Inspection Report

We are the regulator: *Our job is to check whether hospitals, care homes and care services are meeting essential standards.*

The Jessie May Trust

35 Old School House, Kingswood Foundation Estate, Britainnia Road, Kingswood, Bristol, BS15 8DB

Tel: 01179616840

Date of Inspections: 11 January 2013
10 January 2013

Date of Publication: February 2013

We inspected the following standards as part of a routine inspection. This is what we found:

Consent to care and treatment	✓ Met this standard
Care and welfare of people who use services	✓ Met this standard
Requirements relating to workers	✓ Met this standard
Complaints	✓ Met this standard
Records	✓ Met this standard

Details about this location

Registered Provider	The Jessie May Trust
Registered Manager	Mrs. Elizabeth Lewington
Overview of the service	The Jessie May Trust is a registered charity that provides respite (short term) personal care to children with life limiting illnesses in their own homes.
Type of services	Domiciliary care service Hospice services
Regulated activities	Nursing care Personal care Treatment of disease, disorder or injury

Contents

When you read this report, you may find it useful to read the sections towards the back called 'About CQC inspections' and 'How we define our judgements'.

Summary of this inspection

Why we carried out this inspection

This was a routine inspection to check that essential standards of quality and safety referred to on the front page were being met. We sometimes describe this as a scheduled inspection.

This was an announced inspection.

How we carried out this inspection

We looked at the personal care or treatment records of people who use the service, carried out a visit on 10 January 2013 and 11 January 2013, observed how people were being cared for and checked how people were cared for at each stage of their treatment and care. We talked with people who use the service, talked with carers and / or family members and talked with staff.

What people told us and what we found

During our visit to the homes of the children being cared for we observed interactions between the children and the nurses to help us understand their experiences. We saw that the children were being well supported with their nursing and care needs. It also helped us to see that the children (and their parents) were being respected and that strong relationships built on trust and professionalism had been established.

We spoke with ten staff during our inspection. All staff were very motivated, committed and positive about working for The Jessie May Trust. Staff praised the training,teamwork and supportive atmosphere.

Complaints were not commonplace but a complaint that had been made was been handled and responded to effectively. Parents knew how to make a complaint if they had any concerns.

Comments made by parents included "The staff are exceptional, when the service came into our lives we felt as if a great weight had been lifted from our shoulders, the service provided is amazing".

The staff we spoke with were extremely knowledgeable about the nursing and support needs of the children in their care. Staff were friendly and professional. We saw that appropriate recruitment checks had been undertaken before staff began working for The Jessie May Trust.

Records about support provided to the children had been extremely well written, involved the required people, had been kept under review and updated where required.

You can see our judgements on the front page of this report.

More information about the provider

Please see our website www.cqc.org.uk for more information, including our most recent judgements against the essential standards. You can contact us using the telephone number on the back of the report if you have additional questions.

There is a glossary at the back of this report which has definitions for words and phrases we use in the report.

Our judgements for each standard inspected

Consent to care and treatment ✓ Met this standard

Before people are given any examination, care, treatment or support, they should be asked if they agree to it

Our judgement

The provider was meeting this standard.

Where children did not have the capacity to consent, the provider had acted in accordance with legal requirements.

Reasons for our judgement

The children cared for by staff from the Jessie May Trust had life limiting conditions and some children were supported with their end of life care.

The provider had arrangements in place for seeking and obtaining consent for the children who received a service from them.

The Jessie May Trust never assumed that a child did not have the capacity to consent or be involved in decisions about their care. The Trust had followed guidelines produced by the Department of Health in seeking consent when working with children. The guidance sets out the process for obtaining consent from a child that involved healthcare of any kind.

Nurses were consistent in their approach when we asked them about how children were involved. They told us of the use of individual's body language, vocal sounds and facial expressions to determine if a child was happy or in discomfort. Records of visits were comprehensive and showed that the child's wellbeing came first.

The process of obtaining consent was a fundamental part of good practice and a legal requirement. We saw when visiting children being cared for at home that the process for obtaining consent varied. We saw the nurses engaged with the children with simple situations such as assistance with dressing, with the question 'shall I help you?'. Many children supported by this service would be unable to understand, to complex situations where a considerable amount of information would be needed to support decision-making. Where the children were not legally competent (did not 'have capacity') to give consent for themselves, consent from some-one who had 'parental responsibility' for them was been obtained

We saw that the provider had identified who had parental responsibility in the circumstances that a child was not able to give their consent. And this was clearly

documented.

