Home Adaptations -A Parent Led Guide

BATTEN DISEASE FAMILY ASSOCIATION
Together we WILL make a difference
Registered Charity in England and Wales 1205650

This interactive session was led by Paul Taylor, Parent to Stevie who has CLN3 Juvenile Batten Paul talked us through the complex and protracted experience that he went through to get adaptations needed for Stevie and how it affected them. He explained that the process for them was difficult from start to finish, but he has learned so much from it, and wants to help ensure other families are given good information and support to enable them to get the right solutions in good time for their children.

This is Paul's story

At the beginning- A Home No Longer Suitable

We lived in three storey house, we thought it was our forever home. Not long after our daughter, Stevie, was diagnosed, we had an Occupational Therapist (O.T.) who was involved with us, looking at what Stevie would need to help her as her Batten progressed, and she became more dependent on us to care for her. The O.T. decided that the adaptations that we would need wouldn't be possible in our home. It was a huge blow, but we decided to look in our local area, see if we could find either a house or a bungalow that we could adapt and put our property up for sale.

"We didn't want to leave. We were nearly mortgage-free and happy. But we wanted the best for Stevie."

As other parents can appreciate it was already a distressing time, coming to terms with the changes Stevie faced and having to leave the home we loved. We didn't want to leave. We've had a lovely home and were nearly mortgage free. It placed a lot of stress on us as parents, but we wanted the best for Stevie.

BDFA recommends that families new to the adaptations process have all necessary legislation, and government bodies information already to hand. Being well informed at the start of the process helps you, knowing who to complain to at both local and government levels is important.

Delays, Red Tape, and Poor Communication

We did eventually find a bungalow that met our needs. Still quite local to our children's school and close to family and friends and our support network. We wanted home life to be as easy for our children as possible, we sold our home, bought the other property and then rented a house temporarily so we would have a safe base while work was being done. In many ways that was the easy part.

"We were renting one house, paying a mortgage on another, and just trying to get our daughter the home she needed. It was exhausting."

The bungalow needed a lot of work, as well as the adaptations it required a lot of structural work and other things that needed to be done. All of this took some time and once we were settled in the rented home we rearranged a meeting with our O.T. and decided the plans that we were going to go forward with so we could adapt the bungalow to Stevie's current and future needs.
The O.T. advised that the waiting list would be a minimum of 32 weeks, just to be seen and to start discussing the process. I now know that there are certain fast tracks that you can do, especially if you are facing a complex disease like Batten. However, we were still quite shell shocked, so we just believed what she told us.

BThe Royal College of Occupational Therapists produced a guide to planning and delivering home adaptations differently in 2019.

RCOT Adaptations without delay.pdf

So we kind of sat back for a bit thinking that we were going to be waiting 32 weeks. During that time I started to do a bit of research and arranged another meeting with the O.T.

The O.T. came along and advised us to get our own plans drawn up, get them passed through building control, and then we could take a step forward in the process. We agreed to do this at a cost of more than £1k. The O.T. told us that once the plans were passed, we would be able to claim that money back as part of the Disabled Facilities Grant, so we agreed.

Find out about Disabled Facilities Grants for the UK and specific guides for devolved nations here

- ***Disabled Facilities Grants: Overview - GOV.UK***
- ***Funding Adaptations to the home: A guide for homeowners - gov.scot***
- ***Disabled Facilities Grants | nidirect***
- ***Adapt your home if you are disabled or an older person | GOV.WALES***

They recommended an architect to us that they knew really well, who worked for our local authority, someone who had good inside knowledge of what we'd need and what we could do. So again, we just we agreed and we went forward with it. The plans were drawn up, submitted to our local authority and passed.
Things started to happen quickly and we moved into our rental property.

We had the choice to project manage it, we would get the grant money and find and employ all the trades people necessary, but we didn't think we were in the right place emotionally to project manage it ourselves and we were working and supporting the children as well so we asked the local authority to manage it all for us with their own authority approved engineers and tradespeople.

Next steps

Around 12 weeks later and they had a meeting at the property with myself, my wife, the O.T., and a technical officer from the aids and adaptations team.
They came into the property and told us that it would be very expensive and recommended we put £15k towards aids and adaptations, otherwise we would be unlikely to get the grant for it. I questioned that as I knew it would not be means tested as Stevie was a disabled child. They were insistent that the works would go way over the grant and advised that basic works without aids and specific adaptations would be at least £30-£40k.
I felt blindsided, it was such a negative meeting with no thought for what we were going through.

