



Loneliness has long term effects

Dear Friend

"Hello, I'm Jessica. I'm 12 and when I grow up I want to be a doctor, a singer and an author.

But I sometimes worry what my future holds.

When I was six, I felt really tired all the time. One day, my hands and wrists were really sore, and my hands turned blue, so we went to the doctors. Then, when I was walking to school, my knee hurt, so we went back to see them again.

I saw so many doctors. I didn't know why I was getting ill all the time, and why I had to have so many different tests. It was quite scary.

Eventually they discovered that I have arthritis, uveitis and Raynaud's disease. At the time, I had no idea what any of that meant and I felt very confused.

I have arthritis in my knees, ankles, shoulders and hands. But the inflammation isn't only in my joints; my eyes, hands and skin are affected as well.

And it really hurts.

I have tried lots of different medicines. Some helped, some didn't. Some gave me mouth ulcers and made it hard to eat.

I need pain relief most days. I've lost count of the numbers of injections I've had. I have monthly infusions and regular steroid injections and I have a methotrexate injection every week. It makes me feel sick and rubbish the next day, but I know it helps make me less sore all the time.

I have had to miss quite a lot of school for appointments and treatments at the hospital. At first, I didn't like my friends at school knowing why I wasn't there because I just wanted everyone to treat me normally. I didn't want to be different from everyone else.

When I was in P5, I had lots of complications from my condition. I was in a wheelchair and couldn't go to school for a long time.



I missed school. I missed being with my friends and teachers.

I try to join in all activities with my friends. Sometimes I can't because I'm in too much pain, and that's really frustrating. Sometimes my family has to cancel our plans because I am too ill to go out.

It can be lonely having a long-term illness.

I love music and I really enjoy singing in my choir. But I had to stop playing the cello because holding it hurt too much and I've missed a lot of choir practice too.

I love playing basketball. But sometimes it means I'm in pain for days afterwards. People don't treat me differently just because I have arthritis, but most people don't really understand that children can have it too. When I was first diagnosed, I didn't know that this was a condition I might have all my life.

Sometimes I worry about what it will be like when I'm older, and if it will get worse. I worry what that might mean for my future.

Arthritis and the other conditions I have aren't the most important part of who I am, and I will work hard and persevere to do the things I want to do.

When I come to the hospital the ECHC team are on hand to make sure I'm never alone. They listen to me, understand how tough things can be and make sure I have fun. I've made friends and even been on outings with them. It's not so lonely with them beside me".

Jessica

Aged 12, Edinburgh



Jessica will always have to deal with her arthritis. And sadly, she's not the only child who suffers from a long-term, chronic condition. The hospital sees 110,000 children and young people every year, many of whom must attend on an ongoing basis – over weeks, months and years. And this loneliness can have long-term effects on a child.

But, because of you, our wonderful donors, Jessica doesn't have to be lonely.

We need your help to fund:

- **Music, magic and dance right at the bedside so that even those children in clinical isolation feel the fun.**
- **Creative activities and games, which bring children together and provide distraction from the pain, boredom and loneliness of hospital visits.**
- **Support for all the family at such a lonely and frightening time.**

Please give what you can today so children like Jessica are never alone. Just complete the enclosed donation form or visit www.echcharity.org

Thank you.