

Forget Me Not Children's Hospice

Forget Me Not Hospice

Inspection report

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Date of inspection visit: 6 August 2014
Date of publication: 25/02/2015

Ratings

Overall rating for this service

Outstanding 

Is the service safe?

Good 

Is the service effective?

Outstanding 

Is the service caring?

Outstanding 

Is the service responsive?

Outstanding 

Is the service well-led?

Outstanding 

Overall summary

We carried out this inspection under Section 60 of the Health and Social Care Act 2008 as part of our regulatory functions. This inspection was planned to check whether the provider is meeting the legal requirements and regulations associated with the Health and Social Care Act 2008 and to pilot a new inspection process being introduced by CQC which looks at the overall quality of the service.

The inspection was unannounced.

Forget Me Not Children's Hospice provides palliative care services to children and young people from across

Kirklees, Calderdale and Wakefield. The support can be provided at home via the hospice at home service or at the children's hospice known as Russell House. Russell House is a purpose built hospice which opened in December 2012 with places for four children.

There were four children in Russell House on the day of the inspection. A registered manager was in place. A registered manager is a person who has registered with the Care Quality Commission to manage the service and has the legal responsibility for meeting the requirements of the law; as does the provider.

Summary of findings

Staff were highly dedicated and passionate about their roles in caring for children and they placed children at the very heart of their work. Staff focus was on enhancing the quality of life for children and their families and this was unanimously confirmed by families we spoke with.

Teamwork was highly evident throughout the service with all members of staff valued and respected in their roles.

Care was provided to an extremely high standard in a child-centred environment. Care and support was extended to children's family members in a highly inclusive and holistic way.

Families highly commended the service and gave extensive praise for the staff and the management team.

Families described the support they received as being like an extension of their own family and they valued the extended services, such as short breaks, bereavement support, siblings groups, play therapy, music therapy and counselling.

There was excellent leadership and management of the service which resulted in children's care being outstanding. The chief executive demonstrated clear goals for the development of the service with emphasis on ensuring quality experiences for children and their families. The organisations values were known by staff and embedded in practice.

Summary of findings

The five questions we ask about services and what we found

We always ask the following five questions of services.

Is the service safe?

The service was safe. We saw examples of good practice to show children's safety was given paramount importance.

Excellent staffing levels and individual risk management ensured children were safe at all times.

There were thorough procedures in place to minimise the risk of infection, to manage children's medication and to ensure children were safeguarded.

Good



Is the service effective?

The service was effective. Staff were highly skilled in their roles and their skills were matched to the needs of individual children.

Care planning and delivery was firmly focused on each child's needs and the needs of their family.

There was a clear emphasis on ensuring children had high quality, meaningful experiences.

Outstanding



Is the service caring?

The service was caring.

Staff were passionate and committed to their roles and the service was highly family-orientated with extensive emotional support in place for children and their families.

Families highly commended staff for their exceptional caring qualities.

Outstanding



Is the service responsive?

The service was responsive.

The service was extremely knowledgeable about children and families' immediate needs and had robust systems in place to be able to respond in an emergency or unexpected event.

Creative ways, such as the use of the intranet, were used to obtain families feedback as well as opportunities for face to face discussions.

Outstanding



Is the service well-led?

The service was well-led.

There was excellent leadership in a culture of open and transparent communication in which every individual felt valued.

Partnerships were very strong at all levels and there was robust auditing and monitoring of the quality of the service.

Outstanding



Forget Me Not Hospice

Detailed findings

Background to this inspection

The inspection team consisted of an ASC inspector, a specialist professional advisor in children's palliative care and an Expert by Experience, whose expertise was in caring for someone who used this type of service. An Expert by Experience is a person who has experience of using or caring for someone who uses this type of service.

Before the inspection we reviewed information we held about the service. This included notifications sent to us by the provider. We had received the provider information return (PIR), a document that was completed by the provider with information about the performance of the service. We contacted the local authority safeguarding team, local healthwatch and commissioners to ask them for their views on the service and if they had any concerns. None of these agencies expressed any concerns.

At the last inspection in 2013 the home met all regulations and there were no breaches found.

