

“...our home is (his) sanctuary, you know that nothing bad can happen to him here and everybody is for his good” M3

“My child is 100% better in her own home” M2

# Home is where the heart is. Respite in children’s palliative care

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# The impact of caring...



- Majority of care provided by parents at home with the mother most often being the primary carer
- Care impacts on all aspects of family life, home and relationships
- Disrupts family routines and results in chronic fatigue and sleep disruption
- Impacts on finances and employment opportunities
- Frequency, location and type of respite vary according to the child's age, diagnosis, geographical location and family capacity to meet needs

“We were shown a couple of times and we were supervised and that was it, you had to do it...he'll get very panicky and he'll resist...if we didn't manage he'd die ...it's an awful responsibility”D3



# Respite care is an essential component of children's palliative care..??

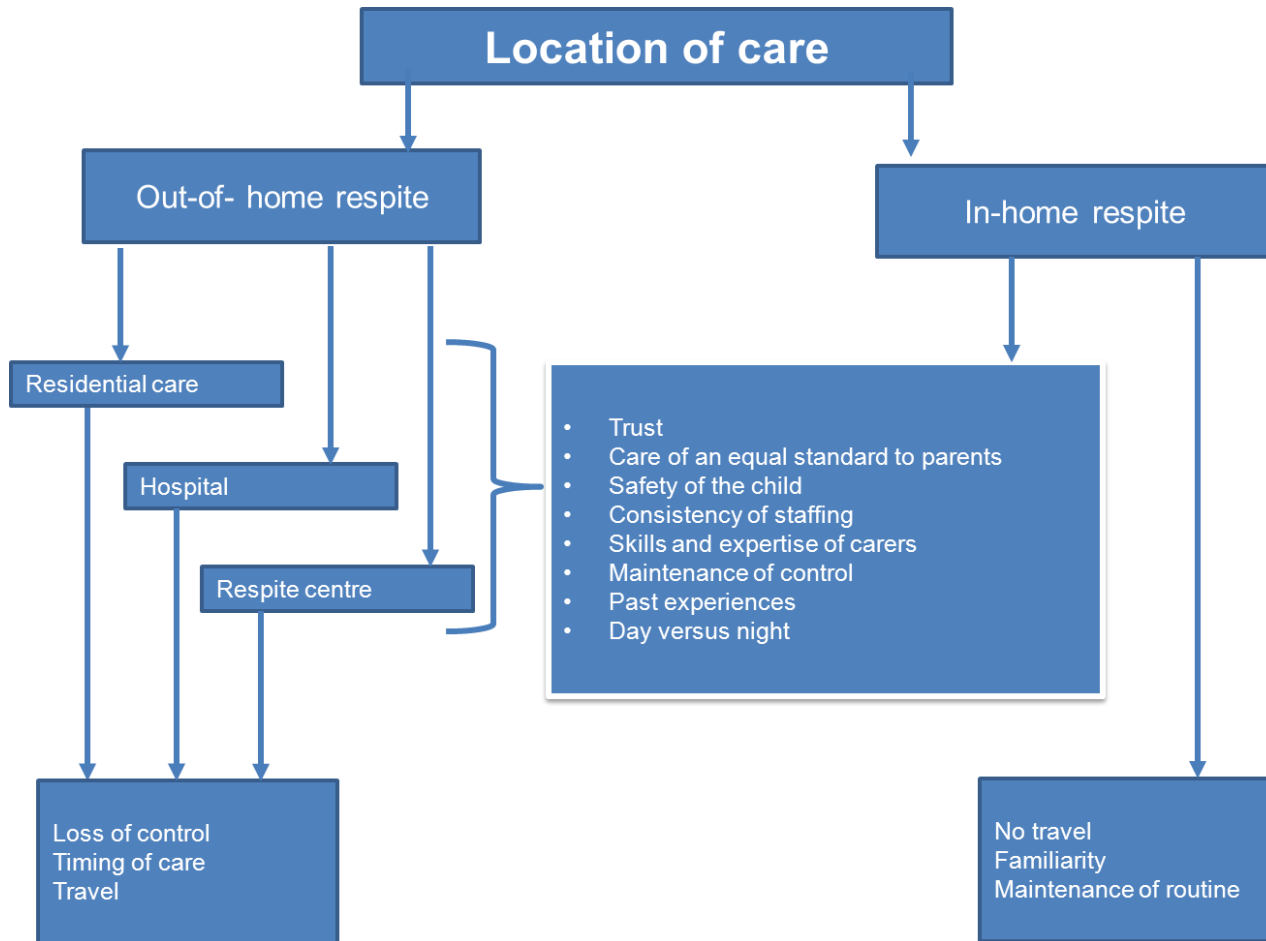


- Not all children with life-limiting conditions need or use respite:

