

Name: Bertie Smith | DOB: 01/01/2024 | NHS No: 987 654 3210



Child and
Young Person's
Advance Care Plan

ID photo

QR code

FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES

Plans can begin antenatally and are suitable for infants, children and young people

Name (baby, infant, child or young person):	Bertie Smith	EDD (if relevant):	
Known as (if different):	Bertie	DOB:	01/01/2024
Address including postcode:	123 Baby Street BA1 1BY		
NHS no:	987 654 3210	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 / ACP Children's 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	05/01/2024
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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

Name: Bertie Smith DOB: 01/01/2024 NHS No: 987 654 3210

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

First language	English	Interpreter required?	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>
Information to help improve communication / support capacity:				
Betty and Brad are Bertie’s parents they have lived in the UK throughout their lives. They get support from friends and family, who all live locally.				
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?				
Betty and Brad wish to be provided up to date information and to be involved in decision making.				
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				
Betty and Brad will have parental responsibility for Bertie and they will make any necessary decisions along with the support of professionals.				

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:					
ACP Children’s Hospice 01234 567 890					
		Name and contact details			Name and contact details
<input type="checkbox"/>	Is there a regional central database?	Upload and note where this can be found:	<input type="checkbox"/>	Respite/Short Break Care provider	
<input checked="" type="checkbox"/>	Ambulance service	Ambulance Service ambulance@nhs.net	<input type="checkbox"/>	School Nurse/Head Teacher	
<input type="checkbox"/>	Lead Paediatrician/Obstetrician	Dr Neonate – Consultant in Neonatal Medicine	<input type="checkbox"/>	Social Services	
<input type="checkbox"/>	Palliative Team*		<input checked="" type="checkbox"/>	Midwife	Fetal Medicine Midwife email:@nhs.net
<input checked="" type="checkbox"/>	Hospice*	ACP Children’s Hospice 01234 567 890	<input type="checkbox"/>	Health Visitor	
<input checked="" type="checkbox"/>	GP	Dr Help, Help Health Centre,	<input type="checkbox"/>	Other (eg Hospital Specialists)	
<input type="checkbox"/>	GP out of hours (if different)		<input checked="" type="checkbox"/>	Other	Paediatric Cardiology team
<input type="checkbox"/>	Children’s Community Nursing*		<input type="checkbox"/>	Other	
<input checked="" type="checkbox"/>	Hospital (ward/Assessment unit)	Women and Children’s Hospital, Baby Town	<input type="checkbox"/>	Other	
<input checked="" type="checkbox"/>	Local Emergency Department	Baby Town	<input type="checkbox"/>	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:

Trisomy 18 (Edwards Syndrome)

Cardiac abnormalities – VSD, possible overriding aorta, coarctation

Medical problems and background information (inc antenatal scans): Medical history, key moments in journey; previous pregnancy losses/neonatal/infant deaths (especially if antenatal plan)

Bertie was diagnosed antenally with Trisomy 18 (Edwards Syndrome).

Antenatal scans showed cardiac abnormalities which have been confirmed as above.

Parents have been fully involved in discussions regarding cardiac surgery and have decided (with full support of professionals) that they do not want to put Bertie through surgery.

They recognise that Bertie's life will be shortened due to his genetic condition and want to focus on his comfort and making the most out of whatever time he has, spending precious time as a family and make lasting memories.

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?

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

Please support parents with techniques they can use to comfort Bertie. At the time of writing Bertie is less than a week old and parents are getting to know Bertie and what he likes or doesn't like.

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

Parents are of Christian belief.

Bertie had a christening shortly after birth.

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

Betty and Brad are married and live together. They strongly value the support of their loving friends and family.

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.

Brad and Betty recognise that Bertie's life will be shortened due to his genetic condition and want to focus on his comfort and making the most out of whatever time he has, spending precious time as a family and make lasting memories. Once Bertie survived birth, plans were made to get Bertie home to help with this.

Betty and Brad have already had music therapy developing a lullaby with his heartbeat. The ward also managed to provide invaluable memory making, art and photos, to which the family are extremely grateful. They continue to engage with ACP Children's Hospice in further activities with Bertie.

Others' wishes: Wider family, school friends, carers

Betty and Brad have friends and family who live locally.

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.

Parents were aware and concerned that Bertie may not survive birth.
They are delighted that he has and value every minute they are able to spend with him.