We visited this service on 6 August 2014. We used a number of different methods to help us understand the experiences of people who use the service. We spoke with five families of children who used the service, nine members of staff, the registered manager, a visiting nurse professional and the Chief Executive. We spent a brief time observing care and support for children before they went on a day trip. The Expert by Experience spent some time observing staff interaction in a child's own home. We looked at two children's care records and other documentation relating to the management of the hospice, such as policies and procedures, training records and staff files.

Is the service safe?

Our findings

Feedback from families we spoke with described the service as outstanding. Families told us they had every confidence their child was safe whilst in the care of the staff and the hospice environment.

The building had very secure access which was gained only by a security coded lock or the receptionist where visitors' identity and purpose of visit was established before entry was allowed. All visitors were required to wear a visitors badge and, prior to access to the main area, were requested to use the available alcohol hand wash. This process was delivered in a friendly manner and it was explained why this was essential, to minimise the risk of infection.

The hospice environment was highly maintained and very pleasant. The entire building was exceptionally clean and tidy yet maintained a homely and friendly atmosphere. There were plenty of toys and educational items for all children to interact with, which we were told had been examined for safety and put through a thorough cleaning process.

Potential risks were very well managed. It was strongly evident in all areas that great care had been taken to ensure children's safety, with no sharp corners or breakable objects. We saw all electrical equipment had been portable appliance tested (PAT) and these tests were all in date. The use of the hydrotherapy pool was extensively risk assessed. The hydrotherapy policy, the evacuation policy, the risk assessment and the testing regime was a good example of joined-up working and the way in which the service processes the clinical standard operation procedures within the regulation framework.

The provider information return (PIR) sent to us before the inspection stated the hospice had a procedure for assessing and managing risk and they encouraged an open reporting culture through the incident reporting procedures.

We spoke with eight of the care team about the safeguarding process and their safeguarding training. All were very clear about their role and how to identify and report any concerns, which ensured children were safe from harm. The care team informed us of the processes for

raising concerns and incident reporting and clearly understood their roles in both these situations. Staff told us they felt if they had raised a concern they were heard and it was taken seriously.

During the inspection we asked about Medicines and Healthcare products Regulatory Agency (MHRA) medicines and medical device alerts. Staff spoke about a recent alert around some potentially contaminated medication. We saw that they dealt with this very effectively and made sure all parents were informed and helped to arrange a new supply for the children affected. They also spoke about how these alerts were quickly disseminated to all staff, which illustrated that the provider acted to ensure that people were protected from potential risk of harm in this situation..

The PIR stated in the last year 30 medicines errors had been reported. We reviewed these report forms and it was clear there had been some over-reporting and some of these incidents were in fact non-events. This reporting demonstrated an open culture within the organisation where staff were empowered to report incidents and near misses. It seemed that most of the incidents were transcription errors and the organisation was addressing this. All these incidents were reported to the Clinical Governance committee, which reviews and monitors action plans. We saw there were no serious incidents and in all cases the parents were immediately informed of any incidents or accidents which demonstrated strong communication to ensure children's safety.

We saw routine medicines were stored in each child's bedroom in a secure cupboard. These were locked with a keypad although we noticed each keypad had the same code. We discussed this with the Director of Care in relation to the security of this and how they would track any errors with regard to what should be in the cupboard at any given time. We felt confident that this message was heard and would be reviewed to improve safety. We saw a very good risk assessment in place for controlled drugs and a recent medicines audit. We found the safe management of medicines was taken very seriously in this organisation.

We discussed recruitment practices with the registered manager and we reviewed information in the PIR. Recruitment procedures were robustly implemented; new recruits were interviewed by a member of the care leadership team and pre-employment checks were carried out.

Is the service safe?

We reviewed and spoke with the care team staff about staffing levels and shift patterns. Staff were confident there were no concerns about their shift patterns or shortness of staff. We saw high staffing levels, with the ability to bring in more staff if a child was in need of acute end-of-life care or a family were in crisis. All staff were registered nurses and therapists, qualified support workers or trained volunteers and all had been employed because of their empathy and understanding of the children's complex and emotional needs.

