

Date Received: _____ JH no: _____ County: _____



RESPITE REFERRAL FORM

PART 1: Details of Child

First Name(s):		Surname:		Date of Birth:	
Known As:		NHS No:	_____		
Gender:	<input type="checkbox"/> Male	<input type="checkbox"/> Female	Religion:		Main Language Spoken:
Home Address:					
Post Code:		Home Telephone No:			
Resides With:	<input type="checkbox"/> Mother & Father	<input type="checkbox"/> Mother	<input type="checkbox"/> Father	<input type="checkbox"/> Other (please specify)	



Ethnic Origin						
Section 1:	White	Black	Asian		Mixed	
Section 2:	British	English	Scottish	Welsh	Irish	Other _____
Section 3:	White & Black Caribbean	White & Black African	White & Asian	Any other Mixed Background _____		
Section 4:	Indian	Pakistani	Bangladeshi	Carribbean	African	Chinese
	Other _____					



Diagnosis (Please give a brief summary of the child's Medical Condition)	
Referring at or after point of diagnosis:	



Current Medication		
Medication Name	Dose and Route	Frequency

Current Treatment (including Complimentary Therapies)		
Type	By Whom	Frequency

PART 2: Current Family Composition

Parents/Carers					
Parent / Legal Guardian 1			Parent / Legal Guardian 2		
Full Name:			Full Name:		
Living at Child's Address:	Yes	No	Living at Child's Address:	Yes	No
If no, full address:			If no, full address:		
Post Code:			Post Code:		
Home Telephone No:			Home Telephone No:		
Mobile Telephone No:			Mobile Telephone No:		
Email Address:			Email Address:		
Preferred Method of Contact:			Preferred Method of Contact:		



Siblings					
Name	Gender (M/F)	Date of Birth	Affected by same or other condition?	Lives at child's address?	
				Yes	No
				Yes	No
				Yes	No
				Yes	No
				Yes	No
				Yes	No



Significant others involved in the Child's Care		
Name	Full Address	Relationship to Child



Any additional information you would like us to know about the family structure (if any)

PART 3: Professionals involved in the care of the Child

A GP Details

Name of GP:		Name of Surgery:		<input type="checkbox"/>
Address:				
Post Code:		Email Address:		
Contact No 1:		Contact No 2:		

B School or Nursery Details

Name of School/Nursery:		Name of Contact:		<input type="checkbox"/>
Address:				
Post Code:		Email Address:		
Contact No 1:		Contact No 2:		

C Please list other professionals that are involved in the care of the Child (e.g. Community Paediatrician, Specialist Consultants, Social Worker, Community Nurse, Health Visitor, etc.)

Role	Name	Address	Contact No	<input type="checkbox"/>

PART 4: To be completed by the Referrer

Full Name:		Relationship to Child:		<input type="checkbox"/>
Address:				
Post Code:		Email Address:		
Contact No 1:		Contact No 2:		
Signature:			Date:	

PART 5: To be completed by the Child's Doctor:

Full Name:		Practice:	
Address:			
Post Code:		Email Address:	
Contact No 1:		Contact No 2:	

Having read the Referral Criteria for Julia's House (see pages 5-12), in your professional opinion does the child meet the criteria for Respite Support from Julia's House? Yes No

Under what TFSL group (see pages 5-6) do you think the child falls into:

Group 1 Group 2 Group 3 Group 4 None stated

Please note if the Child falls into Group 2 or 4, please refer to the additional criteria (pages 7-12)

Summary of Medical Condition
(NB please provide the relevant supporting information as specified in the Referral Criteria)

Signature:		Date:	
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PART 6: To be completed by the Parent or Legal Guardian

I, _____, the Parent/Legal Guardian of _____ (child)
 (print name) (print name of child)

am aware of the contents of this form and consent to this referral being made to Julia's House Children's Respite Service. I also give consent for the Julia's House Nursing Team to request information and liaise with any of the professionals listed within this form that are involved in the care of the above named person.

Signature:		Date:	
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Please return this completed form, marked 'Private and Confidential' to:

Care Administration Team
 Julia's House Children's Hospice
 135 Springdale Road
 Corfe Mullen
 Dorset
 BH18 9BP

Referral Criteria for Julia's House

Introduction

The Children's Hospices of the South East of England have worked together to produce an agreed criteria for referral to the services provided across the region. Children's hospices, in the UK are independent charitable organisations that work in partnership to provide a network of care for children with life limiting and life threatening conditions and their families.

