



STATEMENT OF PURPOSE

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| Statement of Purpose | Date:- June 2011 | Revision No: 2 |
| Written by Head of Care & Service Development | Review date :- June 2012 | |

Background

Noah's Ark was established in December 1999 by the current Chair of Trustees, Michael McInerney following the death of a child in his extended family. It is an independent, charitable and voluntary body. Income is from the charitable giving of individuals, groups, organizations, grants/trusts and corporate sponsorship and in turn we provide a free service to our service users. As a developing children's hospice service we are building a strong community outreach team, which we ultimately aim to complement with a hospice building. We are seeking to serve an estimated 350 life-limited children/young people and their families living in the communities of North London.

Our Service Aims

Our aim is to support families, working in partnership with other agencies, to deliver flexible services that meet the needs of each family. These will range from practical and emotional support, ultimately through to end of life and bereavement care. We are committed to a family-centred approach.

Our service development is informed by the government's recent relevant publications (*Independent Children's Palliative Care Review, Aiming High, Better Care Better Lives*) and will follow the ACT Care Pathway. Working within the North Central London Children's Palliative Care Network (and with other statutory and voluntary agencies), we are committed to identifying gaps in current service provision (as defined by families themselves) and working together to meet these needs. Noah's Ark is an active member of Children's Hospices UK, the umbrella organisation representing the sector.

Registered Providers / Responsible Person and Registered Manager

Under the Care Standards Act 2000, Noah's Ark Children's Hospice will be registered with, and inspected by the Care Quality Commission. Noah's Ark will be registered as an Independent Hospice providing palliative and respite care for children/young people in their homes by a Nurse-led team of trained Family Carers, Nursery Nurses and Respite Child and Young Persons Respite Workers. The Certificate of Registration will be displayed at Noah's Ark Children's Hospice office.

The Registered Provider is:- Board of Trustees

Noah's Ark Children's Hospice
3 Beauchamp Court
Victors Way
Barnet
EN5 5TZ

The Responsible Person is:- Gill Dodge

Noah's Ark Children's Hospice
3 Beauchamp Court
Victors Way
Barnet
EN5 5TZ

The Registered Manager is:- Ghislaine Smith

Noah's Ark Children's Hospice
3 Beauchamp Court
Victors Way
Barnet
EN5 5TZ

Noah's Ark Children's Hospice Registered Charity No. 1081156

Relevant Qualifications and Experience

The Board of Trustees

Michael McInerney, Chairman and Founder - The vision for the need for a Children's Hospice within the area of North London was born out of Michael's experience with a close relative who died as a child on a general medical ward in hospital. In his commercial role, prior to becoming a healthcare operator, Michael was involved in property development. He now owns Brookdale Care, a private healthcare company providing both nursing and residential care for people with Autism in London, Hertfordshire, Bedfordshire and Cambridgeshire.

John Dickie MIAS FFB MBE - John worked for Peterborough Planning Department before leaving to set up John Dickie Associates, a private planning and architectural practice. Since the start of the nineties, the practice commenced work on developments in the healthcare sector and to date has handled over 60 such projects mainly for corporate healthcare clients. Having served on the Board since Noah's Ark's inception, John has been responsible for developing potential designs for a hospice building.

Mary O'Toole Dip in Applied Social Studies, Honours Degree in French, - A resident of Barnet, Mary has over 30 years experience of working with the families of disabled and life-limited children, both through supporting charities which she helped to run and as a Social Worker at Great Ormond Street Children's Hospital. Mary retired from the Disabled Children's Team in Barnet in 2008 and acts as a part-time Social Worker for the Charity on a pro-bono basis.

Jennifer Israel - A resident of Barnet, Jennifer was a Solicitor for nearly 40 years. Having spent the first twenty of these with a city firm, she then opened her own high street firm, where she worked for the remainder of her career. Jennifer was on the Law Society Council for 16 years, dealing with a variety of areas including the Discipline of Solicitors, Land Law, Race Relations and Constitutional Matters. She also has valuable experience of Charity Law.

Jeremy Isaacs - Jeremy joined the Board in 2009, having developed an interest in the services Noah's Ark was delivering local to where he lives. Jeremy has an extensive background in the City's financial world, having held senior positions with Goldman Sachs and Lehman Brothers, before going on to establish the JRJ Group. Jeremy brings valuable commercial experience to the Board and is well placed to further develop our connections with corporate and business professionals.

