



Children's Liver
Disease Foundation

fighting childhood
liver disease

Inspirational

Young People

A booklet to introduce young people with a liver condition to the young people's services provided by Children's Liver Disease Foundation (CLDF)

Introduction

Becoming an adult can be hard but being a young person with a liver condition can be even tougher. It can help to hear stories from other young people in your situation.

CLDF has put this booklet together to provide you with information on what it's like for others to be a young person with a liver condition and the different ways in which we can support you.

Sometimes it's hard,

To know in whom to confide
Someone who **understands**,
From whom you don't need to hide

To just be yourself,
Let your uniqueness run free,
A body that's **always** there;
To encourage you to be

You see, being different isn't easy,
To feel you stand out,
But it's important to understand,
To be heard, you must shout

Not everyone will judge,
But some people do,
Don't let that hold you back.
You do **you**

You may feel pain
But I **promise** you this,
To be able to truly live,
Is life's **greatest gift**

Emma, 20

Zainab, 23



Tell us about yourself...

I love cooking; I make a really good quiche and I also enjoy baking cakes and making biscuits. I love reading and have read nearly all the Harry Potter books. My favourite is the Deathly Hallows.

What is the name of your liver condition?

My liver condition is called Tyrosinemia Type 1. It basically means I have an enzyme missing and I can't break down proteins so I'm on a strict low protein diet. I attend the liver clinic every six months where I get told I'm managing to look after my liver well.

How does having a liver condition affect your life?

I do get regular headaches and I feel very weak on some days but I still get up and carry on with life. When I go to family functions and there are a lot of meat products being served it can be hard explaining to someone who doesn't understand my liver condition why I can't have certain things. During my school days I used to get asked a lot of questions about why I was having my medications at school and it was difficult explaining why. However, I do have brilliant parents who help me through.

Have you moved to adult services?

I moved to adult services when I was 20 as my consultant felt I wasn't quite ready to move before then. I was so used to having my mum and dad speaking to doctors on my behalf. I didn't feel at all confident moving over to fend for myself. Luckily I was well looked after as there is a nurse there called Monica who has been the best help ever and made me feel less scared. Now I'm very much settled in adult services and feel right at home. It was at this time that I first met the support team from CLDF. That's when I let CLDF into my life and began relying so much on their advice and support.

"CLDF has given me the confidence I lost when my health took a turn for the worse and I ended up in ICU (Intensive Care Unit)."

How has CLDF helped you?

CLDF has given me the confidence I lost when my health took a turn for the worse and I ended up in ICU. Joining the team as a volunteer has made me feel so happy and I love helping out. It's basically my way of saying thank you. Thanks to CLDF I've managed to find a possible career prospect in the childcare sector which is my passion in life.

What advice would you give others who have a similar condition to you?

Do not give up hope and remain positive, and please, please let CLDF help you as they are an awesome charity full of awesome people. They helped me be happy again so I can assure you they'll be beneficial to you too.

Tell us about yourself...

I enjoy swimming, guitar, working on cars with my dad and spending time going out with my friends.

What is the name of your liver condition?

My parents found out I had biliary atresia when I was a baby.

How does having a liver condition affect your life?

Having my liver condition does limit me from doing some activities, but I've never let it affect my daily life.

How did you get involved with CLDF?

When I was younger my parents took me to family events and we just stayed in touch.

Have you moved to adult services yet?

Yes and the support I have received from the adult service was amazing. They settled me in to the new environment by meeting me in person at the children's hospital so I could ask any questions before I moved. I had a very smooth transition.

How has CLDF helped you?

They have given me confidence I never had before and a new perspective on my condition. I love having a liver condition now thanks to these experiences and opportunities. I've met so many amazing people and have had great support from them over the years. CLDF has done more for me than I could ask for. They've taken care of me through my hard times and I'm eternally grateful for it. CLDF takes care of a lot of people and I'm happy I'm one of them.