During the inspection the children went on a day trip and we saw their safety had been given paramount consideration. Staff provided one to one support, spoke with the children and explained about the safety procedures, such as wearing their seat belts as they secured them safely in the mini-bus. Staff explained to us how they had risk assessed the trip and how they ensured each child had the necessary equipment to ensure their safety.

Due to the prearranged minibus day trip to York, there was little opportunity to talk with the children. However we had an opportunity to observe the interaction between staff and children whilst the staff took great care and patience to ensure that all safety straps on the minibus were properly secured. We saw the minibus was modern and well equipped to ensure the comfort and safety of the passengers was paramount.

We saw each child had a completed 'day trip consent form' within their care plan and it was clear what each child was being consented for during the trip. Whilst they were out, the trip ran into some bad weather. The care team on the trip called the hospice informing them that they would be back later than expected. This enabled the home team to call parents to ask them to come later to pick the children up and it also stopped the team worrying about the trip.



Is the service effective?

Our findings

We saw children's care was sustained by a number of highly dedicated and friendly staff that understood from both empathic and professional perspectives the needs of each child. The Director of Care told us staff were personally matched with individual families depending upon the need and skills required.

We found robust and regular specialist training was offered to all staff, tailored to their professional needs and to the individual needs of the children. For example, we looked at a toolkit the hospice developed and used called 'Developing our Care Team'. This looked at staff competency and covered seven areas Communication skills; quality assurance; clinical practice; knowledge and skills; grief, loss and bereavement; education; leadership and management and research and development.

These were then developed at different levels for different members of the team, care team member, care coordinator, specialist nurses, highly specialist nurses and members of the care leadership team.

The staff team clearly demonstrated a philosophy of integration and saw they were part of a much bigger jigsaw, recognising that to be able to care for a family with a child with a life-limiting condition. The staff recognised that it was important to work with other providers in partnership, such as with hospitals and another children's hospice and for families to see this partnership working in practice. We had lots of conversations with staff during the inspection illustrating how the team worked in an integrated way with a wide variety of local teams across their catchment area and at a regional and national level with the other children's hospices. We were told how different members of the team sat on regional and national groups. One nurse was shortlisted for the Nursing Times Rising Star award for their compassionate practice and going the extra mile for families and the head of integrated care received the Queen's Nurse Award.

During the inspection we attended a training session, which was delivered by one of the nurses. The session was based on an external study day the nurse had been on and they fed back to the rest of the team. The session was on 'opening the spiritual gate'. This was well delivered in an interactive way and there was good conversation around the issue for some of the families and their cultural and

religious needs. There was a clear understanding within the group about the issues of diversity and equality, which reflected again the effectiveness of care and detail given to families' needs and how holistic the service was.

The PIR stated and staff confirmed that children's choices, wishes and preferences were reflected throughout the care planning process. We saw in children's care plans information was gathered to compile the 'all about me' section which detailed their individual likes, dislikes and wishes. We saw this was supported throughout children's care records which showed children received high levels of support that promoted their well-being.

We found staff were highly committed to the key aim in children's palliative care being around quality of life and not quantity. We found the hospice strived to ensure that each child's quality of life was key and that their end-of-life care was delivered by professionals that knew them well and in their place of choice. On the front of the Hospice Newsletter this point was well made in the following quote: 'Every moment is precious to those who know the value of time'.

A parent quote from the newsletter also backs this up by saying: "Every minute of family time is precious, you have to make the most of every day and above all, stay positive".

We found the team clearly made the most of the time children had. This was evidenced by how well staff clearly knew the children and their families, the attention to detail within their care plans and by the passionate way they spoke about the children at the care team meeting.

We looked at two children's care records and we saw these contained very detailed and thorough information. We saw child-centred plans for care and detailed risk assessments to ensure children's welfare. Communication records were highly detailed and there was extensive evidence of multi-agency working with other professionals to provide the most effective care. Within each child's care plan, we saw an individual 'play passport' showing their personal play preferences and this illustrated excellent attention to detail and care that was taken to ensure children have high quality meaningful experiences.

