

8th February 2018

LUDLOW ROAD SHORT BREAKS CENTRE – PARENTS’ LETTER

Worcestershire County Council – Parents Consultation Response

Further to the notification that Ludlow Road Short Breaks Centre is due to close, some of the parents have written a short statement to try and explain the impact it will have on them and their families. I’ve been gathering this information over the past few days, and I have found it particularly emotional to read some of their stories. We would be grateful if you could circulate this letter to all the people who are involved and voting on the Ludlow Road closure, we need them to know that their decisions will have a huge and lasting impact on lots of vulnerable families and their children.

***Yours Faithfully,
Tracey Rochelle***

Amanda and Andy Danby - Mason’s Mom and Dad:

To me and my family Ludlow Road is not a service, it has been part of our lives for 14 years and as such we class that little bungalow as part of our family, my son has known nothing else outside his family to love and care for him like the staff do there. This is morally wrong and I will fight to keep Ludlow Road open.

Carol - Joshua’s Mom:

As a family, we are relatively new to overnight respite having only done a year and it’s been a life line. It took almost 6 months to settle Joshua in. Having experienced a support worker we now know the overnight respite is the only solution that really gives us a break as a family. Joshua is happy and settled at Ludlow Road, he has friends there and is well looked after in a home from home loving environment .You are putting immense strain on us and without having a disabled child yourself, you have no idea how hard it is to just get up in the mornings, knowing what your day will be like and the preparation it takes just to get out of the house, or to have the energy to get through the day with a child wanting and needing such attention along with trying to keep your other child happy. However, you can feel it is appropriate to close the only little ray of light we get to re charge our batteries and carry onyou should be ashamed.

Natalie - Charlotte’s Mom:

Ludlow Road means the world to Charlotte and our family, she is happy, safe, and around friends. I’m at the point now I trust the Ludlow Road team like a family and can rest easy knowing she is in the very best appropriate care with similar children around her. The idea that Ludlow Road could close has placed considerable stress upon us especially as Charlotte is 16 and we will face respite transition this year and again next year as she reaches 18. This prospect for a child that cannot speak, walk or genuinely understand change, causes us massive concern. These most vulnerable

group of children have been targeted in our community with no solid financial evidence. We urge you to reconsider this suggestion, you've placed children, parents and families in a most hideous limbo.

Zoey - Ellie's Mom:

Having a child with special/additional needs puts an extreme amount of pressure on families and their relationships. My youngest daughter has many conditions affecting her in many different ways, putting additional pressure on our marriage. Our eldest daughter now has to have counselling to support her in dealing with everything she has seen and has to deal with. When your child has additional needs it is very difficult to balance your time, and Ludlow Road provides this invaluable chance. These moments are taken to spend quality time with your other children and on your marriage. However, it is not easy to leave your child with just anyone, the staff at Ludlow Road have an amazing ability to treat Charlotte not only as an individual but also like she was their own. This means the rest of the family can cherish this time knowing your child is surrounded by amazing care, love and support. Ludlow Road supports and loves some of the most vulnerable and it seems a cheap shot to target these children without a voice.

Clare - Sam's Mom:

Sam has had respite at Ludlow Road for the past seven years. The care he receives is outstanding and it has taken years to build up this level of trust. Sam has night seizures and is regularly awake from 3am. Ludlow Road enables us to spend quality time with our teenage daughter and to catch up on sleep. Caring for a disabled child is completely emotionally and physically exhausting. This whole process of consultation is extremely stressful and puts additional unnecessary pressure on families.

Kelly - Madison's Mom:

I am a mother of two children with life limiting conditions which has rendered them severely disabled. This places enormous and exhausting strain on our normal life. Madison is 11 and has been going to Ludlow Road since she was 3 years old. Ludlow Road has provided us as a family, a much needed break, and has provided Madison with the opportunity to mix with other children in a sociable setting. It has taken years for Maddy to get to know her surroundings and the people who care for her, by closing Ludlow Road this removes all of these positive things within her life. It would then take considerable time for Maddy to settle in another unit and she would lose all the staff and friends she has come to know and love. Add in to this the struggle as a parent allowing your child to stay somewhere else and trust the people around her to care for her every need like we, as her family, do. Being non-verbal means it takes time to get to know Maddy's likes, dislikes and her routines. Children like my daughter are unable to do many things other children can do, Ludlow Road provides her with a sense of normality as for Maddy, going there with her friends is like having a sleep over. I hope those making the decision understand the severity of the impact closing Ludlow Road will have on Maddy who has already suffer enough.

