

REFERRAL FORM

About Jessie May

Jessie May provides a Palliative Care Service for children and young people who are not expected to live beyond the age of 19. The Jessie May Care Team (which includes qualified Children's Nurses and Nursery Nurses) visit the family at home to provide short periods of respite, support, advice, terminal nursing care and bereavement support. Each child's care is planned specifically to meet the needs of the individual child and family, working in partnership with both the family and with other professionals involved in supporting them.

Jessie May was established in 1996 and is a registered charity. No charge is made to families receiving the service.

Who can refer a child to Jessie May?

Anyone, including parents, involved in the care of a child (or young person) can refer to Jessie May, provided that:

1. the child (or young person) is not expected to live beyond the age of 19 years
2. parental permission for a referral must be sought, together with consent to obtain information about the child (or young person) from a paediatrician.
3. the child (or young person) lives within the geographical boundaries of one of the following Primary Care Trust (PCT) areas: Bristol, South Gloucestershire, North Somerset, Bath & North East Somerset, or Swindon & Wiltshire. For families within the geographical region of Swindon & Wiltshire please contact Jessie May before completing this form to confirm the referral process.

For further information on the Jessie May referral criteria or process, please contact the Jessie May Care Team who will be happy to discuss any queries or concerns with you on 0117 958 2172 or by e-mail careteam@jessiemay.org.uk

How to make a referral to Jessie May

The person making the referral ("the referrer") will need to be responsible for ensuring that parents/carers and paediatricians complete and sign the form before it is returned to Jessie May. Some parents may wish to ask their paediatrician to complete the form when they have a clinic appointment and can then forward the form to Jessie May themselves if they prefer.

The form is divided in to four sections as follows:

- Section One – Details of the child & family
- Section Two – Permission from parents
- Section Three – Details of person making referral
- Section Four – Medical information from paediatrician

Additional forms attached include Ethnicity Monitoring Information and Home Environment Initial Risk Assessment, both of which should be completed as fully as possible as part of the referral process by the referrer and/or parents.

The referral form must be completed in full before being returned to Jessie May at the address below. Referrals cannot be accepted unless both sections two and four are completed and signed.

What happens next?

On receipt of a completed referral form a member of Jessie May's care team will contact the family to arrange an assessment visit to discuss their needs. A Care Agreement will be drawn up in partnership with parents/carers and/or the young person. Jessie May will complete a Home Record Book containing details of the child's routines, drugs and emergency procedures, which should remain in the home for all future Jessie May visits.

Jessie May
35 Old School House
Kingswood Foundation Estate
Britannia Road
Kingswood
Bristol
BS15 8DB

Telephone:

Care Team 0117 958 2172

Admin Team 0117 961 6840

Fax: 0117 960 7783

E-mail: info@jessiemay.org.uk

Web: www.jessiemay.org.uk

Registered Charity Number 1086048

SECTION ONE: DETAILS OF CHILD & FAMILY

This section can be completed by the family and/or person making referral.

Child's First Name(s):		Last Name:	
Child's Date of Birth:		Sex:	Male <input type="checkbox"/> Female <input type="checkbox"/>
Diagnosis:			
PCT Area Child lives in:			
Child's Address:			
Post Code:			
Parents email address:			
Home telephone number:		Parents' mobile numbers:	
Names and dates of birth of any siblings:			

Mother's Name:	Title:	First Name:	Last Name:
Father's Name:	Title:	First Name:	Last Name:
Who has parental responsibility?			
Address of mother and/or father (please indicate which) if different to the address above		Post Code:	Telephone Number:

Are there any Child in Need or Child Protection concerns in association with this child and family?	YES <input type="checkbox"/>	NO <input type="checkbox"/>	NOT KNOWN <input type="checkbox"/>
Is the family's first language English?	YES <input type="checkbox"/>	NO <input type="checkbox"/>	First language if not English:

Name of Child's GP:	
Address of Child's GP:	
Post Code:	Telephone Number:

SECTION TWO - PERMISSION FROM PARENTS

This section must be completed by the child's parents.