At the time of writing Bertie is preparing to go home with parents. It is expected that they will want to stay at home even if he deteriorates and stay there for end of life care. They know they also have the support of the local midwife and ACP Hospice, to help achieve this.

Parents acknowledge however, that they may struggle to cope on their own at home and know that end of life care is also available in the hospice, should they desire this. They are aware that there may be little warning or that he may be too unwell for transfer at the time and accept this risk, given that at present their desire is to remain at home.

Parents are aware there are options available to parents if their baby sadly dies. At the time of writing, they are unsure where they would want to be and have asked for this to be discussed at the time. For information, this includes transfer to ACP Children's Hospice to use the cool bedroom facilities for up to 5 days or transfer home with a cuddle cot and support from the local CCN team and ACP Children's Hospice Community team. Please discuss these options with parents and contact ACP Children's Hospice on 01324 567890 to discuss in more detail.

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 20 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

The family are aware that it is unlikely that Bertie's organs could be used, but it MAY be possible for tissue donation. This has **not** been discussed with the organ and tissue donation team as parents are unsure if they want this (parents are aware that this would need to be discussed with the team should they want this). Please discuss / explore this sensitively at the time.

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

Parents are of Christian faith. They do have links with their local church. Bertie was christened shortly after birth. If end of life is recognised please offer further support from chaplain if this is possible (parents aware that this may not be possible depending upon the situation).

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.

Parents would like to make as many memories as possible. Please continue to offer them opportunities for this.

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

At the time of writing, it is not expected that there are any predetermined reasons for discussion with the coroner. However, this will depend upon the circumstances at the time.

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

Please support parents at the time and also contact ACP Children's Hospice on 01324 567890 who will offer support including ongoing bereavement support as required.

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

Bertie has been diagnosed with a genetic condition (Trisomy 18 – Edwards Syndrome).

He also has Cardiac Abnormalities VSD, possible overriding aorta, coarctation.

Parents have bravely (with support of professionals) decided that they wish to follow a comfort based approach and do not want to put Bertie through any uncomfortable procedures.

Notes on likely deterioration (if known and relevant): Consider likely cause(s) of deterioration, including signs, symptoms and red flags

Trisomy 18 is often associated with life threatening apnoeas and parents are aware that he may simply stop breathing.

He may also become more breathless due to his cardiac condition.

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

Systems approach to managing deterioration

Airway: Tracheostomy (also note if patent upper airway) and airway adjuncts

Breathing: Oxygen, pressure and ventilation support

Parents do not want to overly medicalise Bertie and have decided that they do not wish to have oxygen in the home. Treat symptoms (e.g. breathlessness) to ensure comfort.

Bertie is at risk of apnoeas but these do not require treatment.

Circulation/cardiac: Access; diuretics; blood pressure support; implants – what patient has, when and how to change or turn off

Bertie has a cardiac condition. Treat symptoms.

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

Depending upon the situation it maybe appropriate to consider oral antibiotics

Nutrition and hydration: Including presence of, or discussion about NG, NJ PEG and JEJ, TPN

Bertie is orally feeding (breast and top ups ([EBM] via syringe and bottle). Be guided by Bertie.

It is unlikely parents will want NG as they wish to focus on comfort and if Bertie reduces his feed they will want to focus on him rather than admit for NG. However, this can be discussed at the time.

Blood tests: Consider frequency, indication and specific tests or stop routine tests

At the time of writing this is not felt to be helpful for Bertie. However, this may be something to consider in the future.

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

At the time of writing this is unlikely to be the right thing for Bertie. However, this may be something to consider in the future.

Condition specific interventions/general: not previously mentioned, may include when to call 999, transfer to hospital

Whilst not intending to have invasive intervention, the local cardiology team are happy to be contacted for advice.

Other patient plans/where to find: symptom management plans; specialty care plans (eg respiratory care plans), etc

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

Parents are likely to be with Bertie most of the time. However, even if they are not with him they do not want to deviate from the plan detailed below.