What advice would you give others who have a similar condition to you?

Don't wish to be normal. It's OK to be special. Being normal is overrated. Take every experience you can and don't let your disease stop you. Life is a lot more fun when you do.

"Don't wish to be normal. It's OK to be special. Being normal is overrated."

Michael, 16



Fin, 17



What hobbies do you have?

I like keeping fish and keeping fit! I have multiple fish species that I keep in various tanks. My dad bought me a fish tank when I was seven, and it's progressed from there to maintaining a fish tank in a café! They are mostly tropical with a few cold-water shrimps. I keep fit by cycling. I've been riding bikes since I was three and have even done a coast to coast cycle for CLDF. I now have quite a collection, including a mountain bike that I used for my Duke of Edinburgh and a bike that I built myself out of a vintage French frame mixed with an old road

bike, stripped down and rebuilt. I cycle because I'm too lazy to walk! Also it means that I don't have to use buses and I can get around easier.

What is/was the name of your liver condition?

Alpha-1 antitrypsin deficiency.

How old were you when you were diagnosed?

I was three months old.

How did you get involved with CLDF?

Well my parents have been involved since I was diagnosed as a baby. As a child I attended the CLDF Conference and went to Drayton Manor. When I was 12 I went on CLDF's Closer to the Edge (now Breakaway). That was a life-changing moment for me because it was the first time I got to chat to other people about life with a liver condition.

How does having a liver condition affect your daily life?

On a daily basis my condition has little effect on me. Because I was diagnosed so young it's just a part of life for me and for my family. I don't take any medication so there's no need to worry about that.

I do avoid any contact with cigarettes and passive smoking but it's just second nature now. I still get a lot of comments about my condition but I don't let them bring me down.

"I've been riding bikes since I was three and have even done a coast to coast cycle for CLDF."

How has CLDF helped you?

CLDF has helped me better understand what I have wrong with me. The team there have really helped me come out of my shell and become more confident in myself and in talking about my condition. I've now got a greatly increased friendship group from all over the country whom I get to contact and see outside of CLDF events as well.

What advice would you give others with the same condition?

I'd probably say don't let it control your life; there's plenty of other things to worry about – look at the bigger picture!

What hobbies do you have?

I like reading, drawing, skating, and playing the guitar.

What is the name of your liver condition?

I was diagnosed with autoimmune liver disease (AILD) when I was 16.

How does having a liver condition affect your daily life?

The main thing is the tiredness, particularly when I come home from work and uni.

Have you moved to adult services yet?

I went straight into adult services, because I had just turned 16 when I was diagnosed. My family, my consultant and CLDF helped me through it. It was difficult, having to sign my own papers, not really fully understanding what I was signing and what I was doing, but my family explained to me that I was going to be just fine, and to listen to both them and the doctors.

How has CLDF helped you?

CLDF means so much to me as they have shown me that I am not alone and that they will help me in every way they can. I have met so many people now who are just like me, which was a real self-esteem booster. I have so many friends now who understand what I go through every day, which is a big help. CLDF has been the best support for me since my diagnosis.

Elle, 20



"If I need some advice or just a chat, I Skype the young people's officer. It's great to know that there's an adult (who's not family) to talk to."

Mackenzie, 21



Tell us about yourself...

I like swimming, paddle boarding, reading, and spending time with friends and family.

What is the name of your liver condition?

I have autoimmune liver disease.

How does having a liver condition affect your daily life?

I think about food and alcohol differently now and I feel stronger as it helped me work out who my real friends are.

How did you get involved with CLDF?

I wanted to meet other people like me so I went along to one of their events.

How has CLDF helped you?

CLDF has given me the opportunity to meet others in similar situations – they have been there for me so much. Going on Talk, Tell, Transform helped me to finally be able to discuss what happened to me – I am so much more confident now.

What advice would you give others who have a similar condition to you?