Please note: Parental permission is required to make a referral to Jessie May, together with consent to obtain information about the child (or young person) from a paediatrician.

I/We give permission that medical information relating to my/our child may be provided to Jessie May (see section four) in connection with this referral from the paediatrician detailed below:

YES NO

Name of child's paediatrician:

Address of paediatrician:

Telephone number:

I/We would like the medical information on this form to be obtained from the paediatrician by

a) myself / ourselves, OR YES NO

b) the person making this referral ("the referrer") YES NO

I am / We are happy for a copy of this referral form to be sent to our GP YES NO

I/We give permission for a referral to be made to Jessie May.

Parent/s Signature:

Date:

The information you give us when completing this form will be kept in accordance with the Data Protection Act 1998 and used by Jessie May to process your referral.

We are committed to keeping your data secure and will not share your personal information with any other company or service provider without your prior permission.

SECTION THREE - DETAILS OF PERSON MAKING REFERRAL

This section must be completed by the person referring the child to Jessie May

Name of Referrer:		
Relationship to Child:		
Contact Address:		
Post Code:		
Telephone number:		
Mobile number:		
Referrer's Signature:		Date:

SECTION FOUR - MEDICAL INFORMATION FROM PAEDIATRICIAN

This section must be completed by the child's paediatrician

Please note: Jessie May provides its nursing and palliative care services only to children whose life expectancy is less than 19 years of age.

Diagnosis: (If known)			
Brief summary of child's condition & medical needs:			
Prognosis:			
Is this child expected to live beyond the age of 19 years?	YES	<input type="checkbox"/>	NO <input type="checkbox"/>
Has this been discussed with parents?	YES	<input type="checkbox"/>	NO <input type="checkbox"/>
Has this been discussed with child/young person?	YES	<input type="checkbox"/>	NO <input type="checkbox"/>

Are there any Child in Need or Child Protection concerns in association with this child and family?

YES NO NOT KNOWN

Please provide photocopies of any other additional information from the child's hospital/medical notes which you feel may be of assistance in caring for this child at home. Please tick if you are enclosing any of the following items:

discharge summary	<input type="checkbox"/>
list of current medication	<input type="checkbox"/>
copy of clinic letter	<input type="checkbox"/>

Paediatrician's
Signature

Signed:

Print Name:

Date:

Address:
(if different from
in Section Two)

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How do I classify myself? Guidance on ethnic codes

White

- **British:** a white person who was born in, or whose forbears originated in the United Kingdom (Scotland, England, Wales, Northern Ireland).
- **Irish:** a white person whose forebears originated in Eire (Southern Ireland).
- **Traveller of Irish Heritage:** a Traveller whose forebears originated in Eire.
- **Gypsy/Roma:** a person with Gypsy Roma descent only.
- **Any other White background:** a white person whose forebears originated in countries other than Britain such as other European countries, Australia, Canada etc.

Mixed

- **White and Black Caribbean:** a person whose forebears originated in the categories defined as 'White' (see above) and categories defined as 'Black Caribbean' (see below).
- **White and Black African:** a person whose forebears originated in categories such as 'White' (see above) and categories defined as 'Black African' (see below).
- **White and Asian:** a person whose forebears originated from categories defined as 'White' (see above) and categories defined as 'Asian' (see below) .
- **Any other Mixed background:** a person whose forebears are from any two distinct ethnic groups not previously identified as the 'Mixed' category.

Asian or Asian British

- **Indian:** a person whose forebears originated in India
- **Any other Asian background:** a person whose forebears come from any part of Asia not previously identified in the 'Asian' categories.

Black or Black British

- **Caribbean:** a black person whose forebears originated in a Caribbean country such as Jamaica, St. Vincent or Trinidad.
- **African:** a black person whose forebears originated in an African country.
- **Any other Black background:** - a black person whose forebears originated in any 'Black or Black British' background other than 'Caribbean' or 'African'.