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 <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Airway repositioning	
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Airway adjuncts	
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Bag and mask/tracheostomy (also note if upper airway patent)/mouth to mouth ventilation	
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Chest compressions	
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Defibrillation	
Airway	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Suction	Parents do not have suction at home but if he attends the hospice (or hospital) this may be appropriate
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Intubation/Supraglottic airway insertion (eg LMA)	
Breathing	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Supplementary oxygen if available	Parents do not have oxygen at home and it is unlikely that they desire this with invasive masks or nasal cannulae but it would not be inappropriate if parents change their mind
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Highflow (eg Optiflow/Vapotherm)	
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Non-invasive ventilation	
Circulation	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Intravenous access	At the time of writing, not for IV Access but could be considered in future
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Intraosseous access	
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Cardiac/ALS drugs (usually in conjunction with chest compressions)	
Other	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	Emergency transfer to hospital	Unlikely parents will want this but it is not unreasonable. Generally worth ringing hospice first to discuss
	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	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

At the time of writing, parents have opted for a comfort based approach and wish to maximise their precious time with Bertie at home. They do not wish for any painful interventions and wish to avoid hospitalisation (this is fully supported by professionals). However, it is understood that this may change over time depending upon how Bertie does.

Parents know ACP Hospice can be contacted to discuss this or any other management concerns at any time. We wish to focus on management within the community at this time.



(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: Bertie Smith **Date completed:** 05/01/2024

2 Shared understanding of my health and current condition:

Summary of relevant information for this plan including **diagnosis** and **relevant personal circumstances:**

Trisomy 18 (Edwards Syndrome)
Cardiac abnormalities – VSD, possible overriding aorta, coarctation

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 an Advance Care Plan (CYPACP) – Please read for further details and background.
 A separate symptom management plan detailing doses is available. Please ask parents (or ACP Hospice) for latest copy.

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 **OR** Prioritise comfort, even at the expense of sustaining life

How would you balance the priorities for your care?

What I most value: Time with my family, creating precious memories	What I most fear/wish to avoid: Discomfort, pain. Wish to avoid Hospital
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4 Clinical recommendations for emergency care and treatment:

Prioritise extending life Clinician’s signature	Balance extending life with comfort and valued outcomes Clinician’s signature	Prioritise comfort Dr Billy Consultant in PPM Clinician’s signature
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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: **This**

Do NOT attempt resuscitation
Do ensure Bertie’s comfort at all times. (See Separate symptom management plan to help this)

Communicate openly and honestly with family.

At the time of writing, parents have opted for a comfort based approach and wish to maximise their precious time with Bertie at home. They do not wish for any painful interventions and wish to avoid hospitalisation (this is fully supported by professionals). However, it is understood that this may change over time depending upon how Bertie does.

Parents know ACP Hospice can be contacted to discuss this or any other management concerns at any time. We wish to focus on management within the community at this time.

CPR attempts recommended Clinician’s signature	For modified CPR (Child and Young Person) Clinician’s signature	CPR attempts NOT recommended Dr Billy Consultant in PPM (05.01.24) Clinician’s signature
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Name: Bertie Smith | DOB: 01/01/2024 | NHS No: 987 654 3210

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?	<input type="checkbox"/> Yes	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
	<input checked="" type="checkbox"/> No	
Document the full capacity assessment in the clinical record		

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	<input type="checkbox"/>	This person has the mental capacity to participate in making these recommendations. They have been fully involved in making this plan.
B	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	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):
	<input type="checkbox"/>	1 They have sufficient maturity and understanding to participate in making this plan.
	<input type="checkbox"/>	2 They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.
	<input checked="" type="checkbox"/>	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:
 05/01/2024 Barbara (CNS) & Dr Billy from ACP Children's Hospice discussions with both parents

7 Clinicians' signatures

Designation (grade/specialty)	Clinician name	GMC/NMC/HCPC Number	Signature/image	Date/Time
Clinical Nurse Specialist	Barbara			05/01/2024

Senior responsible clinician:

Designation (grade/specialty)	Clinician name	GMC/NMC/HCPC Number	Signature	Date/Time
Consultant in PPM	Dr Billy	1234567		05/01/2024

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:	Betty Smith (Mother)	<input checked="" type="checkbox"/>	07123 456 789	
Patient/family:	Brad Smith (Father)	<input checked="" type="checkbox"/>	07123 456 790	
Professional:	ACP Children's Hospice	<input checked="" type="checkbox"/>	01234 567 890	
Professional:		<input type="checkbox"/>		
Professional:		<input type="checkbox"/>		

9 Form reviewed (eg for change of care setting) and remains relevant

Review date	Designation (grade/specialty)	Clinician name	GMC/NMC/HCPC Number	Signature