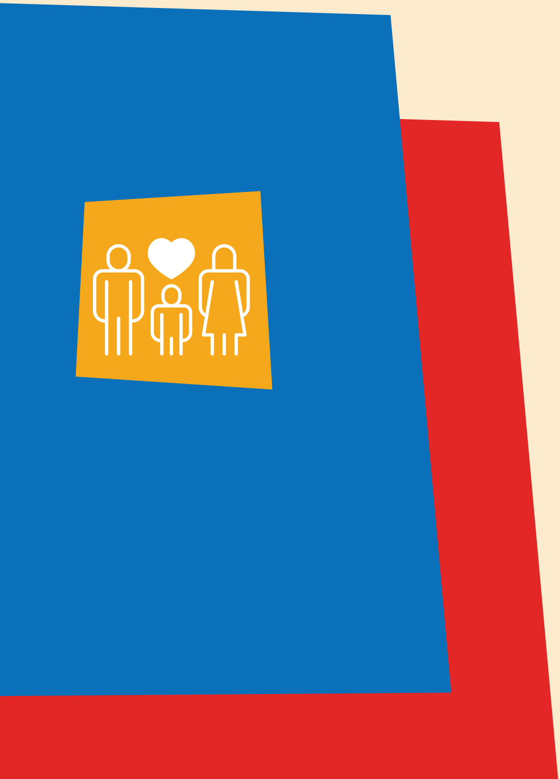
JACK AND JILL
CHILDREN'S FOUNDATION™

MODEL OF CARE



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HISTORY AND EVOLUTION

Jack Irwin -1996

Jack and Jill Children's Foundation was set up in 1997 by Jonathan Irwin and his wife Mary Ann O'Brien (founder of Lily O'Brien's chocolates), in memory of their son Jack who suffered a brain trauma shortly after birth that left him developmentally delayed and shattered the dreams and hopes of his parents. They were traumatised. They wanted Jack to be at home but there was no support for Jack outside of the hospital at the time. Despite this, the family brought Jack home and formulated a homecare plan with the help of five local nurses/carers from their locality.

Baby Jack lived at home for 22 months and died on 13th December 1997, surrounded by the people he loved. This experience demonstrated to his family and friends, the importance of having a child with complex needs being cared for at home and how short lives can have a long-lasting impact. His parents vowed that no other family would have to walk this difficult care journey alone. Jack and Jill Children's Foundation became the pathway from hospital to homecare through Jack's legacy. Jack's homecare plan was the blueprint for the Foundation's unique model of child and family-centred care, that gives the parent/carer support and a break from the intensive home care regime required for a child like Jack.

Jack and Jill Children's Foundation has evolved and grown since then from a team of two people, Founder, Jonathan Irwin and Registered Children's Nurse, MaryJoe Guilfoyle, to a nursing team of fifteen highly skilled and experienced children's nurses and a team of fundraising and administration staff led by the CEO and overseen by the Board of Trustees.

JACK AND JILL CHILDREN'S FOUNDATION IN-HOME RESPITE SERVICE

Jack and Jill Children's Foundation is a nationwide charity providing in-home nursing care and respite support for children up to the age of six with severe to profound neurodevelopmental delay. This may include brain injury, genetic diagnosis, cerebral palsy, and undiagnosed conditions. Another key part of the service is end-of-life care for children up to the age of six, irrespective of diagnosis. The initial blueprint and ethos of family-centred care continue to be the foundation for the service provision. Families refer to the practical service as *'The Gift of Time'* - time to do the ordinary things that others take for granted.

Jack and Jill Children's Foundation use a criteria for referral based on the ACT categories:

Category 1: *"Life-threatening conditions which curative treatment may be feasible but can fail eg. cancer, irreversible organ failures of heart, liver, kidney"*

Jack and Jill Children's Foundation offer a service to children at end-of-life in this category within the age criteria.

Category 2: *"conditions when premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life. Eg. cystic fibrosis, muscular dystrophy"*

Generally, Jack and Jill Children's Foundation do not provide a service to children/families within this category.

Category 3: *"progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. eg. Batten disease, mucopolysaccharidoses"*

Jack and Jill Children's Foundation commonly offer a service to children within this category.

Category 4: *"Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. eg. severe cerebral palsy, multiple disabilities following a brain insult or complex health care needs and a high risk of an unpredictable life-threatening event or episode."*

Jack and Jill Children's Foundation provide a service to children within this category who have a severe neurodevelopmental delay resulting in significant learning difficulties.