Chinese

- **Chinese:** a person whose forebears originated in China or Hong Kong.

Any Other Ethnic Group: a person who feels the above categories do not adequately define their ethnic origin

Ethnicity Monitoring Information

Private and Confidential

Ethnicity Groups	
White	
A	British
B	Irish
C	Any other White background*
Mixed	
D	White and Black Caribbean
E	White and Black African
F	White and Asian
G	Any other mixed background*
Asian or Asian British	
H	Indian
J	Pakistani
K	Bangladeshi
L	Any other Asian background*
Black or Black British	
M	Caribbean
N	African
P	Any other Black background*
Other Ethnic Groups	
R	Chinese
S	Any other ethnic group*
Z	Not stated

The information requested aims to assist Jessie May in identifying individual needs, ensuring that the service we provide will be culturally appropriate.

It also allows us to monitor that the service provided is accessible to all children and their families, thus ensuring that the referral process does not exclude or discourage participation.

Please record the following details:

Child's Name	
Child's ethnicity group	
Parent/carer ethnicity group	
Main Parent/carer's preferred first language	
Is an interpreter needed?	YES <input type="checkbox"/> NO <input type="checkbox"/>
If yes, which language is needed?	

Home Environment - Initial Risk Assessment

Name of Child:

Address:

Form completed by:

Date:

The following checklist is intended to assist Jessie May in identifying the various hazards that may exist for Jessie May Nurses while attending respite visits.

Who lives in the house?			
Home Visit Initial Assessment	YES	NO	COMMENT
Does the area present a specific risk to a lone worker? (e.g. specific environmental factors such as poorly lit streets or a high-risk crime area)			
Is there off street parking available?			
If not, is there ample street parking available?			
Are women especially at risk if they work alone?			
Does the family to be visited, or any other person been associated with the address, have significant history?			
Is there a risk of violence in relationship to this family?			
Do staff have a clear indication of what to do if the child/carer becomes ill has an accident, or there is an emergency? (e.g. availability of Home Record Book)			
Is there a working telephone available - home phone or mobile?			
Are there clear exit routes? Could the home be evacuated quickly?			
Is any training required to ensure competency in safety matters and the respite care of the child?			
Can one person safely handle all the lifting involved?			
Has any equipment, which may be used during the respite visit, been regularly tested?			
Does limited space around equipment, etc, present any additional health and safety issues?			
Are all the medicines/equipment clearly stored in the family home?			
Are there any pets that staff should be made aware of?			
Are there any family members who are likely to enter the house during respite visits e.g. teenage siblings?			
Do any members of the family smoke?			

Further Information for Families

There are important things you should know about the service Jessie May provides, and this is outlined for you in this guide. Please read it carefully and contact us if you have any questions.

About Jessie May

What is Jessie May?

Jessie May is a registered charity set up in 1996. We provide a free, palliative care service for children and young people with a life limiting or terminal illness, in their own home. We aim to provide support to the whole family in order to help maintain and improve quality of life.

These are some of the ways we can help families:

- **Nursing Care**

During a respite visit we can administer prescribed medication if required or carry out other medical procedures such as suctioning or tube feeding. Once the Jessie May Nurse has focused on the nursing care we will spend time interacting with your child, for example read a story or sing a song. Sometimes your child may just want to rest, be cuddled or go to sleep. We are led by your child's wishes and give them every opportunity to make their choices known. We can also give you help and advice on the management of your child's symptoms.

- **End of Life Care**

When a child or young person is at the end of their life we are able to provide more intensive support together with other agencies, which may allow you to care for your child or young person at home, if you so choose, during the last days of their life.

- **Respite Care**

We provide short periods of specialist respite care in your home – usually for about 3 hours at a time, enabling you to take a break from caring. This is flexible and organised around your needs and routines. As all of our nurses are fully qualified you are welcome to leave the house during this time, and can be assured that your child is receiving the best possible care at home.