We saw from care records, children had excellent access to complimentary therapies consultation and the hospice could enable children to have access to therapies such as Indian head massage to encourage better sleep. The PIR demonstrated the wide range of health professionals



Is the service effective?

involved in children's care to provide a seamless service. For example, communication was fully maintained when children moved between services, such as hospitals or another children's hospice. We saw this was clearly documented in the communication records within the children's care plans. We saw a letter from a family liaison officer which highly praised the service and illustrated collaborative working.

We spoke with the chef who told us they prepared food and drinks according to children and families' individual preferences and they had an excellent knowledge of people's individual dietary needs. The chef explained that families were encouraged to eat the freshly made meals

together in the dining room in the homely environment and we saw families had free-flow access to the kitchen. We were told the chef made birthday cakes for the children and we saw a thank-you picture made by a child for the chef. Staff we spoke with told us there was excellent communication with the chef so that children's dietary needs were known and met. For example, where food needed to be pureed or where Halal meat needed to be sourced. The chef said they always tried to have a conversation with a child's parents to find out a list of favourite foods from which to prepare choices in keeping with the child's wishes.



Is the service caring?

Our findings

It was highly evident from our observations that all the staff at the hospice treated all children and their families with the utmost dignity, respect, kindness and compassion. In addition, we saw they treated each other in the same way. There was a clear atmosphere of mutual respect and regard for each other regardless of the role within the organisation.

The PIR stated that as part of the recruitment process, staff compassion was tested, families were involved in interviews, psychometric testing was employed and interview questions were asked relating to compassion.

The ethos of the hospice encompassed family centred care where the child, young person and their family were at the centre of everything that took place. We saw this was extremely evident throughout our inspection. Families received support not only for the physical aspects of care, but also for emotional aspects, such as counselling and bereavement support. Families' social needs were supported through the staff offering practical help for transport, holidays, ironing services and wish fulfilment and their spiritual needs were supported through religious support and memorial services.

We had the opportunity to observe interaction with a child during a home visit. We saw highly dedicated interaction between the child and the member of staff and this was extremely caring, professional and genuine. During the visit the child was supported to choose what games were played and there was a very genuine friendship and trust between the child and the member of staff. At all times respect and dignity were highly promoted with regard to the child and their home and family.

We spoke with five families who had experience of using the hospice services. They all had nothing but the highest praise and described an exceptionally caring service. Their comments included:- "Whatever you want, they do their

utmost to fulfil that need"; "They are truly there for us"; "So much care, thought and consideration goes into everything they do"; "They are there for us all, not just our child"; "This is a special place to us. It's like being in a caring bubble where all anxieties and stresses ease"; "All the staff have such passion and drive"; "It's the staff, you can tell they've been cherry picked just for their qualities"

The Director of Care told us end of life care was delivered in such a way that enabled individual choice and supported families to have control, with care offered at home, in Russell House or in hospital with a mobile workforce. We saw the hospice was extremely well equipped to support end of life management with quiet rooms and highly skilled staff available to support relatives and loved ones. There was also available a self-contained Snowflake Suite where relatives and loved ones were able to come to terms with their bereavement at their own pace. As the suite was in use at the time it was excluded from the inspection. Staff explained that when this room was in use, a snowflake symbol was discreetly displayed on entrance doors so all staff would know to be sensitive in affording privacy and respect to the family.

We spoke with one family who had experience of using the Snowflake Suite and they told us how this had been a superb example of how the staff delivered compassionate and supportive care, over and above their expectations. For example, they told us how their family pet had been allowed to be included and that 'nothing was too much trouble' for the dedicated and motivated staff team.

We saw superb accommodation within the hospice that was designed for the use of families and offered excellent facilities, and, as with the Snowflake Suite, had private and sensitive independent access. We also saw a room dedicated to different religious and cultural users where people were able to pray or relax. The room indicated the direction of Mecca and there were copies of the Quran and Bible available with the room, not overtly dedicated to any single religion but inclusive of all.



Is the service responsive?

Our findings

The hospice was highly proactive in planning children's care and support. We saw family-led care planning underpinned the work the staff carried out with the children. Care plans we looked at were holistic, considering all elements of children's care including their physical, social, emotional and spiritual needs. Care plans illustrated families chose where and when to receive care and their needs, wishes and preferences were fully considered.

