

Complex needs service, 2016



A Child Friendly Leeds for all children and young people: going to school in Leeds with complex medical needs

In 2014, the Children and Families Act brought big changes to improve services for children and young people with special educational needs and disabilities (SEND) of all kinds, including those with medical needs.

One of the key themes of the Act was the need for education, health and social care services to listen to the views of the children and families and take their views into account when developing services.

We want Leeds to be a Child Friendly City for all our children and young people, including those with additional needs. We agree that listening to their voices is really important for making our city better.

In this interview, we talk to 11 year-old Evie about living in Leeds as a child or young person with complex medical needs.

Evie, who attends her local mainstream school, has Crohn's disease. She agreed to share her experiences of school life in this interview to help local teachers and other education workers learn how to deliver the best possible support for other children and young people with medical needs.

All about Evie!

Evie is 11 years old and lives in Leeds with her mum, dad and older brother. She is a huge Little Mix fan, loves hanging out with her friends and painting nails.

Evie began showing signs of Crohn's disease 2 years prior to being diagnosed. Her teacher noted she wasn't concentrating and Evie had increased absence from school, with what was thought at the time to be stomach bugs. Evie said "It was really scary; I wanted to eat but knew if I did eat, I would need the toilet and get stomach cramps". Unfortunately because Evie's blood counts (inflammatory markers) were not raised, Inflammatory Bowel Disease was not considered. Evie's mum felt frustrated at the time because as a parent she knew something wasn't right. Evie had lost a lot of weight, wasn't eating and had no energy

to talk. Evie says: "No one spoke to me; no one asked me what was wrong, how I felt or how much pain I was in".

After several months, Evie was diagnosed with Crohn's disease.

Evie chats to Jackie Claxton-Ruddock and Natalie Samuel from the complex needs service:



All about Crohn's disease:

Crohn's disease (Inflammatory Bowel Disease) is a chronic condition affecting a part, or whole of the digestive system. It is a lifelong condition and typically runs a relapsing and remitting course.

During a flare up (relapse), Evie experiences abdominal pain, an urgent need to go to the toilet, lethargy, joint pain, a high temperature and loss of appetite (often resulting in weight loss). During these times Evie may not be able to attend school or only manage part of the day and she may need hospitalisation to manage her symptoms and bring the disease back under control.

Evie explains, "I can get really tired and even when I want to do fun things I can become exhausted. At my recent birthday party I was having loads of fun with my friends, then half way through I just wanted to go home to rest. It's hard I miss a lot of school and miss my friends. There are times when I need to have a tube up my nose, to feed me on a liquid diet for several weeks and give my stomach a rest. It can be tough. But I always try to stay positive".

Evie goes on to praise the Paediatric Gastro Team and Ward L10 at Leeds Children's Hospital (Leeds General Infirmary). Evie explains that from their first time of meeting, her consultant has always listened to her and spoken directly to her about her health and medication.

Evie says "I want everyone who works with children to know about Crohn's and Colitis (Inflammatory Bowel Disease). That's why I started supporting the national charity Crohn's and Colitis UK by raising awareness and money".

In fact, Evie has done so much work, she was recognised with a Yorkshire Children of Courage Award in 2014 and a Child Friendly Leeds Award in 2015. She received these awards for the work she does to benefit others living with Inflammatory Bowel Disease.

On the right: Evie receives her Child Friendly Leeds Award from Leeds Children's Mayor Amy Eckworth-Jones in 2015.

Going to school with Crohn's:

Going to school with Crohn's has often been hard for Evie. She has missed a lot of school (from having a flare, lethargy, hospital admissions, hospital appointments and regular blood tests).

When Evie is in hospital she is visited by The Home and Hospital Teaching Service, which Evie says is fantastic and really helps her to keep up with school work.

Evie explains, "When I am at school, if I am going through a difficult time with my Crohn's it can be hard. I have to go to the toilet a lot and that means I can miss important parts of the lesson. I often get very tired and my joints ache so it is hard to concentrate and take part in everything".

Evie and her mum Ruth both feel that her local school has offered lots of great support. Evie pointed out how her school helps:

- They understand that I need to sit near the door, so I can get out and go to the toilet quickly.
- They also look after my lunchtime medication and keep my special build up drinks in the fridge.
- I'm first in the dinner queue, so I don't have to wait a long time to eat.
- If I need the toilet during my lunch, the dinner ladies know not to clear my plate.



Evie's school has come together as a community to support Evie, for example supporting a balloon release, to raise funds and awareness for Crohn's and Colitis UK which was really positive and meant a lot to the family.

Evie also mentions, "The first time I was ill, the whole school sent me cards and notes, which made me feel special and still part of the school. Last year my teacher came to visit me on the ward and all the class had wrote cards, jokes and poems. It helped a lot, because when I can't go I miss school. Before I got ill, I used to think it would be great not to have to go to school - but I actually really miss it!"

When Evie was diagnosed, Evie and her parents met with Evie's teacher, deputy head and specialist nurse to talk about living with Crohn's disease (Inflammatory Bowel Disease). It's really important for teachers not to make assumptions or expect all complex medical needs to have the same sort of impact.

