



Quality Accounts 2017-18

Welcome to our Quality Accounts 2017-18

Having joined The Donna Louise in April 2018 it is my pleasure to acknowledge the significant developments in our Care Service reflected in this Quality Account. The team at the Donna Louise have a profound impact on the community, children, young people and their families. The commitment of staff and volunteers are the backbone of this incredible organisation. I believe the information in this Quality Account is an accurate and fair reflection of the services provided by The Donna Louise for children, young people and their families throughout Staffordshire and Cheshire during 2017/18.

This document is designed to provide all stakeholders with information about the quality of these services. In addition, it is an assurance of on-going quality measurement, improvement and a clear demonstration of how future priorities are identified and delivered. The safety, experience and outcomes for our services users are paramount, underpinned by robust clinical and corporate governance frameworks and our Board of Trustees fully endorse the content of this Quality Account.

As you may be aware, we operate in a health and social care environment in which third sector organisations such as ourselves, continue to be challenged to ensure high quality, appropriate services are maintained against a backdrop of diminishing public service provision. This is not going to change for the foreseeable future and does present some unique challenges to the children's hospice sector.

We remain committed, alongside our sector colleagues, to our role in developing financially sustainable services, which identify and address the 'needs' of our service users. This commitment also includes continued representations at the highest levels calling for the services we provide to be valued and fairly funded from statutory sources.

In December 2015, our Board of Trustees developed a long term organisational strategy, aligned to our Vision, Mission and Values. This strategy contained three major strands:

1. To deliver more to our service users and their families, with the same resource
2. To develop outreach services for those unable to readily access our hospice building
3. To create a solution to address the challenges of transition from child to adult services for those reaching adulthood

I am pleased to tell you that the team have made huge progress towards delivering these strategic aims – this is very much underpinned by the development of a dedicated Transition Unit alongside our existing hospice facility, due to open in the Spring of 2019. But this also reflects the unwavering commitment to children and families accessing current services.

Above all, I am privileged to reaffirm that children, young people and their families are central to everything we do, and this steadfast principle is embedded within everyone who contributes to the work of The Donna Louise. I would like to congratulate and thank all those involved for their support and achievements in 2017/18 and I look forward to working with everyone in the years ahead.

Simon Fuller
Chief Executive

VISION

To be a center of excellence for children and young people's palliative care.

MISSION

To provide a quality palliative care service to children, young people and their families through Effective partnership working aligned with our values.

Paediatric Palliative care is a complete approach to treating serious illness that focuses on the physical, psychological and spiritual needs of the child. Its goal is to achieve the best quality of life available to the child or young person by relieving suffering and controlling pain and symptoms

VALUES

Respect – we foster a culture of respect and maintain the environment of team work, growth and diversity

Excellence – we strive to be efficient, effective and innovative, giving our best with passion and consistency and continually searching for ways to do things better

Integrity – we are ethical, professional, honest and accountable in our approach to everything we do

Openness – we encourage an open and transparent culture which fosters trust, collaboration, continual learning and community spirit

Fairness – we endeavor to provide a balanced approach at all times which is equitable and non- discriminatory

Enablement – we support and empower our children, families, staff and volunteers to have a say in the way our services are delivered and to influence the future direction of the organisation.

Section 1: Priorities for Improvement and statements of Assurance from the Board

Following consultation with the children, young people and families; commissioners; stakeholders and staff; the executive management team and Board of Trustees set the 5 year strategy for 2016 -2021. The strategy is composed of three key areas:

- Better use of current resources to deliver extended and improved services to children, young people and families
- Improve the range of services and opportunities to families not resident in Stoke
- The provision of services for young people over 19 years of age

From the strategy DLH confirmed the quality improvement priorities for care in 2018 to 2019 to be as in the 2018-2019 Care Development and Improvement Plan, available upon request.

Progress against the improvement priorities identified in 2017-2018

Overall, significant progress was made against the priorities identified, with the majority of objectives achieved. There were some changes throughout the year as services evolved and priorities shifted.