We spoke with five families, who told us they found the service was very responsive to their children's needs. They said they felt care was highly individualised and staff knew their child's particular preferences. One family said: "I feel like the staff are an extension of me. They know my child so well". Two families commented the hydro-pool was sometimes not working when they would like it to be but one family said they were able to use this at short notice when it was working. One family told us staff took time to engage in dialogue with them at every opportunity. They said: "Staff are on the ball, they check the information about my child every time, they are never ever complacent".

We found the service was highly responsive to clinical need. We attended the staff weekly care meeting, an opportunity for each team to update the other team on the current state of the children. This meeting was key for those members of the team who were part of the on-call rota. There was good open discussion during the meeting and it was truly multi-professional and everyone's voice was being heard. During the meeting we heard of a referral that was received for a child who had died and who the team had not yet met. The family wanted to use the 'special bedroom', which was set aside for children who had died and for their family who wished to spend time together before the funeral. The team made the arrangements and welcomed the family in a timely way.

The service provided rapid response to children's changing needs. For example, they had a 'mobile workforce' which responded to families' needs within the hospice, in the

community or in hospital. Staff spoke about this in a positive way of being able to respond at short notice to the wishes of a family. They had a very effective 24 hour on-call which has been well constructed and worked well for families and staff. This was key as we were informed that things can change very quickly and dramatically, be that the child's condition or within the family. We also saw 'floating staff' were included on the staff rotas to be able to respond to emergency or crisis care.

Staff had a clear understanding of families' differing values and beliefs. End of life care was tailored to meet the needs of diverse cultures and religions, such as responding to requests for weekend death certification and registration to facilitate Muslim burial. The hospice was constantly looking to adapt and include all people's religious and cultural needs, such as responding promptly to a family's request for halal food be made available. The hospice employed the services of interpreters if necessary to ensure that the service could respond promptly to people's needs.

We saw there was a clear and comprehensive system that enabled and encouraged children and their families to bring a complaint should they feel it was needed. All the children had access to staff for any concerns/ complaints to be closely examined and acted upon. When children became upset or anxious there was a qualified counsellor and trained staff available at all times and appropriate support given. Families we spoke with said they had nothing but praise, and expressed no complaints about the service, but they knew the procedure to follow should they wish to raise a concern. Families told us they had confidence their concerns would be acted upon immediately.

Families views were gathered regularly using surveys, focus groups and informally during stays and visits. Feedback from families was published in the hospice birthday magazine and incorporated the children's 'stories' of their experiences. A family internet facility was developed to include a praises and grumbles section and families' views were used to shape the development of the service, such as in the new garden area proposals.



Is the service well-led?

Our findings

The PIR which was sent prior to the inspection was very helpful and informative and our inspection findings verified this information was accurate.

The hospice was very well led and managed with a firm focus on responding to the needs of individual families, not only by the senior management team, but there was a keen sense of a shared responsibility for this throughout the whole team. We saw strong leadership throughout the inspection, highlighted in key points such as a well-delivered meeting and training session we observed.

We saw three clear levels of leadership within the service. We spoke with two care-coordinator nurses. They spoke very clearly and articulately about their role of line-managing a small team of nurses and carers. They illustrated the way in which all staff were cared for and their voice was heard within the organisation.

The care team in turn was led by a very able physiotherapist who chaired the care meeting very effectively and professionally and gave us a very impressive tour of the building which was clearly designed with children and families' needs in mind. We asked two of the nursing staff how they felt about the leadership they experienced and they gave a glowing commendation which suggested creativity and innovation was encouraged: Our line manager] is great and helps us to think in a different way. [They] tell us to "take our nursing heads off" and to see an issue in a different way'.

We spoke with the Director of Care who explained they received high levels of support from senior managers and the team as a whole. They were very articulate about their support network within the organisation and externally at a regional and national level. This demonstrated robust and creative leadership which fostered a culture of encouraging staff to seek support if they needed to, which was then translated into the supervision arrangements within and across the service. All members of the team were expected to engage with clinical supervision, which was in addition to their one to one meetings with their line manager. This approach demonstrated this was a service that took the care of its staff seriously and invested resources in their support as well as the care of the families they served.

The PIR stated that the care leadership worked alongside the team and chaired the monthly case load review meetings so that they had a good understanding of the needs of individual families and the care they received.