- **Bereavement Support**

Loss begins at the realisation there is something wrong with your child or young person, even before the time of diagnosis, and the Jessie May Nurses can support families through loss issues that occur when a child or young person has a life limiting or terminal condition. Jessie May Nurses are also able to help with the practicalities of planning a funeral and offer support after a child or young person has died. A leaflet explaining our Bereavement Service is available. Please contact us if you would like to receive this.

- **Practical, Emotional, and Telephone Support**

Jessie May Nurses can give you advice on a whole range of matters related to caring for your child or young person as well as time to listen when things just get too much. We know that sometimes just having someone to talk to who understands your situation can be important. You can phone us at any time during office hours if you need to get advice, information or just to chat about things.

- **Social and Support Events**

In the summer we organise events for children and families, at the end of the year we always have a Christmas Party, and families are always welcome to catch up with each other at our Family Group Meetings. Bereaved families are invited to join our Purple Group.

What are the Jessie May Nurses unable to do?

We will not hand over the care of your child to someone we do not know without your express permission. We cannot (for insurance reasons) transport children in our own cars, nor can we travel in a family's own car. We are not able to care for a child's brothers or sisters. Our sole responsibility is for your child or young person who is on our caseload.

When is the service available?

Visits can usually be arranged for any time, 24 hours a day seven days a week, to fit in with the family's needs (dependent on availability). However visits need to be arranged in advance with our office, which is open from 9.00am to 4.00pm Monday to Friday, except on public holidays.

Can I get help in an emergency?

We will do everything we can to arrange visits at short notice where there is an emergency. However we cannot guarantee this and it will depend upon the Jessie May Nurse's availability.

About the Jessie May service

What area do you cover?

We cover the areas of Bristol, North Somerset, South Gloucestershire, Bath & North East Somerset, and Swindon & Wiltshire. If you live within these boundaries then we can provide a service to you.

What are the criteria?

The criteria for a child being accepted onto the Jessie May caseload are as follows:

1. that the child or young person lives in the area covered by Jessie May
2. that the child or young person's doctor (paediatrician) has agreed that they are not likely to live past the age of 19 years
3. that parental permission for a referral has been given.

How much will it cost?

Nothing—the service is entirely free of charge. Jessie May is a charity and raises funds in various ways to pay for the services it provides. You can find out more about how you can help fundraise for Jessie May at www.jessiemay.org.uk

Who will look after my child?

Jessie May employs fully qualified, Band 4/5/6 nurses through the National Health Service (NHS). The team of nursery and children's nurses are specialists and are funded by Jessie May through generous donations from our sponsors and fundraisers.

This partnership means our Nurses are free to continue their personal and professional development under the supervision of the NHS. They are also able to work in a hospital environment, alongside doctors, should a child in our care be taken into hospital.

We will match the needs of your child or young person with the particular set of skills of the nursing team. You will be assigned a small group of Jessie May Nurses who will visit you and your family, and you'll have chance to get to know them over time. In particular, they will get to know your child; their likes and dislikes, their character and ways of communicating.

Do Jessie May ever withdraw the service?

We have a duty to protect our Jessie May Nurses. Should the case arise where we believe our nurses are being placed in risky or threatening situations, then we may reluctantly be forced to stop providing services to a family in order to protect our nurses.

What happens if I'm not happy with the service?

If you are dissatisfied with any aspect of our service then we encourage you to make this known to any member of the Jessie May team as soon as possible. We also have regular Family Group Meetings where you can give us direct feedback on any aspect of our service. Jessie May Nurses will also visit and/or telephone you from time to time when you can also make your views known.

If you wish to make a formal complaint you can contact the Jessie May Nursing Team Manager or the Chief Executive by telephone or in writing. Further details are in our leaflet: "Improving our Service". The Care Quality Commission is responsible for ensuring that Jessie May meets the required standards through its inspections of the service. You can look at their reports on our service on their website www.cqc.org.uk. If you so wish you can also complain directly to them, by telephone or in writing:

Care Quality Commission National Correspondence
Citygate, Gallowgate
Newcastle upon Tyne
NE1 4PA
Tel: 03000 616161
Email: southwest@cqc.org.uk

What if I have to cancel a visit?