Additional criteria: *Jack and Jill Children's Foundation offer a service to children with Down syndrome who have two additional nursing needs, i.e. enteral feeding, oxygen therapy, non-invasive ventilation, seizure management, colostomy care and/or bowel washouts and children with Down syndrome who come under category 4.*

REFERRAL PATHWAY

The following graphic explains the referral process to Jack and Jill Children's Foundation:

1

Eligibility / Criteria

Respite support is offered to children up to the age of 6 who have severe neurodevelopmental delay. Another key part of our service is end of life care for all children up to the age of 6, irrespective of diagnosis.

*A family enquiry form, can be completed by a parent/guardian regarding eligibility.

2

Referral Form

A referral form must be completed. It is available to download or fill in online at www.jackandjill.ie/referral-form.

To request a copy by post, simply email familysupport@jackandjill.ie. Please include a medical report/ discharge summary when available.

3

Contact

When a referral is received the Liaison Nurse Manager (LNM) in the local area will contact the family as soon as possible.

4

Assessment

The LNM will arrange a home visit and assess the child and family's needs.

They will explain the service, offer advice and practical support.

Our service is flexible, and family centred.

5

On-going Respite Service and Support

We provide an average of 20-40 in home nursing/respite hours per month (maximum 80 hours).

The LNM's role includes ongoing support, co-ordinating respite, home visits and advocacy. The LNM will liaise with other health professionals as required.

End of Life Care for children up to the age of 6 irrespective of diagnosis

Timely provision of in-home nursing care of 80 hours per month can be provided at end of life. The LNM's will; assist in organising and support nurses; listen and help co-ordinate families wishes; regularly review the child and family's needs; work together with other health care professional and service providers.

ROLE OF THE LIAISON NURSE MANAGER

LIAISON NURSE MANAGER

Empowering Families

Family-Centred Care

Advocate

Emotional Support

Facilitating In-Home Respite

End-of-Life Care & Bereavement Support

Guidance & Advice

Member of the Multidisciplinary Team (MDT)

Hands-on Care

The role of the Liaison Nurse Manager is to offer support and advocate for the child and their family while facilitating an in-home respite service if the family choose to avail of it.

Once a new referral has been received and the Liaison Nurse Manager meets the family, a case assessment is completed to determine what type and amount of support the family need. The case assessment includes the medical needs of the child, the practical needs of the child & family, and the psychosocial needs of the family unit. The needs of the child will dictate whether the family needs a Carer or a Nurse to help support them. These needs may include but are not limited to:

- medication administration
- seizure management
- enteral feeding regimen
- non-invasive or invasive ventilation

Along with the family, a decision as to whether night-time hours, daytime hours or a combination of both will be of most benefit to the family. The number of hours allocated depends on a variety of factors such as:

- the complexity of the care required by the child
- the support the family has from family and/or friends
- the support the family has from other health care agencies
- the personal circumstances of the individuals within the family unit as well as of the entire family

After this initial visit, the Liaison Nurse Manager may assist the family in finding a suitable carer or nurse (or more than one, depending on the hours required) who can fulfil the hours needed by the family. After an introduction to the family, the carer/nurse and the family work together to make a schedule for the Jack and Jill hours. The average number of hours per month is 20-40 but can be up to a maximum of 80 hours per month. When the child turns 5 years old, hours are reduced to 20 per month as a transition for the period of one year and then service stops when the child turns 6 years old. Respite hours are reviewed regularly and adjusted as needed according to the child and family's needs. The family receives a monthly donation to pay the carers/nurses directly.

There are nurses and carers in every community across Ireland, who provide the in-home respite service for the families. The nurses and carers who provide respite hours come from a variety of backgrounds, personally and professionally, but all have the same focus of providing high quality, child-centred care to the family. They often become an important resource for the child and family and can remain with them for many years. Their professionalism and flexibility allow the service to continue along with the support of the Liaison Nurse Manager.

The Liaison Nurse Manager visits, offers support, advocates, and helps coordinate care as needed. They are also available to advise and guide the Nurses and Carers providing the respite hours.

Jack and Jill Children's Foundation recognise that caring for a child at home is a 24-hour-a-day commitment, and that children's needs often become more acute outside of limited-service hours (Nicholl, 2012). For children nearing end-of-life, the Liaison Nurse Manager can be contactable out-of-hours and over the weekend, when appropriate.