Improvement area	Outcome
Improve both the quantity and the quality of home based short breaks and day care	Nurse recruited specifically for the provision of community/ home based care and support. Increase in the number of community support visits – 307 visits undertaken, an increase of 64 on 2016-17 Review and further development of documentation specifically for use in the community
Improve the sibling experience. Increase the quality and quantity of sibling support opportunities both for therapeutic interventions and fun activity based opportunities	Children in need grant secured to develop and implement a 3 year sibling support programme. Dedicated Sibling support worker employed for the above 84 siblings supported (63% of number on caseload and an increase of 33 on 2016/17). We offered a total of 71 spaces to siblings over the last 12 months. 50 children in total attended both outings and in-house events. A bereaved sibling programme was piloted but sadly only very low number engaged. This will be reviewed as part of the children in need project. Saturday sibling Club has been attended by 32 siblings
Improving the Children's experience, including music experience. Ensure that all children and young people using the hospice, including siblings, have a fun-filled, positive experience	Investment in sensory room resulted in the revamp of our sensory room, creating state of the art sensory facilities and opportunities for children to engage in beneficial sensory play. 8 Youth Group Youth Activity sessions held with a total of 49 attendances. In this year we have concentrated on holding more bespoke smaller groups as requested by the young people, to enable us to target need better. The data for these groups isn't captured in the same way, we are exploring how best of capturing this data for 2018/19
Improve the range of opportunities and services to families not resident in Stoke on Trent	Sibling support sessions held in Stafford and Burton on Trent Parent and carer group firmly established in Burton

<p>Ensure the Care team workforce is fit for both safe and effective care delivery both now and in the future. To include volunteer roles</p>	<p>Grow your own nurse's project launched following successful workshop with key stakeholders. Dedicated Care team volunteer post created and recruited to which has resulted in an increase in care team specific roles for which a full evaluation will be available in 2018/19</p>
<p>The provision of services for young people over 19 years of age including improving the transition experience for young people and their families</p>	<p>Full range of services provided to 23 young adults over 18years of age – Employment of adult social worker has resulted in a greater amount of support for families during transition and better awareness of and liaison with adult services 2 young adults have been assisted to live independently Young people feeling they have a voice. Young people and their families feeling much better supported through transition Transition policy developed and implemented</p>
<p>Improve the safety and quality of in-house short breaks through the following:</p> <p>Improved individual child specific risk assessment procedures in place to improve care and safety of children and young people – added in October 2016, following CQC INSPECTION</p> <p>Improved Medicines Management systems</p>	<p>All children with LTV needs have child specific LTV risk assessments which are reviewed annually. Children with other specific clinical needs not covered by the generic clinical risk assessments will also have child specific risk assessments. Review of risk management processes and improvement plan implemented</p> <p>External review of Medicines Management systems commissioned and undertaken resulting in a whole scale overhaul of the medicines management policies and Standard operating procedures, risk assessments / risk management plans and audit programme. Slight progress made in securing the assistance of UHNM in the provision of pharmacy support services</p>

Other service improvements / developments not included in the 2017-18 Care Development Plan.

The care co-ordination service and social workers continue to deliver an essential support service to families, helping them through the minefield of meetings and services to ensure that they are able to access all relevant health and social care support. In 2017 an independent review of this service was commissioned which provided evidence of the impact of the care coordination service and was summarized in the statement below:

“CCs are friendly, professional, supportive, always have a ‘can do attitude’ and provide their families with a ‘one stop shop’ for all of their needs.”

The current organisation of the service is fit for purpose and, feedback suggests, the best use of the time and expertise of this experienced team. Their impact is great and felt on a day to day basis by children, young people and their parents and carers; they support families and improve their quality of life. Suggested improvements include the DLCH employing more CCs to reduce the size of caseloads to a more manageable level, allowing increased flexibility and availability to provide support.