Danny - Charlie's Mom:

At 5 months old Charlie was diagnosed with Cerebral Palsy. We would be lost without Ludlow Road, we went on to have three more boys who love Ludlow Road too. It gives us time with them and we know Charlie is safe and cared for. Charlie has made lots of friends there who he interacts with, Ludlow Road is our life line.

Emma - Millie's Mom:

Millie is 8 years old and has been going to Ludlow Road for nearly 4 years, she has cerebral palsy, epilepsy and global delay, we wouldn't know what to do without Ludlow Road. Millie has huge separation issues and hates to leave me, but the staff at Ludlow Road have worked so hard with her and now she loves going there and seeing her friends. 18 months ago Millie had a seizure under anaesthetic and it took what little function she did have, away. Millie was no longer able to crawl, sign, eat or drink and this in turn has made her frustrated as she is now confined to her chair and is tube fed. The staff took all this in their stride and adapted to Millie's new needs. I trust no one else with my daughter and fear that Millie would not cope if she had to move to another unit. We need Ludlow Road.

Jayne - Freya's Mom:

My daughter Freya has been going to Ludlow road for approximately 8 years. Freya suffers from quadriplegic cerebella palsy, seizures which have stopped her breathing and brittle bones. She is non-verbal and needs 24 hr one to one care. Freya is an extremely vulnerable 16 year old who loves people and has a very naughty sense of humour! At Ludlow Road she gets to have sleep over parties with her friends, as any other 16 year old would. Unfortunately, vulnerable children come as a package with their very vulnerable families, who have been by their amazing and inspirational children's side, step by metaphorical step. Freya is a surviving twin, our daughter India, died at 9 days old, having to bury a child is the most devastating and soul destroying thing a parent can ever do, once this has happened, the trust you need to summon to entrust your surviving, precious child into the care of others is immeasurable. The staff at Ludlow Road have allowed this through their patience, love and understanding. We see the staff at Ludlow Road as our extended family as well as friends and we are so grateful that they have been there for us over the years with all their love empty and support, we quite honestly would be lost without them.

Tina - Dalcie's Mom:

Up until Dalcie was 10 year old I looked after her myself at home, I didn't have or wanted any outside support. When I was first offered respite, I was horrified at the thought of handing my daughter over to complete strangers but Ludlow Road nurtured myself and my family to help us let go and to trust them, we didn't want it but we knew it was getting too difficult to look after her without help. They showed us love, kindness, patients and professionalism and most of all gave Dalcie a home from home, all within the safety of an NHS run establishment. I didn't want to use a foster carers home, mainly because you can't DBS check everyone who pops in for a cup of tea, so I feel there can be real safety issues with children, and this to me was an horrific idea.

I had no choice in the path my daughter has taken me on, my responsibilities for her are there until I die. My daughter is the most vulnerable in society and only has her parents to protect her, but with the support of trusted nursing respite I am able to take those few short hours to try and rest and pick myself to start the day again. I am so upset and I feel vulnerable and scared for the future and I feeling that I am unable to help and protect her from changes that she can't understand.

We are asking you to help us and protect our children for the future, life is hard enough and it's a life you could have no idea of the relentless struggle we have every single day.

Rest assured there will be other parents as I write this that will be going through all the pain and despair you feel in those early days, that you are not getting the healthy child you thought you were.

Dalcie will never become independent, it's a great strain on trying to balance the needs of family life, two other children, a marriage and still be a full time carer. I didn't choose this path or train for any of it .

The trust me and my family have built up in the staff of Ludlow Road has taken us years. My daughter has no voice to let us know if she is unhappy or in pain, that is all guess work, there are only subtle changes that only a person who knows Dalcie well, would be able to spot.

It has taken me years to not telephone Ludlow Road to check Dalcie is OK when she stays and also to relax on that very valuable respite night.

Dalcie is fourteen years old, 5ft 3' and still growing. She has the mental age of a ten month old baby, she cannot walk, talk or feed herself and she wears nappies, and has just started her periods, she cannot function without someone looking after her 24 hrs a day. She runs the risk of choking with possible epileptic fits in the night. She is now taller than me and needs two people to deal with her. The closure will hurt us more than you realise, it is going to take us a long time to rebuild the trust that we have in the Ludlow Road staff. We are hanging on by our finger tips and as the years go by, we're not getting any younger. I am now 54 and my mother, who has tried to help me in the past, is now in her late 70's. We know we are going to need more respite in the future, and we are terrified that we won't be able to get the kind of care that Dalcie needs, with careers we can trust for the rest of her life. I need you to know that if any of my friends read this statement, they would be totally shocked. We have always been a very proud and private family and done our utmost not to burden anyone else with our problems. However, as you can appreciate we have tried to deal with this situation ourselves are now at the stage we cannot manage on our own any longer and we need help.