There are a few things that make Evie sad and would like schools to think more about:

'There are prizes and certificates at school for good attendance and they are handed out in assembly. Children go up on the stage to receive their certificates and everyone claps. I sit there every time watching all my friends go up on stage.

'I know I'll never be able to win a prize or receive a certificate for attendance. I would like there to be prize or a certificate for children with health difficulties, who really try hard to have good attendance and when they are at school they work really hard, even when they are struggling with their health.

'As I've been ill for a few years, this year the class didn't send me cards or messages when I was in hospital. My close friends still sent me cards, visited me and let me know what was happening at school, which cheered me up. But I missed getting cards and news from the whole class. Maybe it's because were older, but it feels like they've forgotten about me, or got bored of me being ill. But I haven't got a choice.

'There are times when I am in pain and then there are times when the pain is so bad I feel I am going to be sick. Sometimes I get scared because of all the symptoms and pain I need to tell a teacher or member of staff, I just need them to be calm and let me know it's going to be ok. Maybe ask me if I need to have a little rest, drink one of my drinks or to ring my mum to collect me. I may need them to take charge and make the decisions for me. I just need to feel safe.

'There have been times when I have to go on a high dose of steroids and I get my 'moon face' and look really bloated. Then I want to say, please don't stare or make comments, I feel awkward enough about how I look. Sometimes it helps for the teacher to have a word with the class or do circle time (restorative practice) to talk about it.'



Left: Evie's school supported a balloon release on World Inflammatory Bowel Disease day to raise awareness and funds for Crohn's and Colitis UK.

If you work in a school or another education setting, here are Evie's top tips for how you can support children and young people with medical needs:

- Learn about the condition the child has, so you can understand what they are going through. Talk to them about how it affects them and listen to them - don't just talk to the adults in their life.
- Remember that every child or young person is different. One child might have the same condition as another child, but it could affect them in a very different way.
- Think about how they can take part in all the activities the rest of the class does. Ask them what they think about this. Don't assume they can or can't do something without asking them.
- Stay calm if a child or young person needs help. Understand that it is not their fault and they can't help it if they interrupt something. Think about how things like policies, prizes, and activities will work for children with medical needs. They might need to be adjusted to give children with a medical need a fair chance to take part.
- If a child has to go to hospital or take time off at home because of their medical needs, sending them letters and messages from their whole class can really help to cheer them up, as well as help them to feel they are not missing out. For children who go to hospital frequently this can be even more important, so try to bear this in mind and keep sending messages each time, rather than just the first time they have to be away.



On the left: Evie's sponsored walk, held at Roundhay Park .

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Other helpful advice for schools and education settings:

- Check the medical needs policy for schools in your area. This explains legal requirements on schools to support learners with medical needs, and local policy and practice. In Leeds, find it on the Leeds Education Hub in the 'policies' section. If you have trouble finding it, or want more advice about how to make it work for your school, please contact the Leeds City Council complex needs service for advice (see details overleaf).
- Make sure an Individual Health Care Plan is in place in school for the learner if they have medical needs. Involving the child and their family in putting the plan together is really important. Asking their health care providers, like their GP and/or their specialist for advice is also important, to make sure you have the right information. Your school nurse and the SENCo will also be helpful when putting the plan together.
- Make sure the plan gets regularly reviewed, so that the actions needed to support the child are still correct and contact numbers are up-to-date.
- If the Individual Health Care Plan involves helping the child with equipment or medication, find out if any training is available for staff. Make sure there are opportunities for staff to talk about the medical need and any support they may need to provide. Provide opportunities for staff to raise questions and any concerns. It is really important that they feel confident and safe about providing support.
- Crohn's and Colitis UK estimates that over 300,000 people in the UK have Crohn's or Colitis. Many are diagnosed in childhood, so it is likely that many primary schools, and most secondary schools, will need to support learners with Inflammatory Bowel Disease at some point. For more guidance on supporting learners with Crohn's and Colitis, you can find plenty of advice in a guide for schools produced by Crohn's and Colitis UK:

<http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Publications/children-schools-IBD-guide.pdf>

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On the right: Evie on ward 10 this year, enjoying crafts provided by the play leaders on the ward.



Contacts for more advice:

- **If you want any more advice or information about supporting children and young people with complex medical needs in Leeds**, please contact the Leeds City Council complex needs service. Email the service's best practice team at bpsteam@leeds.gov.uk and they will make sure your query gets to the right team or officer to help you.
- **Find out more about Crohn's and Colitis at the NHS Choices page:** www.nhs.uk or the Crohn's and Colitis UK site at www.crohnsandcolitis.org.uk
- **To find out more about the great work Evie has done to promote awareness of Crohn's and Colitis**, and support her fund-raising efforts, check out Evie's 'Just Giving' site at <https://www.justgiving.com/eviesway>
- Evie's family also maintain a Twitter and Facebook accounts to raise awareness (Evie does not have access to these accounts, due to her age). Follow them on Twitter under @evie'sway or on Facebook at and www.facebook.com/eviesway

Many thanks to Evie and her family for sharing their experiences with us to benefit schools, children and families in Leeds!



Evie giving a speech at the Child Friendly Leeds staff awards.