



Chief Executive

March 2022

Letter from the Chair

Dear Candidate,

Hello and thank you for considering what I believe is an incredible career opportunity.

My name is Tiggy Atkinson, and I am the Chair of the Board of Trustees here at The Jessie May Trust.

We are an innovative service with a national reputation for providing exceptional care and support to children with life shortening conditions and their families in their own homes. We are family centred and led, and their direct involvement is crucial in everything we do. All of us, our nurses, administration team, fundraisers, trustees and volunteers are without exception passionately committed to improving the lives of the children and families we support.

The Trust was established in 1996 and over the last 5 years we have seen rapid growth in the numbers of children and families we support and the geographical areas we cover. To date we have supported over 420 children and their families across the South West. We provide regular, specialist, palliative care and support to enable families to care for their child at home, intensive care and support to families when a child is at the end of life to enable them to remain at home, and bereavement support for five years after a child has died.

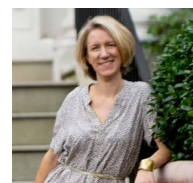
Jessie May is in an exciting phase, where we have the opportunity to develop and expand our services, due to our financial stability. As a Board and Senior Management Team, we met in November 2021 to set our future direction and strategy for the next 5 years, which will see us launch a 24/7 End of Life care project, expand and develop the services we provide to new geographies and provide additional support for the wider family, especially siblings. We will also offer our learning and experience to influence the national palliative care agenda, working with key stakeholders to enable similar services to Jessie May to be established in areas where they currently do not exist, and we will continue to be guided by families in everything we do.

To fund the above activities, we will need to strengthen and diversify income streams through investing in existing and new initiatives and technology to improve income ratios, growth and increase long-term sustainability and of course we will continue to build and develop our exceptional Jessie May team and our network of volunteers.

This is a great time to take on this vital leadership role as there is much to do, but also a huge opportunity to be more innovative, building on the solid foundations we have created since Jessie May was founded and you will have a genuine opportunity to launch initiatives, events and programs that will improve the lives of our children and families, bringing about real change, with the potential to re-imagine how children's palliative care can be provided.

We look forward to speaking to you in more detail around the opportunity.

Tiggy Robinson
on behalf of the Board of Trustees



About Us

Started by a family, for families, and now shaped by families - learn more about how and why Jessie May was established.

Jessie May is a Bristol-based charity, with a national reach providing nursing care at home for children and young people with life shortening conditions who are not expected to live beyond the age of 19.

Jessie May was established in September 1996 by Chris and Philippa Purrington, following the death of their baby daughter Jessica May. She died from a genetic condition known as severe Spinal Muscular Atrophy when she was only 4½ months old.

Whilst the family were visiting relatives in Bristol, Jessica was admitted to the local hospital. It was here that the family learnt that the support they had received back at home in High Wycombe was not available to families caring for their child at home in the Bristol area.

Jessica was cared for by her family at home throughout her illness. She died peacefully at home in her father's arms, in privacy, with dignity and surrounded by all those who loved her.

Jessica's parents were determined to do what they could to enable other children with conditions like Jessica's and their families to have support in their own homes and the choice to die at home when that time comes. After a lot of hard work and perseverance initial funding was secured, and Jessie May was officially launched in 1996.

The Trust receives approximately 25% of funding from statutory sources, so is very reliant upon voluntary funding, and encourages donations from individuals, corporate organisations, community groups and grant-making or charitable trusts. No charge is made to families using the services of the charity. Since Jessie May was founded, we have supported over 420 children and their families across the South West.