Aim

Julia's House aims to provide the following services to young people that fit our criteria in an equitable and fair manner.

- planned respite care in the community
- planned respite day care
- occasional overnight weekend care in our Hospice
- end of life support in both the Community and the Hospice

We aim to ensure that when possible the individual needs of the child and family are met.

Acceptance Criteria

The acceptance criteria for the hospice service is based on the four broad categories of life-limiting conditions described by ACT in 2011 as shown further below. All referrals must fit in to one of these categories. In addition to these categories, the following criteria applies to Julia's House

- Families must reside within Dorset or Wiltshire (the service in Wiltshire is still developing so please contact Julia's House to confirm the current area covered).
- Young people to be under 18 years of age at the time of referral, with a fragile life expectancy;
 - 16 -18 yr. olds will be assessed sensitively according to the needs and life expectancy of the young person
- The parents of the young person and where appropriate the young person must give their consent for the referral.
- The relevant section on the referral form must be completed, clearly identifying how the young person's medical condition fits the criteria – which ACT Category they are in and why - and signed by a medical practitioner.

N.B: New referrals will not normally be accepted for any child already in the acute stages of end of life care. However, each case will be considered individually, and in some cases this may be appropriate.

ACT Categories of Life-Limiting Conditions

Group 1

Life-threatening conditions for which curative treatment may be feasible, but can fail. Access to palliative care services may be necessary prior to or while undergoing corrective treatment or when treatment fails e.g. Children with tracheostomies, Cancer, irreversible organ failures of heart, liver, kidneys.

Please see the additional criteria for Cancer.

Group 2

Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in other activities (e.g. Cystic Fibrosis and Muscular Dystrophy).

Please see the additional criteria for Cystic Fibrosis.

Group 3

Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years (e.g. Batten disease, Mucopolysaccharidoses).

Please see the additional criteria for Rett Syndrome.

Group 4

Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death (e.g. severe cerebral palsy, multiple disabilities such as brain or spinal cord insult).

Please see the additional criteria for:

- Epilepsy
- Neurological Disabilities
- Neonatal Referrals

***If you wish to discuss an individual child before sending a referral please contact either of the Directors of Care for Julia's House; Ali Acaster or Karen Dale on 01202 644220**

Definition of Terms

Young Person

This term is used to describe any child or young person from birth to 19 years of age. It is used for ease of documentation and in an effort not to cause offence.

Life-Limiting Condition

These are conditions for which there can be no reasonable hope of a cure and from which young people will die within months, or more usually, years. Many of these conditions cause a progressive degeneration rendering the young person increasingly dependent upon carers.

Life-Threatening Conditions

These are serious conditions or diseases for which treatment aimed at cure is available but may fail. Access to palliative care services may be necessary when treatment fails.

Palliative Care

This is the active and total care of a young person and their family by a multi-professional team at a time when the young person's condition is not responsive to curative treatment. The young person will be cared for holistically, addressing physical, psychological, social and spiritual needs and extending to support of the family in bereavement.

Terminal Care/End of Life Care

This is the specialist care given when the end of a young person's life is imminent. Special care is taken to make the young person as comfortable and pain free as possible and to cater for their total care in a holistic way.

Bibliography

Together For Short Lives & The Royal College of Paediatrics and Child Health (2003) A Guide to the Development of children's Palliative Care Services

Additional Referral Criteria

Aim

Julia's House aims to provide an equitable service that meets the needs of the children and their families, while being an appropriate use of our resources. Inevitably discussions have to be made about whether or not we can accept a referral. The following additional criteria have been produced to rationalise our decision making in an evidence based way and should be used in conjunction with the generic referral criteria.

Referral Criteria for Accepting Young People with a Neurological Disability

These conditions include severe cerebral palsy, birth injury and those who suffer an insult following illnesses such as meningitis, encephalitis or a severe head injury. The severity of the injury / insult and the long term affects influence whether or not a young person fits our criteria

Acceptance Criteria

Young people being referred under this category are likely to be accepted if they have either c or d in at least 3 categories:

Respiratory

A	Frequent or an increasing number of lower respiratory tract infections	Y	N
B	PICU admission for lower respiratory tract infection	Y	N
C	Requirement for long –term oxygen therapy or non – invasive ventilation at home	Y	N
D	Tracheostomy and / or 24hr ventilation at home	Y	N