Mark Gomar - With experience in investment banking, and having served 6 years on the Board of Trinity Hospice, London, Mark joined the Board in 2009. Living in Hatfield, Mark is married with 4 children and is a graduate in Economics from Cambridge University. His experience as a trustee in the palliative care sector, together with his financial background, means he is able to offer relevant expertise to help Noah's Ark move forward.

Responsible Individual

Gill Dodge - CEO BSc (1st Class Honours) Physiology

Gill joined Noah's Ark in August 2005, realising a long held desire to apply her abilities within the 'not for profit' sector. Having spent 20 years in the commercial healthcare arena (the 5 years preceding her move, as a director in a global team at GlaxoSmithKline), she brings to Noah's Ark a breadth and depth of experience in organisational management and development, financial, marketing and sales disciplines - much sought after skills in the highly competitive charitable sector. Gill believes that it is people that make things happen - her ability to inspire, motivate and build teams to deliver goals will be a key driver of the organisation's future success.

Registered Manager

Ghislaine Smith - Head of Care & Service Development, NNEB, RGN, Midwifery, Dip. Health Visiting

Ghislaine (known as Gill) started her working career as a nursery nurse in a school for children with special and complex needs before embarking on her nursing career, which to date spans 30 years. Following her three years general training she staffed as a nurse in Accident and Emergency before jetting off to work as a Staff Nurse for a year in a children's hospital in Western Australia. Following her return to England she did her midwifery training and once qualified worked as a midwife in a neonatal/special care baby unit. After a spell of travelling whilst working for an airline, Gill returned to nursing and trained to work as a Health Visitor. Over the past 10 years of her career Gill has moved into more of a management and service development role whilst keeping up her clinical practice as a sessional Nurse Practitioner in a Barnet Walk In Centre. Her last post before coming to Noah's Ark was as a Senior Nurse in an out of hours GP service covering two of the boroughs that are served by Noah's Ark, namely Barnet and Enfield.

Relevant Qualifications and Experience of the Care Team Staff

Nurse-led Family Carers Service

| Role | Number employed | Permanent/ Sessional | Relevant Qualification | Relevant Experience |
|--|---|-------------------------|---|---|
| Team Leader | In the first instance x 0.6 equivalent increasing with demand & growth of service | Permanent | RSCN | 3 years post qualification Primary care experience Teaching/ mentorship experience |
| Noah's Ark Bank of Family Carers | x 5 increasing with demand & growth of service | Sessional | QCF Diploma Level 3 in Health & Social Care or willing to undertake QCF Diploma Level 3 in Health & Social Care or NNEB | Experience of working with children in a social/care setting |
| *Respite Nursery Nurse (in post) - Enfield | X1 | Permanent | Diploma in Childcare Postgraduate Certificate in Therapeutic Play | Experience of working with children in an acute or community setting |

*Currently funded by Noah's Ark Children's Hospice but managed by local NHS Trusts.

The wider existing Care Team consisting of Head of Care, Social Worker, Family Support Volunteer Manager, Sibling Support Worker, Play Specialist, Activities Co-ordinator and Care Team Administrator will support the above, but have personal hands on care responsibilities.

Service Provision, Range Of Needs And For Whom The Nurse Led Family Carer Service Is Intended

The Nurse-led Family Carers Service offers care and treatment in the child's/young person's home in order to:-

- give life-limited & life-threatened children/young people and their families the best possible support in life, at no cost to them
- work in partnership with other agencies, to deliver flexible services that meet the needs of each family, these will range from practical and emotional support, ultimately through to end of life, bereavement and beyond
- foster family-centred care in the home and community by acknowledging that the needs of each individual family are unique
- promote best practice in palliative care by example and education
- act as an advocate for life-limited & life-threatened children/young people and their families, both on an individual basis, but also at a strategic and political level through sector wide dialogue
- monitor and review practice ensuring standards are maintained to the highest quality and to meet the needs of the children & young people and their families and to use this insight to shape our service development

Key outcomes

To achieve improved family resilience - defined as their ability to:

- cope as independently as possible, retaining their self-esteem
- live positively, making the most of the time they have together during the life of their child, and beyond.