If you have to cancel a visit at short notice, we ask you to please contact the Jessie May Office on 0117 9616840 as soon as possible and leave a message so that we can give this visit to another family.

Do Jessie May ever cancel visits?

While we do our utmost to meet your requirements, on occasions planned visits may need to be cancelled at short notice. This may be due to the Jessie May Nurses helping a family with a child or young person at the end of their life, or due to staff sickness. You will be notified by telephone as soon as we become aware of the cancellation.

Administration of medication

Our Jessie May Nurses are only able to administer medication which has been 'signed off' (prescribed) by a medical doctor on the Jessie May drug chart. We would ask that you keep this chart up to date.

In the event of an accident

In the event of a serious accident or incident the Jessie May Nurse will in the first instance contact the emergency services. She/he will then make every reasonable attempt to contact you as soon as possible. In the event of a more minor accident she/he will take the appropriate action, such as first aid. All such incidents will be reported to you on your return and will also be recorded by the Jessie May Nurse in writing together with the action taken.

What if my child turns 19?

Our service is only available to children up to the age of 19. We understand that with medical advancements there may be a chance that a child in our care will live past this age. From their 19th birthday the young person would no longer be eligible for Jessie May care and would transition into adult palliative care instead.

During this transition process Jessie May will continue to provide support until adult care is put in place. There are currently adult palliative care services in all areas that we cover. For more information please contact us.

Safeguarding

Procedures to safeguard Jessie May Nurses, Children or Young Person and their families

At the start of a visit the Jessie May Nurse will get a Handover of Care from you which will include checking any medication that needs to be administered, agreed procedures in the event of an emergency (e.g. seizures) and an assessment of any risks. Should the Jessie May Nurse be unhappy with the handover for any reason they may ask you to remain in the house during the visit or alternatively discontinue the visit. We also have very clear safe guarding responsibilities. The Jessie May Nurse will normally discuss any such matters with you if they have any concerns.

Procedures to safeguard the property of service users

Our Jessie May Nurses are very conscious and respectful of the trust you place in them as they look after your child or young person in your own home. However we would ask that you take care not to leave cash or other valuable items around and ensure these are kept in a safe place.

Protecting the health and safety of our Jessie May Nurses

Our Jessie May Nurses often work alone and in an unfamiliar environment and we conduct a risk assessment at each location we visit to highlight any risks to nurses' health or safety. We may discuss these with you if we feel that action could be taken to minimise these.

Professional support for Jessie May Nurses support working out of hours

All of our Jessie May Nurses are employed through The Bristol Royal Hospital for Children, which allows them to draw on support from doctors and nurses at the hospital out of hours if necessary.

Do you have Insurance?

Yes, we have insurances covering different types of risks; Commercial Combined Insurance which includes Employers Liability, Professional Indemnity and Medical Malpractice.

Referrals

How do I apply?

A referral can be made by parents or anyone involved in caring for a child or young person who has a life limiting condition. You can complete the referral form on our website www.jessiemay.org.uk or by contacting Jessie May at the address, telephone number, or email address shown at the end of this leaflet.

We'll need to take some information as part of the referral process to assess whether the child or young person fits our criteria. This will include details from the doctor (paediatrician) who best knows

the child or young person. As long as the child or young person meets our criteria we will then make contact with the family to arrange a visit to discuss their needs.

What happens next?

Assuming your child or young person is accepted onto our caseload then we will arrange to visit you to make a Care Agreement. We will ask you to assess your own needs according to our FRIPP (Framework for Respite in Partnership with Parents and Carers).

We aim to do this as soon as possible so that we can begin to provide you with our service and support we have agreed to.

If you require a large print copy of this leaflet, please contact:

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