Three key issues in children's palliative care are:

1. **24/7 end of Life Care at Home:** Whilst there has been a growth in the number of children's hospices providing End of Life Care there has been much less development of services to support children and families in their own homes. Jessie May remains one of the few services specialising in this and our partnership working will enable us to provide nursing care 24 hours a day 7 days a week at end of life.
2. **Funding:** There has been an increase in funding for the sector with much of this going from central government to children's hospices. At a local level there is very much more of a postcode lottery with some areas funding very little. Thus there are big gaps and differences in the extent of provision across the country.
3. **The Workforce:** There is a national shortage of children's nurses as well as doctors with specialist knowledge and experience in children's palliative care. This presents challenges in enabling services to provide end of life care safely in a child's own home.

Our Services

To be told that your child will die before you will, is something most parents will never have to consider. For our families however this is their reality. Some of these children will die when they're very young, others will deteriorate slowly over a number of years, and their full-time care usually falls to parents who have to cope – 24 hours a day, 7 days a week, 365 days a year.

Jessie May recognises that the whole family is under huge emotional and physical strain. Through our team of dedicated Children's Nurses and Nursery Nurses we provide specialist care and support to help alleviate some of this pressure. This support is provided in the comfort of the family's own home whenever possible, from the time of diagnosis onwards.

Each child is central to the service we provide, and we believe in helping our children reach their potential and to make the most of the precious time they have.

The care we provide is holistic and family-centred, working closely with other professionals involved in supporting the family, to ensure continuity of care and that all needs are met, whether physical, emotional, social or spiritual.

As the conditions or illnesses that the children have are all life-shortening and have no reasonable hope of cure, the service provided by Jessie May is described as children's palliative care, defined as:

"An active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement."

ACT and the Royal College of Paediatrics and Child Health 1993

We provide regular specialist care and support to enable families to take a break from their care and to do some of the things that most of us take for granted. Intensive care and support to families when a child is at the end of life to enable them to remain at home, and bereavement support for five years after a child has died.

Vision, Mission & Values

Our Vision

Our vision is that all children and young people with life shortening conditions are supported to have the very best quality of life possible and to choose to live and to die in their own homes with their families.

Our Mission

Our mission is to provide the very best care and support possible at home for children and young people with life shortening conditions and their whole family, in life, at the end of life, and in bereavement.

Our Values

We put children and families first.
We are kind, passionate and committed.
We are honest, respectful and collaborative.

Equal opportunities policy

Jessie May is an equal opportunity employer. We celebrate diversity and encourage applications from all individuals without regard to race, religion, gender, sexual orientation, national origin, disability or age.

Our Strategy

In November 2021 the Senior Management Team and the Board of Trustees held an away day to review our 5 year strategy. Our ambitious and exciting vision for the future of Jessie May has six key objectives, and a plan for service development and expansion, set out below:

24/7 End of Life Nursing Support: We will prioritise working with others to develop services to provide care and support 24 hours a day, 7 days a week to children who are at the end of their life and their families in their own homes.

Child and Family Care We will expand and develop the services we provide to ensure that children and families are fully supported and that we are there for the wider family, especially siblings.

Family Involvement: Everything we do will be shaped and guided by those who experience caring for a child with complex health needs and a life shortening condition on a daily basis. We will ensure that families are involved in helping to shape the services we develop and are supported and empowered to do so.

Influencing: We will offer our learning and experience, working with key stakeholders to facilitate the further development and improvement of services and to enable similar services to Jessie May to be established in areas where they do not exist.

Sustainable Fundraising: We will strengthen and diversify income streams through investing in new and existing initiatives, people, and technology to improve income ratios, growth and increase long-term sustainability.

Our People: We will invest in our dedicated and committed Jessie May team and volunteers through providing training and development opportunities to enable everyone to achieve their full potential.

Built on Strong Foundations

This is an ambitious programme which requires a strong foundation to be successful. Great strides have been made and we have restructured the organisation to enable us to be best placed to achieve our ambitions. There is still more to do across a number of key areas.

Finance&Fundraising: We have invested in new income streams such as individual giving and products such as lotteries and legacies. The government are allocating additional funds for children's palliative care and we will engage with national and local government to access these. We will also develop options for earned income.

