If end of life recognised, see "Wishes around End of Life" and consider transfer to preferred place. Allergies listed at front

In the event of a likely *reversible* cause for acute life-threatening deterioration such as **choking, tracheostomy blockage or anaphylaxis, please intervene and treat actively (irrespective of resuscitation wishes)**

Note any differences to plan detailed below if parents/carers are not present

If none recorded, assumption will be made to follow plan detailed below, even in absences of parent/carer

No differences to plans detailed below if parents are not present. However, please contact them immediately if they are not with Rowan and he is acutely unwell.

In the event of life-threatening event, provide the following care: add patient-specific detail below

				Comments (patient-specific decisions eg duration)
Basic Life Support	Yes ☒	No ☐	Airway repositioning	
	Yes ☒	No ☐	Airway adjuncts	
	Yes ☒	No ☐	Bag and mask/tracheostomy (also note if upper airway patent)/mouth to mouth ventilation	If deteriorating and parents decide they do not wish for Bag and Mask this is also appropriate
	Yes ☐	No ☒	Chest compressions	
	Yes ☐	No ☒	Defibrillation	
Airway	Yes ☒	No ☐	Suction	
	Yes ☐	No ☒	Intubation/Supraglottic airway insertion (eg LMA)	
Breathing	Yes ☒	No ☐	Supplementary oxygen if available	
	Yes ☒	No ☐	Highflow (eg Optiflow/Vapotherm)	
	Yes ☒	No ☐	Non-invasive ventilation	
Circulation	Yes ☒	No ☐	Intravenous access	
	Yes ☒	No ☐	Intraosseous access	
	Yes ☐	No ☒	Cardiac/ALS drugs (usually in conjunction with chest compressions)	
Other	Yes ☒	No ☐	Emergency transfer to hospital	
	Yes ☐	No ☒	Consider Intensive Care admission	

Additional comments about the above decision or relevant other decisions

Please record details of implantable devices eg VNS/pacemaker/defibrillator, and management at end of life of these devices; long-term IV access; respiratory support (further details may be in separate care plans or "Anticipated Complications" page (eg may include specific information if a life-threatening emergency happens at school).

Consider revoking ACP for planned surgery, etc

Include preferences of transfer, eg local hospital or specialist centre if more suitable (**Note:** preferences may not be possible depending upon situation and local policies).

Consider how interventions will be carried out for emergency clinicians and on-going management plans

Rowan is known to have a life limiting condition (Hypoplastic Left Heart Syndrome).

Reversible conditions should be treated and investigated where possible (and not too onerous) including a short period (up to 5 mins) of bag and mask (with airway manoeuvres) if there is a possibility of a reversible situation like a mucus plug.

It is **unlikely** that transfer to intensive care or intubation would benefit him.

Likewise, if his heart function was so poor it stopped functioning then **NEITHER** Chest compressions **NOR** cardiac medication would be helpful.

If Rowan is recognised to be coming towards the end of his life, please focus on comfort and consider transfer to the hospice.

If at any point parents decide they do not wish for Rowan to undergo resuscitative measures and focus on comfort, professionals who know Rowan would support this.



(as part of the CYPACP [Child and Young Person's Advance Care Plan])
(Recommended Summary Plan for Emergency Care and Treatment Version 3)

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

1	Preferred name:	Rowan	Date completed:	xx.xx.xxxx
2	Shared understanding of my health and current condition:			
Summary of relevant information for this plan including diagnosis and relevant personal circumstances:				
Complex Cardiac Condition (Hypoplastic Left Heart Syndrome (HLHS)) Rowan had surgery (Norwood and Glenn) to help. However, sadly there are no further surgical options available to him. This is a Life Limiting condition.				
Details of other relevant planning documents and where to find them (eg Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency Plan for the carer):				
This is part of a complete Advance Care Plan. Please read this for further useful information about how to manage Rowan in less acute situations.				
I have a legal welfare proxy in place (eg registered welfare attorney; person with parental responsibility). If "yes" provide details in Section 8 Yes ☒ No ☐				
3	What matters to me in decisions about my treatment and care in an emergency:			
Prioritise sustaining life, even at the expense of some comfort Prioritise comfort, even at the expense of sustaining life				