In 2017, a **"Service Evaluation of the Jack and Jill Children's Foundation: Full Report"** was published. Much valuable feedback was gathered about the service and support that the Jack and Jill Foundation provide to families. Families highlighted the support of the Liaison Nurse Manager during focus groups which follow:

> **"The Jack and Jill nurses are passionate about their job. They carry us all emotionally and all the kids, our families, and us."** (Coventry Report, P5, p. 26)

> **"Sometimes doctors and nurses would give different opinions, and then the Jack and Jill nurse would come and she was a sounding board, someone you trusted, someone that you knew was on your side."** (Coventry Report, P11, p. 28)

> **"The Jack and Jill nurse used to meet us in hospital; the nurse was fantastic for advice. They gave us time to be a family, their knowledge from other families, other kids, other facilities that were available to you that you would not have thought of – and I thought that was worth its weight in gold."** (Coventry Report, DFG, p. 28)

ONGOING SUPPORT AND END OF SERVICE

There are 4 possible trajectories for children who meet the criteria for support from Jack and Jill Children's Foundation:

1. Some children achieve positive developmental growth. When this occurs, a plan for withdrawal of service is put in place as they no longer meet our criteria.
2. Many children will 'graduate' from the service when they reach their sixth birthday.
3. For others, they may transition to end-of-life within their first six years due to a deterioration in their underlying condition or a sudden event such as a life-threatening seizure or recurrent infections.
4. Sometimes the family meets the Liaison Nurse Manager for the first time when their child is close to the end of their life.

The funding offered to families for in-home respite ceases when the child turns 6 years old. However, the Liaison Nurse Manager is available as an ongoing support.

THE RAINBOW OF CARE

This model of care is underpinned by the paradigm of the Rainbow of Care*, which in turn is supported by six pillars (6 C's) representing the core values. Jack and Jill Children's Foundation is **committed** to providing **compassionate** and **competent** nursing **care** for children with complex needs and their families, using effective **communication** and **courage** to speak up for them and seek solutions to problems that may arise.

The Rainbow of Care describes the core aspects of what Jack and Jill Children's Foundation provide to children and their families:

Respite: Respite care at home is provided to families with children up to the age of six, with complex and/or palliative care needs. Direct funding is given to families to enable them to finance home respite care. Respite hours are facilitated by local nurses and/or carers.

Advocacy: The Liaison Nurse Manager listens and discusses with parents and families, what their needs and wishes are for their child. The Liaison Nurse Manager can advocate for entitlements, provide advice and information on how to access all the services the child may require. Empowering parents to manage their child's care at home and supporting them in advocating for themselves is also part of the Liaison Nurse Manager's role.

Interdisciplinary work: The Liaison Nurse Manager engages with a range of health and social care professionals to ensure that children and their families receive the best care and quality of life.

Nursing care: In-home respite care is coordinated by the Liaison Nurse Manager in their local area. Individualized nursing care and advice on how best to care for the child at home is fundamental.

Bereavement: The Liaison Nurse Manager provides bereavement support before and after the child's death, and can inform families of additional resources that are available nationally. This is an important aspect of care for families whose children are at end-of-life and after their death. Continuing, ongoing support is offered after death, and is family-led based on their wishes.

Family-Centred Care: Keeping the family at the centre of all information and decision-making, is the goal of Jack and Jill Children's Foundation.

Working Together: The Liaison Nurse Manager works with families as a team through the trajectory of the child's illness and walks alongside the parents and helps them navigate through the process and procedures. As part of the multidisciplinary team, the Liaison Nurse Manager attends meetings and shares relevant information with the rest of the healthcare team both in hospital and at home in the child's community.

*The Rainbow of Care was adapted by Doyle & Clay (cited in Coventry Report, 2017).

GOVERNANCE

Clinical Governance

Liaison Nurse Managers and nurses facilitating respite hours in the home work within the Nursing and Midwifery Board of Ireland's Scope of Practice and Code of Conduct and Ethics (Nursing and Midwifery Board of Ireland, 2015 & 2021). Membership of a union is obligatory for all nurses.

Corporate Governance

In Ireland, The Charities Regulator is the statutory body responsible for monitoring charity compliance with the Charities Act 2009.