The Family Carers Programme is directed and overseen by our Head of Care and Service Development. A Nurse Team Leader manages a group of Family Carers, delivering flexible care packages - agreed with families to meet their specific needs. Wherever possible, a family will receive care from the same Family Carers - enabling them to build up relationships of trust.

Access to the service will be through our established referral system - with children meeting the ACT criteria for life-limiting/life-threatening conditions.

Once accepted, the care team will access the family's needs and current support network and, working with other agencies, ensure that the Family Carers' support is in the context of a package of services that will best support their individual family situation.

Other Current Care Service Provision

Respite & Therapeutic Play

This scheme began in September 2006, since then we have worked with over 120 families in Enfield and Barnet - in partnership with the PCTs and Barnet and Chase Farm Hospital Trust.

Mainly working in the homes of the families, these sessions have created positive therapeutic and recreational play experiences for both the life-limited children and their siblings. Parents/carers benefit by having some measure of respite - a break in the 24/7 care for their child which may often last many years. The Enfield Respite Nursery Nurse place is funded through Noah's Ark but she is employed and managed by Enfield NHS Trust, and co-located in the local NHS Trust. It is our aim to bring her into the full employ of Noah's Ark Children's Hospice, as we did with the Play Specialist, at the beginning of 2011.

Family Support Volunteer Programme

This Family Support Volunteer Service provides tailored made support to meet the needs of individual families, as defined by the families themselves. The programme has a full-time manager who has developed the governance and operational management of the scheme. Volunteers are involved in, e.g. being an extra pair of hands at busy times, play activities and trips out for siblings, help with sibling's school work, help families go out together, collect and do family's ironing when needed, transport and support on medical visits, weekly visits to do shopping, run errands, etc.

Sibling Support Programme

To expand this scheme and develop a bespoke programme for brothers and sisters of life-limited children, since February 2010 we have had a Family Support and Siblings Worker. Feedback from sessions to date has been very encouraging - from both the children participating and their parents.

Social Work Support - Linkworker

Since July 2008, we have been able to offer the pro-bono services of a part-time, senior Social Worker. She works closely with a small group of families and offers a consultation and sign-posting service to others. This work is helping to scope the social work function within our organisation and develop appropriate networks for the future. We have recently changed the title of this post to that of Linkworker.

Family Days

Families receive invitations to outings and other special events held several times a year. These days provide important opportunities for families to go out together, have fun and meet others facing similar situations to their own. These events are free of charge.

Parents Groups

Following a consultation with parents in January 2011, the Parents Groups were launched and are held alternate months. Parents told us how highly they value the ability to spend time with / get to know other parents of life-limited children. It gives them a true sense of belonging and relaxation - among people who truly understand, which brings some relief to their lives which are often full of challenges.

Our parents wanted sessions which were part structured and part unstructured - where speakers would be welcome, as would a specific discussion on a topic of general interest. They were also keen to have as much chance as possible to meet and talk with other parents.

Consultation with Parents, Children and Young People

In order to ensure we are 'Getting it Right' we encourage anyone who comes into contact with Noah's Ark Services be they the child, young person, family, staff, volunteers, sponsors, partners from other agencies or visitors, to give comments about their experiences of our service. All comments, compliments and complaints will be logged and audited. They will help to shape the further development of Noah's Ark Children's Hospice.

There are various ways in which this can be done:-

- **Telephone or email:**

Service users can telephone or email comments:

Telephone:- 020 8449 8877

Email:- info@noahsarkhospice.org.uk

- **Rolling Experience Surveys**

We aim to conduct a "snap-shot" annual survey to ensure we are getting it right, and to compliment the other feedback mechanisms below.

- **Evaluation Forms:**

We use evaluation forms to collect feedback from packages of care at reviews, from family days and events and during volunteer reviews.

- **Focus Forums**

Focus forums will be run bi-annually for anyone who would like to come along to an informal group meeting and chat about our service, what's

good, what's not and how we can move forward. Dates will be advertised in our newsletter as well as an invitation being sent out to all our families. Everyone is welcome.

- **Meetings**

For those families who find it difficult to attend the forums or are uncomfortable in groups we will also periodically visit their home with the family's permission at their convenience to evaluate their experience of our service.