We found excellent systems of communication throughout the service to ensure staff had a thorough knowledge of children's needs. For example, there was feedback given at all the team meetings and there was also a very effective monthly team briefing for those who were not able to attend team meetings due to shift patterns.

We spoke with a visiting professional who was being shown round the hospice. They were very complimentary about the hospice and were aware of their excellent reputation in providing children's palliative care. The member of staff who showed this person round we observed to be a superb ambassador for the work of the hospice and proudly conveyed information about recent achievements.

Another example of the excellence in leadership which we observed was illustrated by the fact that we arrived unannounced for inspection on a very busy day with children going out on a trip, a care team meeting was taking place, a teaching session was due to take place, a film crew were coming to record a short film, for which different members of the team were needed. The Chief Executive was off site. Our arrival and all the other activities going on was managed smoothly and efficiently. Managers and staff fully assisted with the inspection process, produced documentation we needed to see and staff were made available to talk with us and to show us around. We had a telephone discussion with the Chief Executive who spoke passionately about the families, the service and the contributions of the team. He told us the hospice was still at the start of the journey and had experienced accelerated growth. He said they were "absolutely focused on trying to truly understand what children and families want".

The management team consistently put clear vision and strong values into practice. Management were involved in the development of best practice. For example, the Director of Care was part of the Expert Reference Group for the Department of Health guidance: Nursing Values for pre-registration Nursing Recruitment, Education and Transition into Employment. Members of the care team were involved in the recruitment of pre-registration nurse education at Huddersfield University.



Is the service well-led?

It was clear the organisation's values played a key part in the approach taken to leadership and this reflected upon all members of the team. Staff were highly valued and the support staff and volunteers were given due credit by the team as their roles clearly played a major role in the smooth running of the service, as well as making it a safe 'home from home'. We saw how the values of the organisation were embedded in practice and used within the appraisal and behaviour frameworks, thus making them truly integrated into the service. We saw exceptional care given in an inspirational way. This was in line with their vision and with their values.

When we asked members of the team the key question 'Is this service good enough for your child' everyone answered with a very clear 'yes', giving an overwhelming affirmation of the service.

Our discussions with staff showed there was a very friendly yet professional attitude within the hospice. Staff stated: "It's a lovely place to work, even though it can be sad at times we all pull together", "The staff are all lovely and kind and loyal to each other" and "The management interact well with staff and appear open to suggestions". One member of staff we spoke with said "Sometimes the directors try to do things too quick and it can be stressful and put pressure on us (the staff) and one person may leave because of this". However, staff acknowledged the pace of change within the hospice's first year of operation and said: "It can't be helped at times" and that it was only a minor concern and maybe the directors could give them more notice of change. We discussed this with the Director of Care who said there had been a very rapid period of development during the hospice's first year and that senior

leaders were very aware of the impact on all staff and were using this as an opportunity for future learning. Staff confirmed meetings are regular within the hospice and all issues are talked about and new or innovative ideas are put forward.

We saw highly robust systems in place for auditing the quality of the provision. We saw evidence that themed audits took place quarterly as well as monthly audit checks of equipment and practices such as beds, mattresses, hand hygiene, 'bare below the elbow' procedure. Managers competently identified areas to improve and there were clear plans in place, such as the revision of policies. Action plans were quality assured and monitored by the governance groups with incident and risk reports reviewed by the clinical governance committee.

The hospice provided extensive opportunities for families and staff to shape the services through drop-in strategy development sessions, coffee mornings, questionnaires and focus groups. Staff suggestions boxes were in place and staff told us they felt encouraged and confident to raise ideas. Families we spoke with told us their views were highly valued and they felt able to make suggestions that were genuinely listened to and resulted in improvements, such as the development of the children's sensory garden. Families told us they felt fully included and involved in the running of the hospice. They said they particularly found the newsletters and website informative. Two families told us when they no longer needed the services of the hospice they intended to remain affiliated as volunteers. One family said: "They have been our extended family and we want to put something back. This service is superb".

This section is primarily information for the provider

Enforcement actions

The table below shows where regulations were not being met and we have taken enforcement action.