We saw good practices in place to involve children's families in day to day support and advanced decision-making processes. For example, we saw that when meetings were held parents were given clear information about the care, treatment and support options available to their child so they could make an informed decision on behalf of their child. We saw that decisions had been recorded within a 'wishes document'. This clearly outlined the support plan to be provided for the child, their parents and family. The support plan was written in a sensitive manner and showed that discussion and decisions were been made for a child's wishes during life and plans for when a child became more unwell and had acute, life threatening episodes. End of life wishes and wishes for after death were been discussed and recorded. Records showed a professional and caring approach.

One of the nurses told us "advanced care planning is essential and is something we do with the family over a period of time, it could be months or years". The plan stated that "decisions evolve over a period of time through the development of a trusting relationship and an ethos of shared decision making".

Parents told us that "When the Jessie May nurse arrives they always check with me about how my child has been, they ask about any changes and ensure that they have up to date information about how my child needs to be supported". Another parent said "I have total confidence in the nurse's ability to care for my child, they know exactly what their responsibilities are and I put my full trust in them".

Care and welfare of people who use services ✓ Met this standard

People should get safe and appropriate care that meets their needs and supports their rights

Our judgement

The provider was meeting this standard.

The provider was meeting this standard. The children experienced care, treatment and support that met their needs and protected their rights.

Reasons for our judgement

When we visited children being cared for in their homes we saw the nursing staff supporting them in a sensitive and caring manner. We observed good interaction between the staff the children and parents. This was appropriate, respectful and supportive.

All of the parents we spoke with were full of praise for both the staff and the services provided by The Jessie May Trust. Comments made by parents included "The staff are exceptional, when the service came into our lives we felt as if a great weight had been lifted from our shoulders, the service provided is amazing". Another parent told us "Without the support of The Jessie May nurses I don't know how we would have survived, they have been our guardian angels". As well meeting parents we also spoke to some by telephone to ask them about their view of the service provided. Parents consistently told us that they were extremely satisfied with the service, that the nurses were competent, caring and professional. One parent told us "I know they (the nurses) are not family, but they are so wonderful and we feel so lucky to have them supporting our child in our home".

We asked the manager about how the service was initiated and how the assessment for the service was completed. We were told that parents referred themselves for the service and it was the parents who completed an assessment of their child's needs. The manager told us "We listen to the families and are guided by them as to the level of service and support they need. The assessment framework for respite in partnership with parents (FRiPP) was aimed at engaging families in identifying and articulating the support they required. Parents told us the assessments were unique in that they were led by parents and allowed them to say what support their child and the family needed. One parent said, "We receive support from a number of agencies and this is the only one which allows us as parents to give our view as to what support our child needs, we are listened to and our voices are heard, the service is truly tailored to the needs of our child".

Children's needs were assessed and care and support was planned and delivered in line with their individual care plan and individual wishes. We looked at five care files, all of which were very detailed and person centred. This meant they gave detailed information about child's individual needs and how they preferred to be supported.

We saw that the care plans consisted of a personal support plan which was informative and where able people had been involved in developing. The support plans had been

signed, dated, kept under review and updated when required. We saw that care files contained risk assessments, pen profiles, hospital admission assessments, risk assessments, activities and behaviour indicators of the child's well-being. Records we saw were extremely detailed and provided clear guidance for staff on how the child wanted to be supported.

The well-being of each child was documented in daily records and within a staff handover sheet. These recorded the child's activities, their behaviours, communication, body language and facial gestures. These provided a clear and overall picture of the child's well-being.

We asked staff about the way they communicated with the children. We were told that during the initial assessments of the child's needs, there was a discussion with the parents about communication. We were told that some children could communicate verbally but needed time to respond, while others used facial expressions. Staff demonstrated a sound understanding of supporting each child on an individual basis and told us of their responding to the non verbal indicators of the child such as understanding their body language and facial expressions.

Staff were extremely knowledgeable about children in their care. Communication was effective between staff so that they were aware of any changes for the children in their care. Many of the staff had worked at the Trust for a number of years.

