

Name: Jay Ali

DOB: 01/01/2006

NHS No: 123 456 7890



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):	Jay Ali	EDD (if relevant):	
Known as (if different):		DOB:	01/01/2006
Address including postcode:	1 Taps Close Sandygate Coletown, AH1 2BD		
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
Other situations:	ABC Hospice – 01234 567 890 (24/7 contact number)

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	10/05/2023
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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 <input checked="" type="checkbox"/>	No <input type="checkbox"/>
<b>Information to help improve communication / support capacity:</b>				
Parents' first language is Urdu so interpreter may be required for communication with whole family. Jay would like important information communicated to him electronically in addition to verbally.				
<b>Decision-making details/preferences:</b> 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?				
Jay has full capacity to make decisions relating to his health and wellbeing currently.				
<b>Important information relating to capacity and where further information can be found.</b>				
Further guidance will be available on the CYPACP website. See also last page				
Jay would like to be involved in discussions and decision-making and would like his parents present where possible.				

**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)**

<b>Responsibility for changes / distribution of CYPACP (please contact if you believe this version to be inaccurate)</b>					
<b>Name/Role/Department/Organisation and contact details:</b>					
ABC Hospice 01234 567 890 (24/7 contact number)					
		<b>Name and contact details</b>			<b>Name and contact details</b>
<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		<input type="checkbox"/>	School Nurse/Head Teacher	
<input checked="" type="checkbox"/>	Lead Paediatrician/Obstetrician		<input checked="" type="checkbox"/>	Social Services	Continuing Healthcare
<input checked="" type="checkbox"/>	Palliative Team*		<input type="checkbox"/>	Midwife	
<input checked="" type="checkbox"/>	Hospice*	ABC Hospice 01234 567 890 (24/7)	<input type="checkbox"/>	Health Visitor	
<input checked="" type="checkbox"/>	GP		<input checked="" type="checkbox"/>	Other (eg Hospital Specialists)	Respiratory team
<input type="checkbox"/>	GP out of hours (if different)		<input checked="" type="checkbox"/>	Other	Neuromuscular team
<input checked="" type="checkbox"/>	Children's Community Nursing*		<input checked="" type="checkbox"/>	Other	Adult community nurse team
<input checked="" type="checkbox"/>	Hospital (ward/Assessment unit)		<input type="checkbox"/>	Other	
<input checked="" type="checkbox"/>	Local Emergency Department		<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:

Duchenne muscular dystrophy with NIV overnight and early stage heart failure. Jay has had some deterioration of his health over the past 12 mths with four hospital admissions with chest infections the most recent episode requiring ITU.

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

Cardiac system – early stage heart failure managed with ACE inhibitor

Respiratory – reduced lung function on night NIV and daily cough assist

Gastro – enterally fed via a gastrostomy to supplement oral diet.

Mobility – uses a wheelchair, limited upper limb mobility requiring specialist equipment (hoist, bed). Jay is unable to move independently. Severe hip and joint pain.

## 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?

Jay is a happy and lively young man who enjoys a good social life with friends and is at college planning to go to university. He recognises early symptoms of a chest infection and will seek medical review and treatment.

**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

Jay enjoys gaming and uses it to distract him at times. Jay appreciates people being open and honest and involving him in decisions about his care needs/treatment.

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

Jay attends college with support of a carer and also attends extra-curricular activities. He supports his local football team and likes to watch with his friends. Jay participates in the youth group at the hospice. Jay has a strong Muslim faith, and his parents support his engagement to practice.

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

Jay lives in a private rental house with his parents, mum, Ameena, and dad, Mohammed. He has two younger siblings: Femi who is 10 years old and Kaso who is 8 years old. Maternal and paternal grandparents live locally and support the 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

Jay would like to be cared for at home with his family as much as possible and avoid hospital admission. Jay would like his daily prayer practice to be supported in all settings. He continues to attend school as much as possible and would like to maintain his independent social life. His goal is to study maths at university.

**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.

Jay's family enjoy spending time together and are supportive of Jay's wishes and goals for the future. Jay's siblings are supported by the hospice sibling team.

**Others' wishes:** Wider family, school friends, carers

Jay enjoys it when his friends are able to visit him or stay with him at the hospice.

## 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.

Jay would prefer to have end of life care in the hospice and he would like all of his family members and carers to be present.

**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

Donation has been discussed and the family do not wish for this.

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

Jay's family would like a rapid burial to be facilitated in accordance with their Muslim faith. Parents will advise on how they would like him cared for after his death.

**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.

Jay has started to compile a digital legacy for his friends and family (see link).

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

Jay and his parents are aware of the medical examiner process and would want early burial facilitated. Out of hours contact for the medical examiner may be required (Tel: 01234 234234).