Systemsandprocesses: New technology will enable us to be more efficient and to become as 'paper light' as possible.

Governance: We will recruit new talent onto our Board of Trustees and supplement this by bringing in specialist expertise to support our Sub-Committees and working groups.

We have recently re-defined our service offering and referral criteria and are currently reviewing the bereavement service we offer. We are also on a journey to becoming a more data driven organisation. We have an ambitious budget and have recently invested in digital tools and platforms to enable us to operate more efficiently. We also have a number of projects in flight to deliver and are now looking to drive out the benefits of these investments, to ensure we can deliver more fundraising and better serve our children and families.

The Role

The Chief Executive role will play a vital role in delivering our strategic aims and will be supported by members of our hugely capable Senior Management Team (Director of Fundraising, Director of Nursing, Office Manager), our Executive Assistant and of course by myself and our Board.

We are looking for an empathetic and emotionally intelligent professional who is passionate about the provision of exceptional children's and family services. You will bring the ability to translate strategy into actionable plans and also knowledge and experience of how to drive efficiencies to help us maximise the use of our precious resources.

In the role, you will need to strike a careful balance between supporting our incredible team, working closely with our families and also being 'out there', being the public face of Jessie May, influencing and driving the national agenda in children's palliative care.

It is not necessary to have clinical experience, but the right person should be open to learning about how the service works and be continually curious and keen to undertake whatever self-learning is required in order to understand the trends, issues, and opportunities.

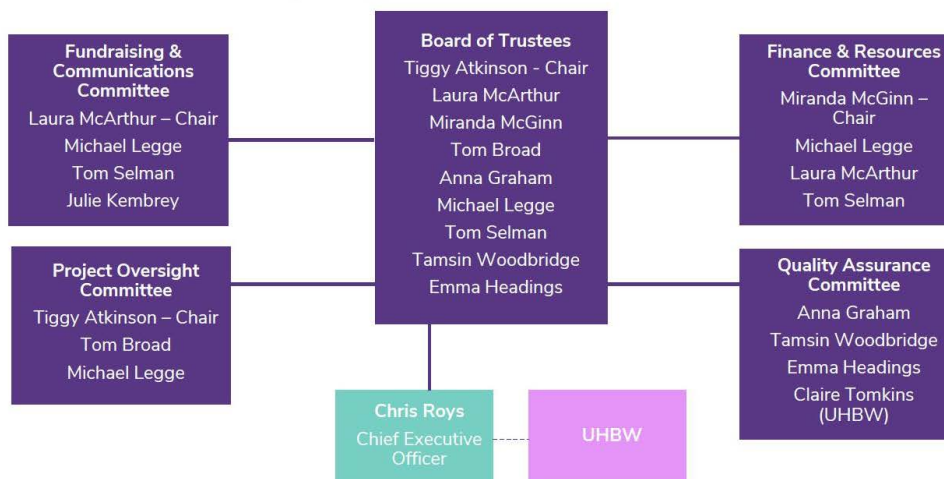
You will be joining and leading a staff team who are hugely committed to and passionate about the work we do. The Board of Trustees bring a wealth and diversity of expertise and energy to support you in this exciting and important role.

Organisation Structure

Senior Management Team



Governance



Job Description

Job Title:	Chief Executive
Responsible to:	Chair of Trustees
Responsible for:	Line management of Senior Leadership Team (Director of Nursing, Director of Fundraising & Marketing, Office Manager) and Executive Assistant

Main Purpose of the Role

- To work with the Trustees of the Jessie May Trust to ensure that the charity achieves its objectives to develop, lead and promote the Jessie May Trust as a valued provider of specialist palliative nursing care and support for children with life shortening conditions and complex health needs.
- To execute Jessie May's 5 year strategic plan.
- To work with the Trustees to ensure compliance with the Trust's statutory and legal obligations.
- To take a lead in setting a clear direction for the future with service development and expansion, and to manage and lead the Jessie May team and volunteers so that high quality services are consistently provided.
- To develop and enhance relationships with partners for new services and expand and develop existing provision as above.
- To establish and communicate the brand and values of the Jessie May Trust acting as an Ambassador for the Jessie May Trust, advocating and influencing the national children's palliative and terminal care agenda and influencing donors.