Feeding Factors

A	Gastrostomy / Jejeunostomy / Nasogastric tube	Y	N
B	Severe uncontrolled reflux despite maximum treatment	Y	N
C	Not gaining weight or maintaining weight due to feeding difficulties	Y	N
D	Pain / distress associated with feeding	Y	N

Seizure Related Factors

A	Epileptic activity needing medication	Y	N
B	Poor seizure control despite numerous medications	Y	N
C	Frequent use of rescue medication (at least weekly)	Y	N
D	Episodes of status epilepticus requiring intensive treatment in the last 12 months	Y	N

Locomotor Factors

A	Spastic quadriplegia / total body involvement	Y	N
B	Poor head control / fixed spinal curvature	Y	N
C	Dependant on a wheelchair driven by a carer	Y	N
D	Difficulty with maintaining sitting position	Y	N

***Can the Medical Practitioner completing the Summary of Medical Condition please indicate on the above form which of the symptoms the young person has.**

Ref : Helen and Douglas House

Referral Criteria for Accepting Young People with a Cancer

The outlook for children with malignant disease continues to improve; 2/3 can expect to be cured i.e. be free of disease for 5 years. (Plowman & Pinkerton 1997) Some childhood cancers are known to have a worse prognosis than others. (Childhood Cancer Research Group 2004)

Most children dying from malignant disease die from the progressive spread of their tumour, but a small percentage die from complications of treatment aimed at curing their disease. (Goldman 1999)

Given the complexity of childhood cancer, the child's consultant will be asked to give an estimation of the child's prognosis on an individual basis.

Acceptance Criteria

- Children with Acute Lymphoblastic Leukaemia or Acute Myeloid Leukaemia following first relapse.
- Any child considered by a Consultant Paediatric Oncologist to have less than a 40% chance of achieving 5 years disease free survival.
- Any child with a cancer that is known not to be curable at diagnosis or whose cancer may be treatable but treatment may fail e.g. removal of tumours.

References

Cancer Stats. Childhood Cancer – UK (2004) Cancer Research UK www.cancerresearchuk.org

Goldman A. ed (1999) Care of the Dying Child Oxford University Press Oxford

Plowman P., Pinkerton C.R. (eds) (1997) Paediatric Oncology – Clinical Practice and Controversies Chapman Hall London

Referral Criteria for Accepting Young People with Rett Syndrome

Acceptance Criteria

Young people with Rett Syndrome who meet the criteria would normally have at least 3 of the following:

- a diagnosis of Classic, rather than Non-classic, Rett
- Severely reduced or increased tone
- Inability to have walked
- Frequent epileptic fits (other than vacant episodes)
- Blackouts associated with respiratory disturbance
- Severe feeding difficulties
- Inadequate weight gain

***Can the Medical practitioner completing the Summary of Medical Condition of the Respite Referral form please indicate which of the above symptoms the young person has.**

Sources:

Kerr, A.M., (2002). Annotation: Rett Syndrome: recent progress and implications for research and clinical practice. *Journal of Child Psychology and Psychiatry*, 43:3, 277-287.

Referral Criteria for Accepting Young People with Epilepsy

This severity of this condition can vary greatly both between clients and during the course of the condition. For this reason, for some children during their life, support by a children's' hospice service may be appropriate while for other families referral may cause unnecessary stress.

This referral criteria helps to identify to referrers when a referral for a young person with a stand alone diagnosis of epilepsy is appropriate. The criteria should be used in conjunction with the generic referral criteria. This criteria should not be used for a young person whose epilepsy is part of another underlying condition e.g. Cerebral Palsy.

Acceptance Criteria

Young people being referred under this category need to fulfil at least 2 of the following criteria:

- ❑ Poorly controlled seizures which are having a negative impact on the quality of life, despite optimum treatment.
- ❑ Emergency medication is required for major seizures at least weekly.
- ❑ Oxygen therapy and / or suction is required as part of the management of the seizures at least monthly.
- ❑ Hospital admission for treatment of seizures has been required at least 4 times in the last year.

***Can the Medical practitioner completing the Summary of Medical Condition of the Respite Referral form please indicate which of the above symptoms the young person has.**

Referral Criteria for Accepting Young People with Cystic Fibrosis

Although most hospices have Cystic Fibrosis (CF) as a target disease, the increasing variability in the disease is causing difficulties in assessing the appropriateness of referrals. This problem is being compounded by reductions in respite care offered by Social services and so hospices are being asked to “fill the gap”- which is not the best or appropriate use of these facilities or resources.