“I don’t need a break from my children” M4

“She wouldn’t want to be seen as different...you see sick kids everywhere” M5

- Diagnosis matters:
- Different services are available dependent on diagnosis
- Respite need and utilisation is higher in children in ACT category 4 than in those with other conditions





## Living with uncertainty...

- “...the emotion and trauma that’s been built around watching those apnoeas and thinking is he going to take that next breath and you know thinking in the background well we have to make funeral arrangements...then suddenly...he’s thriving” M8

# The role of extended family...

“everyone who comes in to her we have to pay... there is nobody who really comes in here like just to sit with (her)... give us a dig out there is no one... people are busy”  
M1

“...they don't actually offer to be honest...they're just I suppose afraid” M8



- Initially good but reduced over time
- More likely to help with well siblings
- ‘Frightened’ of dealing with child's care needs

# Consistency of staffing



# Maintenance of control and routine & protection from harm



“...feeding times were not important...we wanted respite to be a continuation of home...we still have a huge problem handing her over because we know that routine is so important... if you don't give everything on time then she will suffer” M1

Risk of infection = *'safe guarding precarious survival'*<sup>1</sup>

1. Rempel g., Harrison M. (2007) Safeguarding precarious survival: Parenting children who have life-threatening heart disease. *Qualitative Research* 17(6):824-837



# Past experience...



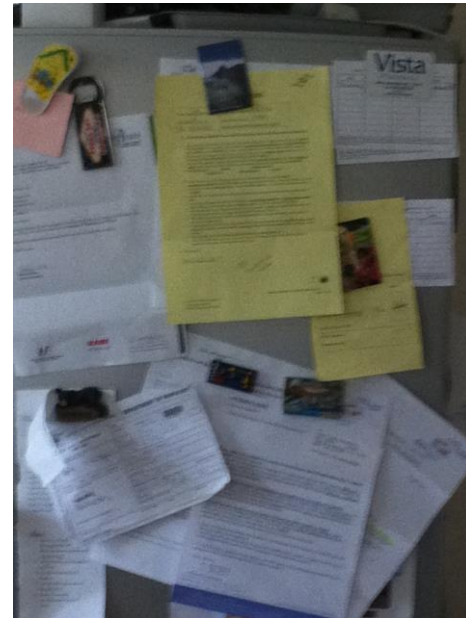
“she is never in hospital that’s one thing as a family we say would destroy us when she goes to hospital because we have to stay there... is impossible to give the care she needs in a busy ward where children are going to theatre and there’s infections and it is just the worst scenario for us is if (she) ends up in hospital”...“I would have been in the children’s hospital for months on end and left (my son) with my mother and different people and that is very tough... you want to be in both places but you can’t” M1

“when he’s in hospital it’s a killer... you have to be with your child all the time, you won’t get the care because they’re so busy... (mother) is so used to looking after him now, she'd be nearly left to her own devices...they know we know better than they do a lot of the time” D3

“because she doesn’t get looked after properly...she would be left in the bed all day basically ...” M2

# Challenges of home respite...

- Getting carers
- Home environment
- Impact on family life
- Social isolation
- Travel & appointments
- Equipment





*“this room is ideal for carer’s because they had a huge problem in our home with the busy, busy dinner, homework, football boots and they were trying to get (her) drugs ready and it was very difficult for them...it’s not (her) that’s the problem it is all that comes with her the fact that she needs staff with her ... the fact that it is somebody in your home even though they are out here you can’t really let go with the children and discipline them or you know you’re very conscious that you are actually in your own home but yet you can’t relax you couldn’t come down in your pyjamas ...it’s just different...(brother) would come out of the bedroom and ask if there is anybody here? ... because he can’t like slouch around ...like he has to be kind of on edge in your own home when there is a carer here...but the kids know we need carers ...we know we need carers we wouldn’t be able to have (her) at home without carers”*

# Conclusions



- Undisputed preference for care (& respite) at home
- Changes to the home environment & impact on family life
- Risk of infection
- Equipment & travel
- Sleep deprivation
- Misconception that family provide respite