Statements of Assurance from the Board:

The following are statements that all providers must include in their Quality Account. Many of these statements are not directly applicable to specialist palliative care providers, and therefore explanations of what these statements mean are also given:

Review of services

During 2017- 2018 the hospice provided the following services to NHS patients:

- In- patient services
- Day care services
- Community services
- Counselling and psychological support services
- Care Co-ordination services
- Family Support services

The hospice has reviewed all the data available to us on the quality of care in these services.

The DLH Clinical Governance and Care Development Committee receive regular reports, which enable them to review both the quality and quantity of care provided by all clinical services. A report on all clinical incidents, including medication errors and accidents is provided bi-annually.

All services delivered by the Hospice are funded through a combination of fundraising activity and contracts with the NHS. The NHS contracts mean that all services delivered by the hospice are part funded by the NHS.

Where NHS funding is secured this only partially contributes to the costs of care of children. The costs of provision of a holistic family focused service are borne by the charity through fundraising activity. For example, counselling and emotional support, play and recreational services, music specialist, family accommodation, hospitality, bereavement care, on-going supplies and provisions, costs of maintaining the house and gardens are all reliant upon fundraising/ charitable income.

Participation in National audits

During 2017-18 the hospice was ineligible to participate in the national clinical audit and national confidential enquiries. This is because there were no audits or enquiries relating specifically to specialist children's palliative care in 2017-18.

Research

The number of patients receiving NHS services provided or subcontracted by the hospice in 2017-18 that were recruited during that period to participate in research approved by research this committee was 0.

What others say about us:

The hospice is required to register with the Care Quality Commission (CQC) and its current registration status is unconditional. The hospice has no conditions on registration. The CQC has not taken any enforcement action against the hospice during 2017- 18.

The hospice has no actions to take and no points were made in the CQC's assessment. The hospice was fully compliant and rated as low risk. An inspection in 2016 resulted in a 'Good' rating from CQC.

Part 3: Review of Quality Performance 2017-18

Total number of current open and post bereaved cases Total Cases during 2017-18 (open and post bereaved) No of families actually supported in 2017-18	267 Families supported 189 active cases <i>This is a 30% increase in activity since 2014/15</i>
Number of referrals received – % accepted, % declined	57 received 39 accepted (68%) 21 declined (36%)
No of Bed nights Available (based on 5 beds) No of Bed Nights Taken % occupancy	1713 1637 95% occupancy of beds available
Number discharged from care	12
Number in transition (aged 16- 18)	as at 31.3.18 there were 43 young people aged between 14 and 18 inclusive
Number of adults supported	23
Number of day care episodes	295
Number of home support episodes	307
Number of counselling/ emotional support intervention sessions	1254 Art therapy sessions 241
Number of Care coordination interventions	2537
Number of social worker interventions	1173
Number of physiotherapy interventions	268
No of youth group support sessions delivered and numbers attended	49 attendances by young people aged 12 and over to 8 youth group sessions
No of sibling group activities and sessions delivered and number of siblings attending	84 siblings supported (63% of number on caseload) We offered a total of 71 spaces to siblings over the last 12 months. 50 children in total attended both outings and in-house events.
No of siblings supported via volunteer led activities	32 siblings attended Saturday club
No of parent & carers attending group activities	105 parents attending 15 events
Number of episodes of end of life care Number of nights provided	7 episodes 56 nights
Number of complaints requiring further investigation and response	1
Garden Room Number of Nights/Cases	50 nights for 7 children

Local quality measures

From April 2016 we have had a set of quality performance indicators as an internal measure. Some of these are also used as part of the external quality monitoring mechanisms. There were no issues identified in 2017/18 from the QPI's. Any areas that needed attention were addressed as part of the Care Development and improvement plan and where this was not possible an action plan would be developed.

A full QPI report is available on request.

In addition the following measures reflect our performance.

