

## Respite Care

Caring for someone that you love with a disability can be very hard and often lonely. As parents we find it hard to let go from our duties of providing the vital care that we give to our children. Being a parent is arguably the hardest job going, add in the role of a carer too and then things can get really hard. We at CDKL5 UK realised early on that getting the chance to rest, regroup and recharge was vital in keeping us well enough to keep up the important job of raising our children.

- Local Authority social service departments have a duty to safeguard and promote the welfare of children within their area who are in need. Children Act 1989 s17(1)
- Your Local Authority is responsible for providing any non medical care services that your child is assessed as needing. This includes access to play schemes and respite care. **NHS choices**

To be able to access these services you will need to contact your local authority social services department and ask for a needs assessment. If you are caring for a child you will be able to also ask for a carer's assessment for you and your family. The assessment should take into account three domains:

1. The child's developmental needs
2. The parents or caregivers capacities to respond appropriately to those needs
3. The wider family and environmental factors

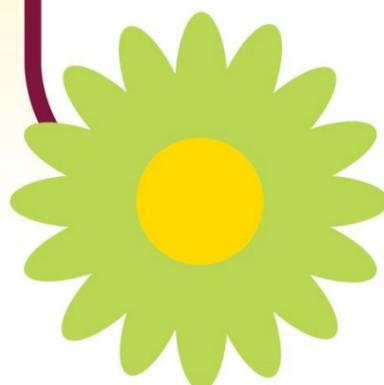
Respite care is defined as the provision of short-term accommodation in a facility outside of the home in which a loved one maybe placed. This provides temporary relief to those who provide the care. The value of respite can never be undervalued. It has proven to reduce stress in families and enhance the families' coping abilities. It increases the caregivers well being allowing opportunities for social activities and involvement outside of the home.

At CDKL5 UK we know that our children are the most important things to us. They are to be loved, cherished and protected. For us as parents to be able to do that properly we must acknowledge that it can be the hardest but most rewarding job going. Respite Care is a positive tool and resource to help us to do that. Being able to have short breaks whilst in the knowledge your child is being cared for and having fun is priceless and allows us to continue to be the greatest parents we can be.

### Personal Story

Initially I was very sceptical about sending my child away, because that is just what it felt like 'sending them away'. Huge feelings of guilt, is what I remember the most thinking that in some way I had failed as a mum. I had gotten used to that feeling of tiredness and just being weary, it was the norm and I didn't know any different. We love our daughter more than we can say and without even noticing her care and medical needs had just taken over. It wasn't a noticeable thing but something that happened gradually over time as she grew so did her needs. We had less time for friends and drifted apart as our constant answer to invites was always a polite decline. And eventually we found our 'date nights' were almost none existent and turned into 'sleep nights'.

Things for us came to a head when we had our second child and Respite became a more viable option. Don't get me wrong I still felt huge feelings of guilt but we decided as a family to give it a try. The process itself was very seamless and our local authority social service team couldn't have been more helpful. We were assessed as a family and all of our needs and feelings were taken into account. Once the process was complete our daughter was awarded two overnight stays a month at our local children's respite centre. She has a key worker who knows her 'almost as well as us' and has a ball when she stays out.



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