Before staff worked alone with a child they undertook shadowing visits with another colleague. This was to meet with the child and their parents and to learn in the home environment how to care for them. Parents told us "New members of staff never come alone on their first visit, this gives them a chance to get to know my child first and to get to know how to care for them".

The Jessie May Trust held family group meetings, these provided an opportunity for parents to meet other parents and to represent the view of parents to the Trust. Parents had said that the meetings provided good support and provided an opportunity to exchange lots of useful information from each other as well as learning about Jessie May developments and to hear about other useful organisations. We saw that the most recent meeting held on October 16 2012 provided parents with an opportunity to review the Jessie May school holiday respite sessions. Feedback was welcomed and listened to.

Parents were able to contribute to the clinical governance meetings and were kept informed about the service developments.

Requirements relating to workers ✓ Met this standard

People should be cared for by staff who are properly qualified and able to do their job

Our judgement

The provider was meeting this standard.

Children were cared for, or supported by, suitably qualified, skilled and experienced staff.

Reasons for our judgement

The children using the services of The Jessie May Trust were safe and their health and welfare needs were met by staff that were fit and appropriately qualified to do their job. This was because the provider had effective recruitment and selection processes in place.

There was a stable staff team at The Jessie May Trust and there had only been one new member of staff recently employed. We spoke with ten staff during our inspection. This included nurses, team leaders, the CEO a member of the business support team and the manager. All staff were very motivated, caring and positive about working for the Trust and praised the teamwork and supportive atmosphere

The manager confirmed to us that all staff were recruited, selected and appointed in line with the provider's policies. We looked at staff personnel files and saw that effective recruitment and selection processes were in place. We saw evidence of staff interviews and judgements about people's suitability to work.

We also saw that there were processes in place to check people's criminal records to ensure that they were of suitable character to work with vulnerable people. Appropriate checks had been undertaken before staff began working at The Jessie May Trust. We saw that when the staff member had been offered a position Criminal Records Bureau (CRB) checks and references were requested. Staff were issued with a job description and terms and conditions of their employment. This meant they had been given clear information on their role and responsibilities, their rights and the duties of their employer.

The manager told us that as well as ensuring that staff had the skills, training and knowledge to undertake their duties they also ensured that staff 'matched' the child and the family. One parent explained this to us and said 'We are a lively, loud household, there is always something going on. The nurse that supports us is similar to us in their personality, if they were a shy and retiring type they wouldn't fit in with our household".

When we spoke with parents about the support they and their child received from staff people told us that the staff were polite, caring and friendly. One person told us; "I get on well with the staff they are all really nice", another person said: "I don't have any complaints; the staff are wonderful, I have full confidence in them".

Children that were supported at home are kept safe and their health and welfare needs

were met by staff that were fit and appropriately qualified to do their job. This was because the provider had effective recruitment and selection processes in place.

We spoke with a member of staff that was new to the team and looked at their recruitment file. The member of staff told us about their previous experience and was able to demonstrate a sound understanding of their role and responsibilities. Through looking at the documents contained within this persons file we saw that an application form had been completed, records had been retained about the interview process and two references and a Criminal Records Bureau check had been obtained. We also saw a copy of the presentation this person had did during their interview, it was of an excellent standard.

Staff agreed that The Jessie May Trust was a good place to work. The staff that supported the children were all qualified nurses. Staff spoken with, told us they were well supported to access the training and support they needed. When we asked a member of staff about their induction they said "I had an in depth induction and this helped me to understand my role and what was expected of me, in turn enabling me to understand the needs of the children that I am here to support".

Complaints ✓ Met this standard

People should have their complaints listened to and acted on properly

Our judgement

The provider was meeting this standard.

There was an effective complaints system available. Comments and complaints people made would be responded to appropriately.

Reasons for our judgement

We were told by the manager (and nursing staff) that all complaints would be taken seriously, that they would be recorded and responded to in line with the Trusts' policy. The manager confirmed to us that there were no current complaints and no complaints had been raised to us prior to or during the inspection about the services provided by The Jessie May Trust.

Complaints were not commonplace but a complaint that had been made had been handled and responded to effectively. Parents knew how to make a complaint if they had any concerns. They were keen to point out to us that they had no complaints and that they had never had to raise any concerns about the service.