' We've got to do what we've got to do, if we have to remortgage again, we will do that'.

And another sting right after as the Technical Officer advised we needed to get plans drawn up. At last, something we could be ahead of, I explained that we'd already got the plans. They've been passed, everything was in there, but they told us these plans can't be used, that they were not valid and the money we paid was lost as we couldn't claim it back. (The architect that we were advised to use was an employee of this Council as such they were not permitted contractually to work on private properties in the area.)

At that point I had to have a break from the meeting, I was angry. I explained that the financial burden we were under meant we just had to get the work started. We were in a rented property paying rent, mortgage, Council tax, everything on two properties.

We did a walk round of the property and discussed the things that we'd need. Again, so negative. We needed some access to the back garden at the new property, but because it's about a two metre drop from the rear patio doors they advised, 'You're probably going to need a lift down to there, but that would eat the complete budget. You'd have nothing for any internal work. In my opinion, I don't think she'll need access to the garden, if you're going to spend £30k for someone that's not going to be here that long, I recommend you spend it inside'.
Such a crass and inhumane comment at a time that our stress was building throughout the meeting. I asked them to leave and for their manager to formally attend the day after.

The manager didn't attend, I had to ring and explain the situation and the concerns. They agreed to send a different technical officer out with our O.T.
This was a much better meeting, they agreed that work could start. They were going to fast track us and they were going to try and get things moving as quick as possible. Great!

Google search – 'Are DFG's for disabled children means tested'
From the Local Authority Website (all L.A.'s have the same)

There is no means test for a DFG where the application is for a child/young person under the age of 19, for whom child benefit is payable. If you are the parent or guardian of a disabled child, your income and savings are not considered for a mandatory DFG (up to £30,000).

If works are needed that will cost more than the mandatory grant awarded to the applicant, we will provide advice and assistance in considering options, including other sources of help, and an option for home owners to defer payment (see Discretionary DFG).

The Work Starts

12 weeks later the work commenced again, but it was poorly managed, tradespeople turned up when they wanted to. We arranged times with them to let them in because obviously we weren't living there. But they didn't come. We would then get a phone call two days later saying 'We're at your property. Where are you?' We didn't receive any schedules of work to tell us exactly what they would be doing, as we would have expected with the local authority project managing, but it was me on the phone, constantly asking when they were coming, what materials they were going to be using.

I'm a tradesman, so I know quite a lot, and I knew some of the tradespeople that were coming in and I knew what they should be doing and the ways they should be working, and they just weren't sticking to any plans or anything they were just pretty much doing what they wanted to do, so I raised this issue with the councils manager again, but the communication from them was so poor. He never got back to me, never called me. And that went on for probably two months. I never actually spoke to him.

In the meantime, it seemed to me that the tradespeople were cutting corners everywhere. They were using the cheapest materials as possible and doing it the easiest, quickest and cheapest way, it created a lot of issues and a lot of stress that we didn't need at the time. With a lot of arguing we did get what we wanted.

Involving our MP

I went to see my local MP at the drop in centre and got him involved. He wrote a letter to the council director and that helped. Things moved a lot quicker after that letter landed. They seemed to want to help us then, much more than before.

Paul's top tip-

Anybody that's going through adaptations and there are hold ups, try and get your local MP involved. Get them on your side, get as much support as you can, because our children can't wait.

Getting your home right

We needed a ramp to the front of the home and a parking space for a Wheelchair Accessible Vehicle (W.A.V.). I wanted it to look nice, but they wanted to put a metal ramp from the road straight to the front door, a big ugly green metal ramp. I disagreed, the builder on site said it would be cheaper to put in block paving and concrete. So that's what we did, with a lot of arguing, and it looks homely and smart. It seems that councils have one way, one formula for how they do things, but it's not necessarily the best or cheapest way.

"It seemed like the council had one formula for everything — not the best, not the cheapest, just the easiest."

If you want something a certain way, just stick to your guns. You will get what you want, it's your home. You may have to shout from the rooftops and you'll have to get people behind you to support you. But if you do, you will get what you want.
We then talked about the drive and parking space, it was about 10 x 6 metres around, but they only budget for a space of 3x3 metres. We agreed to pay for the drive and the council would reimburse us for the 3x3 metre patch once finished and passed by building control. They told me I would be reimbursed after 5 working days, 2 weeks before Christmas, but I got it 2 weeks after the new year, despite calling and emailing and complaining. I felt like they just they weren't interested, at all.

