

What a “short break” is for parents and carers in Cambridgeshire

The Cambridgeshire Vision Statement

For disabled children, young people and their families to have the support they need to lead ordinary lives as a matter of course.

The Cambridgeshire stance on short breaks:

Short breaks will be developed in line with the Aiming High Guidance that says that they are to give:

- * Disabled children and young people enjoyable experiences away from their primary carers, thereby contributing to their personal and social development and reducing social isolation;

- * Parents and families a necessary and valuable break from caring responsibilities.

In Cambridgeshire, we accept that for some disabled children and families the short break may mean that they spend time together with extra support provided for them to do things together with others sharing the care.

We have been asking parents what a short break means to them. This is what they told us. We have told the EDCM Strategy Group that this is what parents want.

Someone to sit with my children so I can go out with my partner (Day Care/sitting service)

Organise more family outings during the holidays

Secure play environments for children with trained workers to intervene if needed and to supervise, for example a play barn soft play facility

Funding for Opportunities Groups (similar to one in Stetchworth), but for all age ranges of children. Children could play and be supervised whilst parents meet

More choice and availability of play schemes and activities in the summer, and during other major holiday periods (i.e. Easter and Christmas)

More activities generally for disabled children; opportunities for them to participate whilst being supervised, in inclusive activities. For example: bowling and more film clubs.

Spending some "quiet time" at home alone to have some "thinking" time

To go away...

Time to go on holiday with my whole family: I can't remember the last time I did that

Time to be ill

A short break for me would be a whole Saturday morn/afternoon/or day without [child] where I would spend some really good quality time with my other two girls, preferably once a month

Access to a babysitter who is qualified/understanding of my child's disability so that I can have an occasional night out with my wife and/or other child

A couple of weeks childcare in the summer holidays so that my wife and myself don't have to take different weeks off plus take unpaid leave, in order to cover childcare over 6 week holiday

Short break 2 hours each week where they can go off to an activity they enjoy

Once a year a few days away allowing the siblings a break

A few hours to do some jobs in the house or garden, without looking over your shoulder

RESPIRE. Any period of time when I can spend time with the rest of the family together at a time of my choosing

As a parent a short break is: time to relax; time to talk; time to catch up (housework, coursework, but mainly housework)

time to be me
time for my husband

Whole day and night (at least) where I can be confident my son is happy, enjoying himself doing activities with other children (writing unclear). Safe and well-cared for by a person/persons who is fully trained and experienced and who is well briefed and knows my son well and is up to date with his life, his behaviour and needs. This means in addition to the time they spend with my child during the short break time they are paid to attend training courses, meetings related to my son

To be able to sleep, relax or close my eyes;
To find me and my marriage

To not supervise 3 disabled children 24/7, 365 and police what they do

Taxi after school later to access out of school provision

Had Link, kept breaking down and more trouble than its worth

As a single parent it would be so helpful to have experienced assistance to help take my son away on a short break i.e. long weekend – this would omit guilt on my behalf if he has to leave me and the home for me to get respite and also cut out his lack of ‘self esteem’ when he has to be sent away from home, where he loves to be

Some time to relax in my own home

A lie in!

Time to spend with NT sibling

It needs to be individually tailored

Someone who will be able to take on some of the burden brought by raising an autistic child by: - helping with the home program – helping with the other child while I implement my disabled child’s program – helping with housework while I work with my child

I do not want my child to be taken away to be taken away as it will feel as a failure

I want to help him. I want help to help me help him. It would be a break for all the family not just me (for his sister as well)

Day out with whole family with help

Spend time with youngest – activities for her rather than disabled sister

Whole night uninterrupted sleep

By the seaside

Visit the park

Day out with disabled child with carer/s along to help!

Others that people called out:

Time for yourself

Listen to parents

Giving me space so I can help him out of house – I’ve no car

Hydrotherapy at Spring Common – open session of swimming

Open sensory room at Spring Common – but staffing issues

HomeStart

Vouchers for Center Parcs

Affordable babysitting that all can access

The Little Stars group discussed short breaks with individual parents and the result was unanimous:

No parent wanted a situation where their pre-school children were offered respite away from the rest of the family

The ideal situation was a holiday that provided facilities that all the family could enjoy including facilities for the children with special needs (soft play, sensory room, hydro-therapy, etc) and provided additional support to care for the children so that parents could sleep, have a break, pay attention to each other or siblings

Access to trained carers coming in to the family home for short periods of time so that parents could go to the hairdressers or dentist etc. This is provided to some families through Community Support, Crossroads and other agencies but the provision is patchy....parents rely heavily on friends or family but not everyone has this sort of support available

It concerns the other parent volunteers that so many of the parents attending [Little Stars] have disturbed nights and can be sleep deprived and then have a full-on day with a child who requires close monitoring.

A dad sent us this after coming to a parental involvement network meeting

I also forgot to give you my thoughts about what a 'short break' means for me. Well personally, it means C going out and about with someone who can care effectively for him and keep him safe. Crucially it's important I have absolute confidence in that person, so that I can truly relax and get most benefit from 'me' time. C gets bored and unintentionally destructive if he's indoors for too long, so this is why it's best for us. He adores going out and doing lots of physical activity: swimming, soft play, parks etc etc. If I know C is having a good time - I really get most benefit from respite. I personally find that lunch time to early evening is good for a break, as C's frustration with being indoors builds as the day progresses. I obviously take him out as much as I can, but do need to be around the house with him from time to time to catch up on housework etc! Overnight stays are great for me too a) because I'm very lucky that C enjoys these & copes well b) because I then have a chance to have a bit of a 'normal' social life and catch up with friends, which is crucial for my sanity! Basically any breaks offered are invaluable for me AND C. If I get a break from caring, I feel I have more energy, and am more effective as a carer when C is with me. Please share these comments too, if you feel it would help.

What parents in Fenland told us:

Short break away with the family away from the home in a different environment

My son going on a fun holiday while the rest of us just able to have quality time

Quality time together

Relaxing time

Break away from stress

Clubs for kids

Children to enjoy themselves

Carer to come with us so I can have a break

A chance to relax, recharge my batteries where I know my boys are safe and other people accept them

An opportunity for me to worry about nothing but myself...have my children taken care of and a chance to recharge my batteries, and enable me to be a better parent

Someone to take him out during the school holidays to give the family a break

Someone to sit with him in the evening so that we can go out as a family

A park without dogs (he won't go in a park where there is dogs)

Saturday Club while they go shopping or just time out appropriate to child's condition (sibling)

Time away from routine and quality time together

Break in safe environment on same level ground.

Respite (ha ha) - time out with my partner as a couple

A place where family can enjoy without standing out.