Referrals

2012-13	57 received, 38 accepted (66%)
2013-14	41 received, 26 accepted (63%)
2014-15	52 received, 39 accepted (75%)
2015-16	44 received, 29 accepted (65%)
2016-17	66 received, 43 accepted (65%)
2017-18	57 received, 39 accepted (68%)

Our participation in clinical audits

To ensure that the hospice is providing a consistently high quality service, we undertake our own clinical audits, using national audit tools, where available, developed specifically for hospices, which have been peer reviewed and quality assessed. This allows us to monitor the quality of care being provided in a systematic way and creates a framework by which we can review this information and make improvements where needed.

Each year the Clinical Governance Committee approves the audit schedule for the coming year. Priorities are selected in accordance with what is required by our regulators and any areas where a formal audit would inform the risk management processes within the hospice.

Through the Clinical Governance report, the Board of Trustees is kept fully informed about the audit results and any identified shortfalls. Through this process, the Board has received an assurance of the quality of the services provided.

The following audits were completed between 1st April 2017 and 31st March 2018:

- Manual Handling
- Safeguarding:
- Medicines management:
- Infection control
- Documentation:
- Clinical supervision
- Mandatory Training
- Record keeping

Quality Metrics/ Quality Markers we have chosen to measure

Services are monitored using a set of QPI's to report on.

We are now reporting against an agreed set of quality indicators to the Staffordshire CCG's Clinical Quality Review Meeting.

Patient Safety

Number of incidents/accident (<i>full report available upon request</i>)	106 total for the organization
Number of reportable (to local safeguarding services) safe-guarding incidents occurring in the organization	0
Infection Prevention and Control rates: Total number of children admitted with known infection	0
Total number of children developing infection at hospice	0

Clinical Effectiveness

Please see section on local audits. *Full report available on audit activity in 2017/18 on request*

Child, young adult and family experience



“Coming to The Donna Louise is great because it allows me to be a mum and not a nurse. We all look forward to it because it is a chance for us to spend time together as a family. Any spare time I have is taken up looking after James, planning his next feed and getting his medication ready, so it's a real luxury when I come to The Donna Louise to just be able to read a book or have a shower.”
Amanda (mum of James)

When William comes to The Donna Louise, he's a boy and not a diagnosis. He's a child who can play, run, smile and do all the things he wants to do.”
Tracey (William's mum)

““We would be absolutely lost without the support of The Donna Louise and we really look forward to coming, it's a break for the whole family. Death is a part of what they do but it's only a small part. The hospice is about love, support and fun.” Laura (Milo's mum)



“When you come here, you know that the kids are in a safe environment, the mums can have a cup of tea and a chat; you can be breaking, just need a hug, sometimes just having a cuppa makes a big difference.” Sharon (Kav's mum)

“When you are caring for a really poorly child, or you are bereaved, you can feel so alone but in reality you are not. It's so important to be able to talk to other men who are going through the same journey as you. It can be hard to talk to friends, family and colleagues. They can't always understand what you are going through. Sometimes they just don't know what to say, they can be scared of upsetting you. With the other dads, we can be honest about how we feel and help each other.” Jason, bereaved dad, supported by Men's group – Journey for Men



“I always think that I have three homes – my actual home, the hospital and The Donna Louise. In fact my mum often says that she thinks I'd move in to The Donna Louise if I could, and she's probably right!” Chloe 19 years old

“Some people in my situation could become dependent upon parents, and not want anybody else to care for them. But I have been coming to the hospice, and staying here by myself, for many years, it has helped me to be independent and not rely on my family for everything.” Tilly, 18 years old.



“We don't know what's going to happen day to day with William's illness, but we know The Donna Louise is always there for us when we need it.” Tracey (Williams' mum)

Staff information and Experience

As of 1st April 2017 we had 98 members of staff (excluding bank staff).

By 31st March 2018 we had 110 members of staff giving a staff turnover rate of 13.46% this is a decrease on the previous year's figure of 15.95%. There is not any current data from TFSL to make the comparison between hospices as there is no longer a formal HR forum group.

In addition to the data above we collate and evaluate information from exit interviews when staff leave the organization. For this reporting period 12 people left the organisation but only 41% (5 out of 12) completed voluntary exit interviews/questionnaires. The reasons for this were explored and were varied.