We saw the provider's policy and procedure for responding to and dealing with complaints or concerns raised and saw that it was recorded that comments and complaints would be listened to and acted on, without the fear that people using the service would be discriminated against for making a complain

We saw that each family using the service had a copy of the procedure in their information pack about the services provided at their home with details for them on how to raise any concerns they may have externally.

We saw that parents were given support by the provider to make a comment or complaint where they needed assistance. We also saw that parents were asked as part of the care plan review process whether they had any concerns they wanted to raise about their child's care and the complaints procedure was discussed with them.

We asked all of the parents we spoke with if they knew how to raise concerns if they were not happy with the service their child was receiving. All parents knew how to contact the manager and were aware of the process.

Records ✓ Met this standard

People's personal records, including medical records, should be accurate and kept safe and confidential

Our judgement

The provider was meeting this standard.

The provider was meeting this standard. Children were always protected from the risks of unsafe or inappropriate care and treatment because accurate and appropriate records were maintained.

Reasons for our judgement

Records relevant to the management of the services were fit for purpose. As part of our inspection we looked at a range or records. These included care records, visit report forms, risk assessments, staff personnel records, organisational policies and procedures, the service improvement log, minutes of family group meetings and minutes of clinical governance meetings.

All the records were easily accessible when we asked for them. Records held on computer were password protected and could only be accessed by authorised staff. Paper held records containing information about the people who used the services were stored in locked filing cabinets.

The staff we spoke with were confident in the quality of information in the care files and maintained individual's daily records so that they were up to date at the start of each shift.

When we spoke to the CEO they were clear about what information would and would not be shared with other agencies. We saw that the provider had clear systems in place to ensure that information that would constitute an unwarranted invasion of personal privacy would not be available under the freedom of information act.

The care team manual given to staff contained detailed information about their role in respect of confidentiality, information governance and data protection. We also saw that record keeping guidelines had been produced for staff in order that they knew what their responsibilities were. During our visits to the children's homes we saw staff completing care records, these were detailed, well maintained and contained up to date information. We saw that the language and descriptions of treatment and care provided within care records were at all times respectful, polite and professional. One nurse told us "The records we maintain are the property of the family and are a legal document, it is crucial our records contain accurate information".

About CQC inspections

We are the regulator of health and social care in England.

All providers of regulated health and social care services have a legal responsibility to make sure they are meeting essential standards of quality and safety. These are the standards everyone should be able to expect when they receive care.

The essential standards are described in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009. We regulate against these standards, which we sometimes describe as "government standards".

We carry out unannounced inspections of all care homes, acute hospitals and domiciliary care services in England at least once a year to judge whether or not the essential standards are being met. We carry out inspections of dentists and other services at least once every two years. All of our inspections are unannounced unless there is a good reason to let the provider know we are coming.

There are 16 essential standards that relate most directly to the quality and safety of care and these are grouped into five key areas. When we inspect we could check all or part of any of the 16 standards at any time depending on the individual circumstances of the service. Because of this we often check different standards at different times but we always inspect at least one standard from each of the five key areas every year. We may check fewer key areas in the case of dentists and some other services.

When we inspect, we always visit and we do things like observe how people are cared for, and we talk to people who use the service, to their carers and to staff. We also review information we have gathered about the provider, check the service's records and check whether the right systems and processes are in place.

We focus on whether or not the provider is meeting the standards and we are guided by whether people are experiencing the outcomes they should be able to expect when the standards are being met. By outcomes we mean the impact care has on the health, safety and welfare of people who use the service, and the experience they have whilst receiving it.

Our inspectors judge if any action is required by the provider of the service to improve the standard of care being provided. Where providers are non-compliant with the regulations, we take enforcement action against them. If we require a service to take action, or if we take enforcement action, we re-inspect it before its next routine inspection was due. This could mean we re-inspect a service several times in one year. We also might decide to re-inspect a service if new concerns emerge about it before the next routine inspection.

In between inspections we continually monitor information we have about providers. The information comes from the public, the provider, other organisations, and from care workers.

You can tell us about your experience of this provider on our website.

How we define our judgements

The following pages show our findings and regulatory judgement for each essential standard or part of the standard that we inspected. Our judgements are based on the ongoing review and analysis of the information gathered by CQC about this provider and the evidence collected during this inspection.

We reach one of the following judgements for each essential standard inspected.