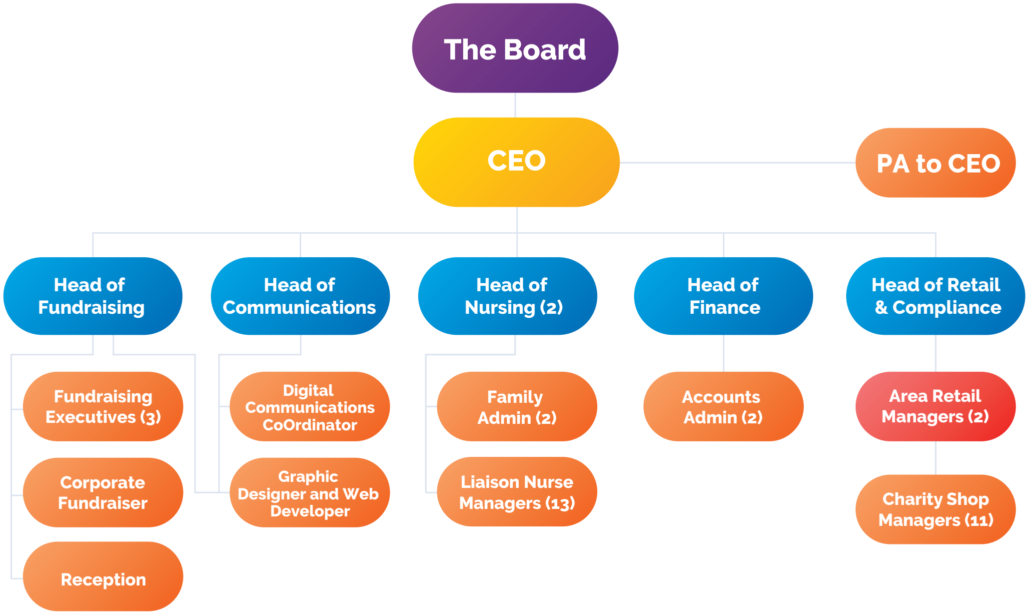
Corporate governance is about the methods and processes Jack and Jill Children’s Foundation has put in place to provide for the proper guidance and oversight of the organisation. Good corporate governance is at the heart of the organisation, constantly reviewed, evaluated and improved.

Each charity is required to declare their compliance with the Charities Regulator Governance Code of which there are six principles: (www.charitiesregulator.ie)

- Advancing charitable purpose
- Behaving with integrity
- Leading people
- Exercising control
- Working effectively
- Being accountable and transparent

Jack and Jill Children’s Foundation has reviewed and accepted all the above principles at Board and Management level. It is the duty and responsibility of the Board and the Senior Management Team to ensure that the operation and adoption of the above principles is undertaken across the organisation.

JACK AND JILL CHILDREN’S FOUNDATION TEAM



- The Board
  - CEO
    - PA to CEO
    - Head of Fundraising
      - Fundraising Executives (3)
      - Corporate Fundraiser
      - Reception
    - Head of Communications
      - Digital Communications CoOrdinator
      - Graphic Designer and Web Developer
    - Head of Nursing (2)
      - Family Admin (2)
      - Liaison Nurse Managers (13)
    - Head of Finance
      - Accounts Admin (2)
    - Head of Retail & Compliance
      - Area Retail Managers (2)
        - Charity Shop Managers (11)

Each member of the Jack and Jill Foundation has an important role to play to be able to offer the service that is provided to families. The Board of Trustees work to ensure all decisions are made with the best intentions for the families to whom the services are provided. The Administration Team make the day-to-day workings of the foundation run in a seamless manner. The Communications, Fundraising, and Retail Teams at the Jack and Jill Foundation are instrumental in the functioning of the service. Fundraising and advertising are paramount for the continuing success of Jack and Jill Children’s Foundation.

"We aim to maintain family fundamentals, we strive to listen, to learn and to improve our service, while also aspiring to make the lives of the children and families we support a little bit easier".

Founder - Jonathan Irwin

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APPENDIX

Examples of known neurological conditions associated with developmental delay.

- Retts syndrome
- Polymicrogyria
- Canavan's disease
- Alperts disease
- Angleman's syndrome
- Ohtahara syndrome
- Joubert syndrome
- Aicardi syndrome
- Zellweger syndrome

Global developmental delay (GDD)

- Undiagnosed cause of GDD
- Hypoxic ischaemic encephalopathy
- Peri-ventricular leukomalacia
- Epileptic encephalopathy
- GDD due to prematurity

Other

- Children with Down syndrome with 2 additional medical/nursing issues
- Acquired brain injury

End of Life

Jack and Jill Children's Foundation's service is offered irrespective of diagnosis within the age limit of the service provision.

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