How would you balance the priorities for your care?	
What I most value: Rowan's comfort	What I most fear/wish to avoid: Distressing interventions if they are unable to help Rowan

4 Clinical recommendations for emergency care and treatment:		
Prioritise extending life	Balance extending life with comfort and valued outcomes	Prioritise comfort
OR	Dr I Care	OR
Clinician's signature	Clinician's signature	Clinician's signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

SUMMARY Management in EMERGENCY

NO – Intensive Care / Intubation / Cardiac Compressions / Cardiac Drugs

YES – Oxygen, IV / IO access, Bag and Mask ventilation (up to 5 minutes) for potentially reversible situations.
 (see also page 'Management of an Acute Significant Deterioration/Emergency' on Advance Care Plan for further breakdown):

Detail of above: Reversible conditions should be treated and investigated where possible (and not too onerous) including a short period of bag and mask (with airway manoeuvres)[up to 5 minutes] if there is a possibility of a reversible situation like a mucus plug.

It is unlikely that transfer to intensive care or intubation would benefit him.

Likewise, if his heart function was so poor it stopped functioning then NEITHER Chest compressions NOR cardiac medication would be helpful.

If at any point parents decide they do not wish for Rowan to undergo resuscitative measures and focus on comfort, professionals who know Rowan would support this.

If Rowan is recognised to be coming towards the end of his life please focus on comfort and consider transfer to the hospice. Cardiac team and Palliative team available for support for symptom management if required.

CPR attempts recommended	For modified CPR (Child and Young Person)	CPR attempts NOT recommended
Clinician's signature	Dr I Care Consultant in Paediatrics Clinician's signature	Clinician's signature

Name: Rowan DOB: 01.01.2022 NHS No: 123 456 7890

5 Capacity and representation at time of completion (see also "Decision Making" section)				
Does the person have sufficient capacity to participate in making the recommendations on this plan?		☐ Yes ☒ No		
Document the full capacity assessment in the clinical record		If "no" in what way does this person lack capacity? If the person lacks capacity, a ReSPECT conversation must take place with the family and/or legal welfare proxy		
6 Involvement in making this plan				
The clinician(s) signing this plan is/are confirmation that: (Select A, B or C, OR complete section D below):				
A	☐	This person has the mental capacity to participate in making these recommendations. They have been fully involved in making this plan.		
B	☐	This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.		
C	☒	This person is less than 18 years old (16 in Scotland) and (please select 1 or 2, and also 3 as applicable or explain in section D below):		
	☐	1	They have sufficient maturity and understanding to participate in making this plan.	
	☐	2	They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.	
	☒	3	Those holding parental responsibility have been fully involved in discussing and making this plan.	
D	If no other option has been selected, valid reasons must be stated here. (Document full explanation in clinical record):			
Record date, names and roles of those involved in decision-making, and where records of discussions can be found: xx.xx.xxxx – Both parents and Dr I Care and in full agreement with the contents of this care plan. (We have not asked parents to sign this, as this is not a legal document, but they have confirmed they are in agreement with it).				
7 Clinicians' signatures				
Designation (grade/specialty)	Clinician name	GMC/NMC/HCPC Number	Signature/image	Date/Time
Senior responsible clinician:				
Designation (grade/specialty)	Clinician name	GMC/NMC/HCPC Number	Signature	Date/Time
Consultant in Paediatrics	Dr I Care	111111	Dr I Care	xx.xx.xxxx
8 Emergency contacts and those involved in discussing this plan				
Emergency contact name (Primary contacts in purple)	Role/Relationship	24 hr contact Tick if Yes	Emergency contact number	Signature (optional)
Patient/family:	Dad	☒	01111 111111	
Patient/family:	Mum	☒	02222 222222	
Professional:		☐		
Professional:		☐		
Professional:		☐		
9 Form reviewed (eg for change of care setting) and remains relevant				
Review date	Designation (grade/specialty)	Clinician name	GMC/NMC/HCPC Number	Signature