- **Feedback Form**

Alternatively, service users can add their comments to the comment slip in the Family Information booklet and return it to the address below:

Noah's Ark Children's Hospice

3 Beauchamp Court

10 Victors Way

Barnet,

EN5 5TZ

Tel:- 020 8449 8877

Email:- info@noahsarkhospice.org.uk or

Web:- www.noahsarkhospice.org.uk

Arrangements For Dealing With Complaints

Complaints to Noah's Ark Children's Hospice, whether verbal or written, are dealt with in a swift and effective manner which ensures complete fairness for both staff and complainant.

Our comprehensive Complaints Policy & Procedure aims to be responsive and flexible to address the issues identified by the complainant.

Complaints will be used to improve services, reduce incidents and to improve overall quality.

Receiving the complaint

- Complaints may be initiated with front line staff who will deal with the complaint in a sensitive manner
- Complaints may be made verbally or in writing to any member of staff
- Front line staff will pass verbal complaints in writing to the line manager
- All complaints verbal and written will be registered within the organization by completion of the hospice's complaints form
- All complaints should be registered within the organisation:

Details to be recorded are:

- Nature of complaint
- Result of the investigation
- Action taken
- Resolution of complaint
- Whether the complaint was upheld

Acknowledgement of complaint

- All complaints will receive a written acknowledgement of their complaint within seven working days. This letter will detail the complaints process.

Investigation of complaint

- A nominated person will investigate the complaint. This individual will have received training in managing and investigating complaints.
- The complaint investigation will be handled in a manner which acknowledges that being subject to a complaint can be a stressful and anxious time for staff.
- All findings will be fully documented. Any communication with the complainant will be documented.
- A full response will be sent to the complainant within 20 working days of receipt of the complaint.
- If it is not possible to send a full response within the 20 day timescale, a letter explaining the delay will be sent to the complainant.

Resolution of the complaint

- Once the investigation has been completed, a letter will be sent to the complainant within 5 working days outlining the findings and the proposed action to be taken.
- The findings of the complaint together with the action to be taken will be completed on the complaint register.
- Action plans following the complaint will be completed together with a timescale for action and review; this will involve the staff concerned whenever possible.
- The anonymised complaint will be reported to the management committee to ensure lessons are learned and practice is improved/changed, as indicated by the results of investigation.

Referral to the Care Quality Commission (CQC)

- If the complainant is unhappy with the outcome of the complaint, in the first instance the complaint will be passed to the Noah's Ark Children's Hospice Board of Trustees for Independent Review
- If the complainant is still unhappy with the outcome of the complaint, they can complain to the Care Quality Commission (CQC) at:-

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

Privacy and Dignity of Children and Young People

Noah's Ark Children's Hospice is committed to preserving the privacy and dignity of all the children & young people who use our service. We do this through:-

- Recognising the diversity values and human rights of the children, young people and families who use our service
- Upholding the privacy, dignity and independence of the children, young people and families who use our service
- Putting the child, young person and their family at the centre of their care, treatment and support by involving them in the decision making
- Providing information that supports children, young people and families who use our service, to make informed decisions about their care, treatment and support
- Supporting the child, young person and their family in understanding the care, treatment and support we provide

- Enabling the child, young person and their family to be as independent as possible
- Encouraging and enabling the children, young people and families who use our service to be involved in how the service is run
- Encouraging and enabling the child, young person and their family to be an active part of their community in appropriate settings
- Reflecting needs, preferences and diversity
- Ensuring that plans of care, treatment and support are in place, and implemented. They will be flexible, regularly reviewed and changed where necessary, being kept up to date in recognition of the changing needs of the child, young person and their family who use our service.

Children, Young People and Families who use our services will:-

- Be listened to
- Given the information they need to make choices
- Be active in the planning, assessment and carrying out of their care, treatment and support
- Have their decisions respected by all staff
- Have their needs, welfare and safety always at the heart of our thinking.

Review of Statement of Purpose

The Registered Person will:-

- a) Keep under review annually, and where appropriate revise the Statement of Purpose
- b) Notify the Care Quality Commission (CQC) of any material revision within 28 days
- c) Make a copy of the Statement of Purpose available on request for inspection at the agency premises for every service user and any person acting on behalf of the service user