**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

Muslim burial with local Imam to support the funeral arrangements. On-going bereavement support for the family will be offered by the hospice.

**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

Please see Jay's symptom management plan – Version 1

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

Likely heart failure or respiratory decline (infection/increasing ventilatory requirements).

**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

See symptom management plan which details ceilings of care.

### Systems approach to managing deterioration

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

Jay does not want a tracheostomy.

**Breathing:** Oxygen, pressure and ventilation support

See ventilation protocol. For maximum non-invasive ventilation to avoid intubation and ventilation.

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

Optimise diuretics and medication.

**Neurology:** State if VP shunt or reservoir present and action if blocked; role of pulsed steroids in neurological decline; acute seizure management

N/A

**Management of commonly occurring infections:** Including central line and stated temperatures for individual child

Jay would like to avoid hospital if possible but accept short term IVAB for reversible causes.

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

Jay has a gastrostomy to maintain medical administration and nutrition/hydration.

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

Jay would like to avoid unnecessary blood tests where necessary.

**Blood products:** Consider type, frequency and indication eg blood test or clinical symptoms

Discuss with Jay at the time, if required.

**IV/SC access:** Portacath; Hickman; Midline; other; and discussions about subcutaneous access

Would consider IV/SC access if required.

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

See ventilation escalation plan.

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

Symptom management plan

## 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

None

### 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 checked="" type="checkbox"/>	No <input type="checkbox"/>	Airway adjuncts	
	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Bag and mask/tracheostomy (also note if upper airway patent)/mouth to mouth ventilation	A short period (eg 5 minutes) may be appropriate to try and correct short term reversible issues (eg sputum plugs).
	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	
	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	
	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Highflow (eg Optiflow/Vapotherm)	
	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Non-invasive ventilation	
Circulation	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Intravenous access	
	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 checked="" type="checkbox"/>	No <input type="checkbox"/>	Emergency transfer to hospital	
	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

Jay does not want to have a tracheostomy inserted.

See ReSPECT form on last two pages



**(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.

<b>1 Preferred name:</b>	Jay Ali	<b>Date completed:</b>	10.05.23
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**2 Shared understanding of my health and current condition:**

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

Duchenne muscular dystrophy with NIV overnight and early stage heart failure. Declining respiration with increased ventilation support. Escalate to hospital for reversible causes within agreed ceilings of care.

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):

See ACP pages 6-7 for more information. Symptom Management Plan in place.

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
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How would you balance the priorities for your care?

What I most value: Having my family and friends around me and supported to die at the hospice.	What I most fear/wish to avoid: Dying in hospital.
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**4 Clinical recommendations for emergency care and treatment:**

Prioritise extending life  Clinician’s signature	OR	Balance extending life with comfort and valued outcomes X Dr Smith Consultant in Palliative Medicine Clinician’s signature	OR	Prioritise comfort  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:

**Appropriate (and desired) limitations to interventions are:**

- **NO Chest Compressions / Debifibrillation – NOR associated Cardiac Drugs**
- **NO Intubation / Supraglottic Airway (LMA)**
- **NO Admission to ICU**

A short period (e.g. 5 Minutes) of **bag and mask ventilation MAY BE appropriate** to help reverse short term respiratory deterioration (e.g. Mucous Plugs).

See also the ‘Symptoms approach to managing deterioration’ and ‘Management of an Acute Significant Deterioration/Emergency’ sections in the attached ACP for more detailed appropriate management wishes/ plans.

CPR attempts recommended	For modified CPR (Child and Young Person)	CPR attempts <b>NOT</b> recommended
Clinician’s signature	X Dr Smith Consultant in Palliative Medicine Clinician’s signature	Clinician’s signature



Name: Jay Ali | DOB: 01/01/2006 | 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?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	<p>→ 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</p>
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 checked="" 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 checked="" 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 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:  
10/05/23 – Jay Ali, Ameena Ali (mum), Mohammed Ali (dad), A N Other, Hospice

**7 Clinicians' signatures**

Designation (grade/specialty)	Clinician name	GMC/NMC/HCPC Number	Signature/image	Date/Time
Clinical Nurse Specialist	A N Other	1234	X	10/05/2023 at 11.00

**Senior responsible clinician:**

Designation (grade/specialty)	Clinician name	GMC/NMC/HCPC Number	Signature	Date/Time
Consultant at ABC Hospice	Dr Smith	12345689	X	10/05/2023 at 11.00

**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:	Father	<input checked="" type="checkbox"/>	01234 123412	
Patient/family:	Mother	<input checked="" type="checkbox"/>	01234 123412	
Professional:	ABC Hospice	<input checked="" type="checkbox"/>	01234 567901	
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