

A Quality Improvement project to address the holistic wellbeing priorities for families with childhood brain tumours from the point of diagnosis

Angela Logun, Daniella Logun Foundation & Nikki Davey, QICLearn

## Problem Statement

**OUR INSPIRATION**

Using Dannie's Story To Share Lived Experience

Learnings Around:  
Early Signs & Symptoms | Diagnosis | Care planning | Bereavement

What is the problem we are trying to solve?

When a child is diagnosed with a brain tumour, medical care takes over. Wellbeing of the child and family is completely neglected. The costs of emotional trauma play out for life.

## Diagnostics

If everyone cares, then why does this inadvertent wellbeing neglect still occur?

N=20 families with childhood brain tumours that were offered 'holistic' wellbeing support at the point of diagnosis.

Shortage of childhood brain tumour specific resources  
High emotional disconnect between families & NHS  
Poor awareness of childhood brain tumours

Materials: Informational resources, Support resources, Practical resources  
Processes: Referral process, Assessment process, Care planning process, Delivery of care process, End of life process  
People: Families, NHS staff, Support groups, Volunteers, Researchers

Neglect for 'holistic wellbeing' for families with Childhood Brain Tumours

The child's medical needs become central & the family's wellbeing is inadvertently neglected.

Annual summary: End of life care for children and young people

Why focus on the diagnosis phase?

Multiple GP visits = misdiagnosis/late diagnosis  
Referral to specialist centre  
Multiple symptoms & investigations = misdiagnosis/late diagnosis

Diagnosis of a brain tumour in a child

Early Stages: Assembling MDT & Specialist Lead  
Care Planning: Advanced Care Planning, records & Wishes & Ambitions etc  
Delivery of Care: Delivering planned treatments  
End of Life: Help family prepare; update treatments etc.  
Bereavement care: Death, Other care

Medical care takes over  
Earliest life changing impact  
Desire to understand crisis overwhelms wellbeing  
Earliest search for meaning of life  
Why Me?

## Aim & Measurement Definition

What are we measuring?

AIM

By the end of August 2021, the family of every child with a brain tumour living in Hillingdon will be offered holistic wellbeing support from the point of their child's diagnosis.

3 Dimensional Wellbeing Support  
Emotional: feelings & thoughts  
Spiritual: faith & meaning of life  
Physical: tangible care needs

**Chosen measure** Wellbeing support offered to the child with a brain tumour and their family at the point of diagnosis

**Family** The key relationships around the child – established via the **Holistic Needs Assessment** form and identified by the child's parents/main carers/guardians

**Point of Diagnosis** The time at which the 'lead medical specialist' tells the family that their child has a brain tumour until the 'care planning' phase

## Change ideas

- Dannie's Gift Box: provide a wellbeing resource kit to families with childhood brain tumours at the point of diagnosis.
- Holistic Needs Assessment (HNA): Implement a form to capture the holistic needs of the family from the point of diagnosis
- Family Champions: Assign to each family to provide ongoing 1:1 family support and advocacy
- Emotional, Spiritual & Practical support: provide practical help as requested by family
- Redo Fishbone diagram: test PDSAs and share it with various stakeholders etc.

## PDSA Cycles

Personal wellbeing resources in a gift wrapped box to help the family cope beyond the diagnosis phase

An anchor through often fast and overwhelming changes

Dannie's Gift Box – PDSA 1.0

- Reconsider purpose & contents. Focus on items to support family wellbeing. Redo box and test again.
- Need to rethink purpose of box contents. Items should focus more on wellbeing support.
- Discuss the 1<sup>st</sup> version of Dannie's Gift Box with internal stakeholders & request feedback.
- Shared box with the board of trustees from the Daniella Logun Foundation.

Dannie's Gift Box – PDSA 1.1

- Re-consider contents & quality. Redo box & test again.
- Comments around quality of the box content. Needs to contain better quality items.
- Share 2<sup>nd</sup> version of Dannie's Gift Box with internal stakeholders & request feedback.
- Shared box with a senior paediatric specialist at Great Ormond Street Hospital.

Dannie's Gift Box – PDSA 1.2

- Explore timing & impact with parents.
- Explore the take-home-ability & consider virtual box option.
- Redo box and test again.
- Share the 3<sup>rd</sup> version of Dannie's Gift Box with external stakeholders & request feedback.
- Shared box with a few parents of children diagnosed with brain tumours.
- Multiple questions around impact & take-home-ability of the box.

Dannie's Gift Box – PDSA 1.3

- Mitigate for user risks.
- Explore box size, handling, delivery, recipient options. Redo box and test again.
- Share the 4<sup>th</sup> version of Dannie's Gift Box with an external stakeholder & request feedback.
- Shared box with the lead paediatric oncologist at Hillingdon Hospital.
- Needs to be self-supporting.
- Questions around logistics, size, delivery, recipient, timing & risk factors.