In order to address this problem Julia’s House is proposing to start using the banding process used by most Regional CF Centres. The criterion for each band clearly indicates the amount of treatment (and therefore disease severity) the child is likely to have received in a 12-month period. By using the child’s identified band Julia’s House would have a clear indication of the child’s disease severity and the likely burden of daily treatment on the child and family.

Children in the newly diagnosed band and lower bands (1 & 2) are unlikely to require hospice care but could be considered if there is other supporting evidence i.e. another condition which either complicates their CF or warrants referral to hospice in its own right e.g. Muscular Dystrophy.

- New Diagnosis Band:** This is for children within the first twelve months of their CF diagnosis – regardless of their actual age at diagnosis. Although this band usually applies to babies picked up on newborn screening it will also apply to older children. It is unlikely that a CF child in this band would require hospice care but there maybe circumstances depending on additional diagnosis, social background etc.

- Band 1:** Patients who only receive outpatient care from doctors, nurses, physiotherapists etc. No intravenous antibiotics required. No in-patient admissions apart from an annual assessment and review as a day case.

- Band 1a:** Previously as above BUT require up to 14 days of intravenous antibiotics (at home or in hospital) and spend a maximum of 7 days in hospital over the course of a 12 month period OR receive short-term (up to 3 months) nebulised antibiotics for eradication treatment.

- Band 2:** Patients who require maintenance nebulised antibiotics for pseudomonas infection or maintenance nebulised Dornase alpha. Patients receive up to 28 days of intravenous antibiotics in a 12 month period OR spend a maximum of 14 days in hospital.

- Band 2a:** Patients who receive both nebulised antibiotics and Dornase alpha and require up to 56 days of antibiotics intravenously at home or in hospital in 12 month period OR spend a maximum of 14 days in hospital.

Children entering band 3 or above should be considered for hospice care. It is important that before a referral is actioned families understand the significance of hospice care and the aims of the service - to provide high quality palliative care which focuses on the quality of life and includes respite services.

- Band 3:** Patients who have more frequent in-patient visits, have up to a maximum of 84 days on intravenous antibiotics (at home or in hospital) in a 12 month period OR spend up to 57 days in hospital OR patients with gastrostomy feeding or any of listed CF complications namely CF related.

Band 4: Patients who have severe disease and usually spend up to 112 days in hospital in a 12 month period, although it is recognised that some patients at this stage of their illness, prefer to be treated/supported at home with the support of the CF multidisciplinary team. Patients require a minimum of 85 days per year on intravenous antibiotics (at home or in hospital). Patients have CF-related complications of diabetes, pneumothorax or haemoptysis.

Band 5: Patients are severely ill and stay in hospital for greater than 113 days per year, awaiting transplantation or receiving palliative care. Patient's life expectancy is usually no more than a year to 18 months.

The above is not exclusive criteria and each case will still require an individual assessment. However it is hoped that they will provide a guide to help those making referrals so that we can ensure that the services available e.g. community based respite or end of life support can be targeted at the right group of children.

***Can the Medical practitioner completing the Summary of Medical Condition of the Respite Referral form please indicate which of the above bands the young person is in and enclose a copy of their last annual review.**

Sources:

Thanks go to Judi Maddison Cystic Fibrosis Specialist Nurse at Southampton General Hospital for her help with developing this criteria.

Referral Criteria for Accepting Neonates

Identifying a category for neonates from the ACT Life – limiting categories may present additional challenges for the referrer because of the difficulties in predicting the long – term outcome for this particular group of clients. The following criteria may help to clarify if a referral to Julia's House is appropriate.

Neurological Disabilities:

2 of the following sections should apply

- Ongoing need for interventions to maintain respirations e.g
 - suction
 - long – term low flow oxygen
 - ventilation
 - tracheostomy

- Active apnoea episodes requiring ventilation

- Poorly controlled seizures

- Poor swallow requiring long-term support with an alternative feeding method e.g ng tube

OR

- A stable neonate with a congenital abnormality requiring additional nursing support while awaiting corrective surgery e.g. catheterisation or an alternative feeding method.

OR

End of Life Care

This is not suitable for infants born at less than 32 weeks gestation who die within the first week of life.

If you wish to discuss a referral please contact either Karen Dale or Ali Acaster on 01202 644220