THE IMPORTANCE OF RESPITE CARE: A PARENT’S PERSPECTIVE

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Context

Family: Rachel & Bob, Kirk (15), Mae (12), Frank (8)
We live, work, & go to school in London

Frank

- Has Late Infantile Batten Disease
  - Symptoms 2011 (age 3), diagnosed 2012 (age 4), fully dependent (age 5)
  - Life expectancy 5-12 years

Meeting Milestones

Seizures & Regression

Dependent on Caregivers

Frank

- Living with Late Infantile Batten Disease
  - Devastating, progressive, Neurodegenerative
    - Life limiting, frequent seizures (intractable & multiple types), blindness, cognitive regression (dementia), spinal curvature
    - Loss of: motor skills, speech, safe swallow
    - Extensive medication, gastrostomy fed, incontinent, requires suction, immobile requiring positioning, head support, custom wheelchair
    - Extensive home and family lifestyle adaptions

Respite

Temporary relief/time away from caring to look after own needs and those of other family members.

What do Short Breaks mean to our family?

A break from 24 hour caring role that benefits the whole family

- Frank gets:
  - to enjoy 1-2-1 interaction (parent carers have multiple responsibilities)
  - variety of fun tailored activities and engagement from a range of caregivers
  - independence
  - time away from his parents and siblings (as most 8 year olds would have)
  - activities requiring two people (swing, bath time etc)

What do Short Breaks mean to our family?

- Frank gets (continued):
  - parents who can better meet his needs
  - a less stressed household environment
  - positive relationship with siblings
  - time that isn't always rushed
  - comfort of a regular routine
  - medication, feed and therapy he needs

What do Short Breaks mean to our family?

- Siblings get:
  - to be free from caring burden
  - to maintain a healthy relationship with Frank
  - 1-2-1 time with parents
  - a parent to help with homework, to attend school events etc

What do Short Breaks mean to our family?

- Siblings get (continued):
  - time when parents can be attentive to them
  - time to discuss their feelings
  - to enjoy normal childhood
  - a less stressed family environment
  - a functioning household
  - a more stable family life

What do Short Breaks mean to our family?

- Parents get:
  - time to spend on regular parenting activities
  - time to plan for Frank’s needs (deal with forms, medical appointments, equipment/medical supplies etc)
  - the chance to have difficult conversations without Frank being present
  - to keep their jobs, homes & relationships
  - time to plan family activities

What do Short Breaks mean to our family?

- Parents get (continued):
  - time to maintain their mental health (think, unwind, catch up on sleep, take exercise, meet a friend for coffee)
  - time for their other children (including finding support for them)
  - time to prepare a meal and sit together to eat
  - deal with general household activities (groceries, laundry, bills, cleaning, mowing the lawn)
  - the strength to carry on and time to go to the bathroom!

Respite

Above all it enables us to give Frank the best quality of life possible as we deal with his increasing needs from this devastating illness.

Respite helps our family function and have some quality time together with Frank during his short life.

Five other parents said….

“Rest, recuperating, having the strength to go on, giving our child dignity and a chance to explore her wider community, given her social opportunities, "she deserves time away from us, as she is non verbal I'm sure if she could speak she'd say as a 10 year old 'see ya, I need my own space’!”

Five other parents said….

“Time to recharge and get decent rest which is vital to staying positive. We stay at the hospice with James and it gives me time to be a mother and not a nurse. I can play and enjoy my time with James and the girls without worrying about his next meds or feed. I can go out during the day for some quality time with the girls knowing that James is having fun and great care. I meet other families during respite who totally understand the pressures we are under. We become ‘normal’!

Five other parents said….

Some peace ..a little freedom ..time to reconnect with the rest of my family and when she comes back we are all a bit happier and more able to be patient ..she rules our house again !”

Five other parents said….

“It's so important for siblings to have their mum and dad to themselves for a little while. I see so many siblings who are so strong and so brave, they are simply amazing. They are part carers a lot of the time. They need to be kids at times, to just hang out with their parents. (I say this also thinking of how I can already see how much Abi takes on being a younger sibling)”

Five other parents said….

“Respite means the world to our family, Krista and I get to relax, sleep, recharge, feel like normal human beings among people who understand. Molly as the older sibling gets to play to her hearts content with other siblings or Mum and Dad who have time for her when staying at Martin House. The staff are like friends, social workers, therapists all rolled into one and we tell them things we would not anyone else and feel better for it. Zac is looked after and loved and snuggled by other people not just his close family!”