Dannie's Gift Box – PDSA 1.4

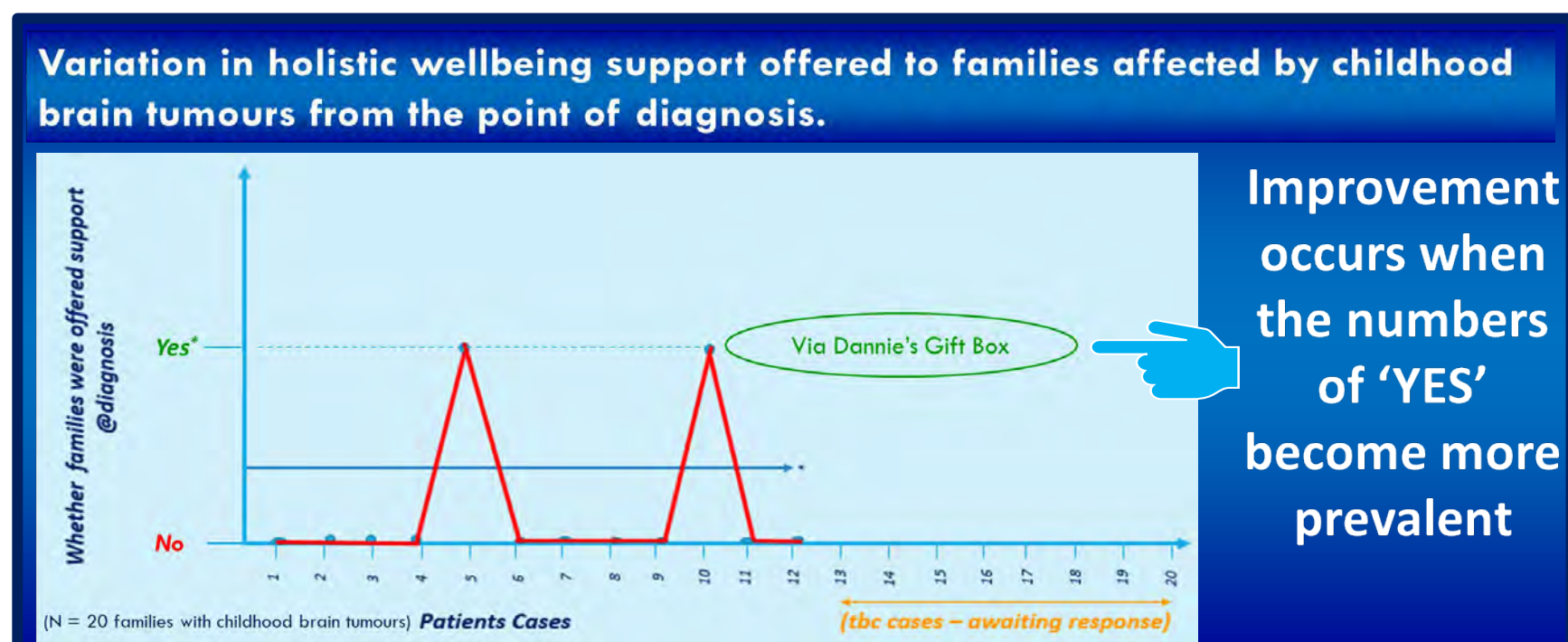
- Refine action & information gathering process for each family.
- Reduce repetition & integrate with other home.
- Redo box & test again.
- Share the 5<sup>th</sup> version of Dannie's Gift Box with an external stakeholder & request feedback.
- Shared box with the lead paediatric psychologist at Great Ormond Street Hospital.
- Questions around box administration & information gathering process for each potential family.

PDSA cycles

Delivered within 0 – 3 months of the child's diagnosis (flexible)

Hand – delivered to the primary adult care giver of the child

## Run chart



## Reflections & learning

**MODEL FOR IMPROVEMENT**

AIM: What do I want to achieve?  
Offering holistic wellbeing support to families with childhood brain tumours living in London Borough of Hillingdon from the point of diagnosis.

MEASURES: How will I know if I've achieved it?  
If holistic wellbeing support is offered to future families with childhood brain tumours, living in London Borough of Hillingdon from the point of diagnosis.

CHANGE IDEAS: What ideas have I got to help me achieve my aim?  
Design Dannie's Gift Box to be handed out to families with childhood brain tumours living in London Borough of Hillingdon from the point of diagnosis.

How will I test my ideas?  
Measure how many families with childhood brain tumours living within London Borough of Hillingdon are gifted with Dannie's Gift Box within 3 months of their child's diagnosis.

ACT, PLAN, DO, STUDY