The Garden

Then came the garden a two metre drop from the patio doors at the rear of the house, in future we know Stevie will need Personal Assistants to help her in the future, and she loves the garden so why shouldn't she access it?
I asked before that started if I could have a meeting with the applications manager, I wanted to discuss things and get a few things off my chest so at that meeting. They came out and saw us at the new home, apologised and said they couldn't believe what we've been going through. They explained that they were going to do their best going forward to make sure that the last phase of the project was smooth.

If anything, it got worse. They came and they put the concrete pads down for the lift, but didn't think about the electrical supply for the lift. Rather than installing the cable underground in conduit according to regulations, they ran it across the top of my path down to the side of bungalow with about 50mm of cover on top of it. And said that's how it was staying.

Understand what might be VAT exempt if you are paying for gods and materials specifically for your child with Batten.

Get VAT relief on certain goods if you have a disability - GOV.UK

BDFA Support

I complained, and we got Sarah from BDFA involved and together we looked at electrical installation regulations. The cable should have been laid 450mm underground with markers to identify it to comply with regulations. Despite being told this, it took Sarah to write to them pointing out the liability should there be an accident or incident with the easily dislodged cable. Then they finally agreed that the whole work that they've done would have to be ripped out and started again.
Which put us back about another two months. They came and ripped it all out, started again, then they left a 2 metre drop from the patio doors with no barriers around it. When I complained I was told it was a construction site, and we shouldn't be out there. They returned to put barriers around it. Finally, some 14 weeks later the work was finished, it could have been done in 2 weeks if the contractors had been aligned to each other properly.

The complaints process was a whole other ordeal, we found out that there was not one record of any tasks or meetings around our application or works process, no evidence, at all. I have been so affected by this process, as has the family and I would not want this to happen to other families, so I have lodged a complaint with the Ombudsman.

If you've never gone through the adaptations process before, you're new to it all, it's a stressful time. Get some support. Make sure you have a good OT, and ask BDFA for help.

Paul advises

- ***Find out the complaints procedure before the process starts, ask for a copy to be sent to you, they are hard to find online***
- ***Get the names and emails of the responsible application advisor and line manager, you may be told this information is not given out due to GDPR, in which case ask for a meeting with the senior manager to have a discussion. It's not an aggression tactic, more showing that you understand your rights and your child's rights.***
- ***Also, as the meetings/work goes on ask for all correspondence in email, if you don't get it, send them an email and ask for them to respond. Take photo's of works as they are being done. Hopefully you won't need it, but this is your evidence in case of a dispute.***

Hard-Earned Lessons for Other Families

Paul's experience highlights how difficult the adaptations process can be — and how crucial it is to get the right support early on.

Paul's advice to other parents:

- **Get help early.** Contact your OT and the BDFA for guidance.
- **Keep records.** Document every meeting, quote, and communication.
- **Don't be afraid to challenge decisions.** It's your home and your child's future.
- **Think long-term.** Consider future needs like hoists, wider doorways, and storage.
- **Stick to your guns.** You know your child's needs best.

"If you want something done a certain way, keep pushing. You will get there — but you'll need support behind you."

Here is a fact sheet for people with Disabilities (or someone caring for them) who are experiencing problems with adaptations to their home and may be considering making a complaint to the Ombudsman.

Housing adaptations for people with disabilities - Local Government and Social Care Ombudsman

Shared Experiences from Other Parents

Paul's presentation for the other families involved in the session was extremely moving to hear and other parents gave their experiences. What became clear is that they all had different experiences, were given different advice and it also highlighted their concerns for adaptations while the child is under 18 and how different it may be when they are over 18.

Sarah Dodkin, parent to Finlay and Harrison who both have CLN3 Batten advised other parents to think further along the disease process and look at how a build can be functional for now but also be easily adaptable for a future need such as an overhead hoist, and the width of doors to accommodate a specialist wheelchairs, also to always think of storage as you will find you need more as time goes on.

'These future needs are not things you want to think about, but getting the home right gives you huge peace of mind'

We hope Paul's experience, and the links to websites are helpful for parents as they face home adaptations. The BDFA is here to support families navigating the adaptations process. We can provide advice, connect you with other parents who've been through it, and signpost to resources to make the journey smoother.

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With thanks to parents Paul, James, Sarah, Becky, and Tracey. (2025)