Main Duties & Responsibilities

Service Development, Planning, Delivery and Family Engagement

- To ensure that Jessie May services are planned, resourced, developed with family involvement and delivered with clear outcomes, in line with local need.
- To ensure Jessie May services are reviewed appropriately and are monitored and reported on, on a regular basis.
- To manage the strategic planning process, developing strategic, business and service implementation plans and ensuring that the monitoring and reporting process is effectively implemented, including the accurate and timely provision of data to key partners.
- To ensure that service development is in accordance with the aims, objects, values and beliefs of the organisation.
- To continue to respond to the changing needs of children and families to ensure their identified needs are met, running services effectively and ensuring that safeguarding and quality are embedded in all service provision.

Job Description

Financial and Resource Management

- To work with the Director of Fundraising to secure and manage income from a wide variety of sources, ensuring that funding conditions and requirements are met.
- To work with the Senior Management Team, the outsourced Finance Services and other staff to review budgets, cash flow forecasts, management accounts and our operating costs.
- To ensure that financial management and quality standards across the organisation are in line with our internal financial governance standards and those of the charity commission.
- To be accountable for overseeing the management of premises and equipment, working with the Office Manager who is responsible for managing these activities.
- To ensure the organisation has sound and reliable administrative, human resource management and development, financial, health and safety and other systems in place, that these are actively implemented and regularly reviewed.
- To identify, carry out and respond accordingly to risk assessments.
- To ensure the organisation takes full advantage of new technology and digital media to market, manage and streamline its work.

External Relations & Partnerships

- To develop and implement partnership working with other organisations to achieve organisational objectives including joint delivery of services where appropriate.
- To ensure that the Jessie May Trust is effectively represented at relevant meetings, events, conferences, management groups etc and those issues that impact children and young people with life shortening conditions and their families.
- To be the principal spokesperson for all external press, digital and social media communications.
- To ensure that the organisation contributes learning and experience to influence children's palliative care events, policy and practice at a local, regional and national level.
- To lead on, develop and grow key relationships with the UHBW, the RUH, GWH, the Children's Hospice, Together for Short Lives, Hospice UK, CCGs/ICSs and any other key external partnerships.
- To seek to influence at key commissioning and decision-making levels within the Health Service and other relevant bodies.
- To understand and make use of the opportunities to influence and liaise with key donors at appropriate local and national levels.

Board, Statutory & Governance

- To attend relevant Trustee Board meetings presenting oral or written reports as agreed.
- To ensure that the decisions of the Board are implemented and that the organisation complies with relevant charity, company, employment, fiscal and other legal requirements.
- To ensure timely and robust communications with Trustees on issues particularly relating to: service activity and development; financial management; risk management; human resources issues; development of and changes to internal policies and procedures; external issues and their impact upon the organisation and the Trust's reputation plus any other areas that may require Trustee input or approval.
- To assume the Company Secretary role, reporting to the Board of Trustees, at agreed intervals on issues relating to Company Secretarial, Governance and Legal responsibilities.
- To support the Board of Trustees in their roles and responsibilities and to ensure that they operate in accordance with the Articles of Association, Code of Conduct, general good practice and any legal requirements relating to the management of the Jessie May Trust.

General Responsibilities

- Under the Health & Safety at Work Act 1974 and associated guidance it is the duty of all staff while at work to take adequate care for the health and safety of themselves and other persons who may be affected by their actions or omissions.
- To carry out other such duties in relation to the objectives of the Jessie May Trust as may reasonably be required from time to time and as required by the Board.