Key themes were quite difficult to identify as reasons for leaving varied – promotional opportunities elsewhere, dream job offer, lack of job satisfaction/shift patterns, suited personal circumstances to return to a former job closer to home were identified.

Staff Survey was conducted Nov 2017.

62% of staff took part – an increase of 24% in respondents compared to the last survey in 2015.

We learnt that we have a good mix between new people coming into the organisation, balanced with staff that are organisationally experienced and committed. This is a really healthy sign for the organisation as it implies that there is growth while maintaining stability amongst us all as a staff team.

- 98% of staff feel positive and proud to work for the Donna Louise and no one disagreed with this statement.
- 93% of staff feel they have the opportunity to do our best every day -
- 85% of staff know what is expected from them at work, know how it should be done following correct policies and procedures, and feel that their opinions are listened to and that there is a strong emphasis on health, safety and wellbeing.

We learned from the comments that, where people were unsure what was expected of them at work or were less clear on policies and procedures they tended to be newer members of the team who were getting orientated.

As a result of this we are reviewing the induction process and have already included more detail on policies and procedures as part of the induction process.

Over 80% of staff who responded to the survey reported that they have regular reviews, have the materials/equipment to do the job, feel respected and valued at work and see cooperative, supportive and appreciative relationships amongst colleagues.

Over 70% of staff felt they received recognition, praise, are fairly rewarded, have opportunities to learn and grow.

Over 70% feel there is a culture that encourages openness and honesty.

The majority of staff wanted to stay with the organisation and felt the benefits offered meet needs.

63% of respondents said they agreed that they see teams work collaboratively, share responsibility and resolve conflict quickly and constructively. This was the question that recorded the lowest degree of satisfaction and again is the area that we know we can and shall improve on.

This result reflects how people work within their teams but from the comments given this isn't necessarily reflected across the organisation or across departments. There are some organisation learning points that we can take from some of the comments made in the survey and we will endeavour to find ways and means for us all to share, challenge, and support each other better going forward. We know that moving forward when the bigger decisions that affect us all we need to find better ways to make those decisions together.

Common themes raised were:

- Infrastructure concerns - the primary concern was around IT, IG and training opportunities across the whole organisation.
- Need for strong leadership as we go forward.

Education, Training and Development

Principles of the DLCHT Education & Development Strategy

- To enable learning in the care team workforce to ensure the safe & effective delivery of care that recognizes the holistic needs and health care experience of the child, young person & family.
- To generate a culture of learning and empowerment in the workplace that sustains developments in practice and individual, team & organisational effectiveness.

The Education & Development Team continue to strive to achieve this through the core elements of Practice Development, development & assessment of core skills & competencies, delivery of mandatory training, facilitation of structured reflective practice and support during induction.

We continue to support local & national universities by offering practice placements, mentoring, involvement in student selection, lecturing and attendance at workshops & a research group.

A number of nurses & CSWs have completed or are currently undertaking level 6 & 7 courses in children's palliative care, therapeutic play, spirituality in palliative care & child health & development for adult trained nurses.

Four Care Support Workers are currently undertaking an internal development programme to upgrade their skills to Senior Care Support Worker roles. This involves competencies in medicines administration, care of the child with a tracheostomy, long term ventilation and assessment & care planning.

The past 12 months has been busy & challenging as always. The culture of learning within the care team has deepened & strengthened as the Practice Development model has become embedded. This is demonstrated by the significant increase in percentage of staff with full sets of in date competencies, attendance at mandatory training and supervision, compliance with e-learning requirements, positive attitudes towards new initiatives e.g. Practice observations & clinical discussion groups and staff identifying & addressing potential for service developments. Excellent feedback from students backs this up, alongside feedback from families which shows their confidence in the care provided for their children.

Challenges for the year ahead include induction & training for the adult service, opportunities to develop our own staff through new trailblazer apprenticeships and the 'grow our own' project to support the growth of the children's nursing workforce at The Donna Louise.17