✓ **Met this standard**	This means that the standard was being met in that the provider was compliant with the regulation. If we find that standards were met, we take no regulatory action but we may make comments that may be useful to the provider and to the public about minor improvements that could be made.
✖ **Action needed**	This means that the standard was not being met in that the provider was non-compliant with the regulation. We may have set a compliance action requiring the provider to produce a report setting out how and by when changes will be made to make sure they comply with the standard. We monitor the implementation of action plans in these reports and, if necessary, take further action. We may have identified a breach of a regulation which is more serious, and we will make sure action is taken. We will report on this when it is complete.
✖ **Enforcement action taken**	If the breach of the regulation was more serious, or there have been several or continual breaches, we have a range of actions we take using the criminal and/or civil procedures in the Health and Social Care Act 2008 and relevant regulations. These enforcement powers include issuing a warning notice; restricting or suspending the services a provider can offer, or the number of people it can care for; issuing fines and formal cautions; in extreme cases, cancelling a provider or managers registration or prosecuting a manager or provider. These enforcement powers are set out in law and mean that we can take swift, targeted action where services are failing people.

How we define our judgements (continued)

Where we find non-compliance with a regulation (or part of a regulation), we state which part of the regulation has been breached. We make a judgement about the level of impact on people who use the service (and others, if appropriate to the regulation) from the breach. This could be a minor, moderate or major impact.

Minor impact – people who use the service experienced poor care that had an impact on their health, safety or welfare or there was a risk of this happening. The impact was not significant and the matter could be managed or resolved quickly.

Moderate impact – people who use the service experienced poor care that had a significant effect on their health, safety or welfare or there was a risk of this happening. The matter may need to be resolved quickly.

Major impact – people who use the service experienced poor care that had a serious current or long term impact on their health, safety and welfare, or there was a risk of this happening. The matter needs to be resolved quickly

We decide the most appropriate action to take to ensure that the necessary changes are made. We always follow up to check whether action has been taken to meet the standards.

Glossary of terms we use in this report

Essential standard

The essential standards of quality and safety are described in our *Guidance about compliance: Essential standards of quality and safety*. They consist of a significant number of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009. These regulations describe the essential standards of quality and safety that people who use health and adult social care services have a right to expect. A full list of the standards can be found within the *Guidance about compliance*. The 16 essential standards are:

Respecting and involving people who use services - Outcome 1 (Regulation 17)
Consent to care and treatment - Outcome 2 (Regulation 18)
Care and welfare of people who use services - Outcome 4 (Regulation 9)
Meeting Nutritional Needs - Outcome 5 (Regulation 14)
Cooperating with other providers - Outcome 6 (Regulation 24)
Safeguarding people who use services from abuse - Outcome 7 (Regulation 11)
Cleanliness and infection control - Outcome 8 (Regulation 12)
Management of medicines - Outcome 9 (Regulation 13)
Safety and suitability of premises - Outcome 10 (Regulation 15)
Safety, availability and suitability of equipment - Outcome 11 (Regulation 16)
Requirements relating to workers - Outcome 12 (Regulation 21)
Staffing - Outcome 13 (Regulation 22)
Supporting Staff - Outcome 14 (Regulation 23)
Assessing and monitoring the quality of service provision - Outcome 16 (Regulation 10)
Complaints - Outcome 17 (Regulation 19)
Records - Outcome 21 (Regulation 20)

Regulated activity

These are prescribed activities related to care and treatment that require registration with CQC. These are set out in legislation, and reflect the services provided.

Glossary of terms we use in this report (continued)

(Registered) Provider

There are several legal terms relating to the providers of services. These include registered person, service provider and registered manager. The term 'provider' means anyone with a legal responsibility for ensuring that the requirements of the law are carried out. On our website we often refer to providers as a 'service'.

Regulations

We regulate against the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009.

Responsive inspection

This is carried out at any time in relation to identified concerns.

Routine inspection

This is planned and could occur at any time. We sometimes describe this as a scheduled inspection.

Themed inspection

This is targeted to look at specific standards, sectors or types of care.

Contact us

Phone:	03000 616161
Email:	enquiries@cqc.org.uk
Write to us at:	Care Quality Commission Citygate Gallowgate Newcastle upon Tyne NE1 4PA
Website:	www.cqc.org.uk