The list of duties in this job description is not intended to be complete but is expected to act as a guide to main areas of key responsibilities.



Person Specification

Knowledge & Experience

- Senior executive experience of managing a relevant organisation or management at a senior level; that includes responsibility for strategic direction, leadership and management.
- Experience of financial management and control, including budget oversight, cost control and contractual valuation with a budget in excess of £1m.
- Previous experience working closely with families, volunteers and service user participation and involvement.
- Knowledge of the current national and local health and social care agendas and their impact up on voluntary sector organisations and services in Children's Palliative Care.
- Experience of fundraising through a diverse range of income streams and securing funding, including bid writing/tender development/negotiating contracts and the ability to maximise income from a wide range of sources.
- Knowledge, experience and understanding of strategic planning and service development planning; including facilitation, implementation and review/evaluation and organisational change.
- Experience of developing chargeable services (desirable).
- Knowledge of the governance role of Trustees and an understanding of the importance of working with them.
- Demonstrable experience of target setting and improving efficiencies and performance

Skills & Abilities

- Commitment to and empathy with children's palliative care and a knowledge of the families' needs.
- Skills to develop and lead a team of staff and volunteers.
- Commitment to diversity and inclusion and understanding how to drive its development organisationally.
- Proven skills to develop new ideas and projects from conception to implementation, or to change projects, based on evidence of need and changing demographics.
- Effective interpersonal communication skills with all levels of team members, families/service users, volunteers, external bodies, media and funders (including excellent presentation skills).
- Strong written communication skills, ability to present complex ideas clearly.
- Availability to work occasionally at weekends and evenings and attend all family events.
- Ability to form partnerships with voluntary, statutory or commercial parties in order jointly deliver services.
- Ability to deliver demanding objectives within agreed deadlines and to manage competing priorities.
- Understanding of technology solutions which can support the charity to be as efficient and effective as possible.

Person Specification

Job Title:	Chief Executive
Hours:	Full time (35 hours per week) Expectation of 3 days per week at the Jessie May offices, with remaining days working remotely if desired
Contract:	Permanent
Salary:	£60,000 - £70,000
Location:	Brittania Road, Kingswood, Bristol, BS15 8DB. Expectation of 3 days per week being office based the with remaining days working remotely if desired
Benefits:	<ul style="list-style-type: none"> • 27 days annual leave (progressing to 29 days after 5 years and 33 days after 10 years) • Up to 5% matched pension contribution • Death in service • Flexible working hours • Employee Assistance Programme, e.g. counselling • Mobile phone • Onsite parking • Car allowance - £2,000 per annum • Enhanced sick pay – 6 months full pay, 6 months half pay

It is the aim of the employing organisation to ensure that no job applicant or employee receives less favourable treatment on grounds of gender, religion, race, colour, sexual orientation, nationality, ethnic or national origins or disability or is placed at a disadvantage by conditions or requirements which cannot be shown to be justifiable. To this end, there is an Equal Opportunities Policy in place and it is for each employee to contribute to its success.

How to apply

Panoramic Associates Ltd is acting as a retained employment agency to Jessie May Trust on this appointment.

For a more in-depth conversation about the role please contact Ben Pountney, Lead Practice Director, who is leading on the process. His email address is **b.pountney@panoramicassociates.co.uk**.

We hope you will consider applying for this fantastic opportunity. To make an application you will need the following –

- A CV, tailored for the role
- A supporting statement that sets out your understanding of both the role and the organisation, and how your experience matches the key criteria on the personal specification

Closing date

Friday 21st April

Preliminary interviews with Panoramic Associates

24th April – 3rd May

Shortlisting by Panoramic Associates and Jessie May

4th -6th May

Interviews with Jessie May

Monday 9th May

1st Interview

Panel Interview

Meeting with nursing staff

Tuesday 17th May (AM)

Final Interview

Panel interview

Internal Stakeholder focus group