Before going to liver appointments write down questions you have, so you remember to ask them; it's your body after all!

"I feel stronger as it helped me work out who my real friends are."

"Live life how you want to."

What hobbies do you have?

I do a lot of drawing and designing things, I'm currently at art college. I love being outside. My favourite place is the beach.

What is the name of your liver condition?

Biliary atresia.

How old were you when you were diagnosed?

I was a baby and when I was two years old I had a liver transplant.

How does having a liver condition affect your daily life?

It doesn't affect me to a great extent. I've been very healthy regarding my liver for years. I also have Crohn's disease and sometimes the transplant can cause things to be that bit more complex in that regard. Because I was only two at the time of the transplant I don't have much memory of it but I do still worry that things might go wrong in the future. However, I know that I have a great support network from my mum and CLDF if that happens.

How has CLDF helped you?

They have always been there for me, just a phone call away, and all the residential trips I've been on with them have made me the stronger, more confident person I am today and I am forever grateful. Through CLDF I have met other people who live with a liver condition, people who have become really good friends. We are able to support each other.

What advice would you give others who have a similar condition to you?

Live life how you want to and always cherish your health and happiness because life is for living, and don't let things get to you too much.

Caragh, 18



Catherine, 18



"Now I live an almost 'normal' life, am enjoying university and looking forward to my future!"

Tell us about yourself...

I love walking, visiting historical sites, the theatre, going to the gym, and swimming. I relax with TV and music.

What is the name of your liver condition?

Biliary atresia.

How old were you when you were diagnosed?

I was diagnosed and had my liver transplant when I was a baby so I don't remember it. I may need another in the future though and I worry about the medical and physical implications such as increased appointments, needles, tablets, jaundice and gaining weight.

What difference has having a transplant made?

I know that if I had not received a transplant, I would have died not long after. Now I live an almost 'normal' life, am enjoying university and looking forward to my future!

How does having a liver condition affect your daily life?

I take medication every morning and night. I use hand sanitisers where appropriate and in the summer I use

lots of sun protection. Lastly, I avoid fizzy drinks, raw fish, salty foods, and alcohol of course!

Have you moved to adult services yet?

Yes.

Who supported you during this time?

When I met the transition nurse she was brilliant but I must admit I was very overwhelmed by the whole experience.

How has CLDF helped you?

CLDF has often been there to 'pick up the pieces' where I have been left confused or curious about my condition. They are very helpful for emotional support, guidance and advice.

What advice would you give others with the same condition?

I would say to enjoy every day and those around you. Make the most of your life and take every opportunity available, it's good to look at what you've experienced or achieved on the days you don't feel as well.

"I've been on all the young people's trips, some family days and am now a CLDF young ambassador."

Tell us about yourself...

I am a young Brownie leader, I love photography, playing the bass guitar, and travelling – my favourite place is Mexico!

How old were you when you were diagnosed?

I was 13 when I found out I had autoimmune hepatitis.

Jordan, 17



How did you get involved with CLDF?

My family were going on holiday and we needed travel insurance, so my mum contacted CLDF. She spoke to the families' officer who told us about the charity. A while later we went bowling and we've been involved ever since. I've been on all the young people's trips, some family days and am now a CLDF young ambassador.

How does having a liver condition affect your daily life?

It's not too bad. I've met some amazing people from across the UK and have connections all over the country. I've even made a best friend from CLDF! The bad side is taking medication, the constant reminder of having an illness even when I'm feeling well, and not being able to drink.

How has CLDF helped you?

They have helped me in many ways. I've met lots of new people and had experiences I otherwise would not have had. They have even helped me with my CV! I now have much more confidence in meeting new people.

Lizzie, 18



"I didn't really have much contact with CLDF until I was about 15 and despite being really shy, I went to Talk, Tell, Transform. Now I'm really involved and it's the best thing I've ever done."

What hobbies do you have?

When I am not working as a healthcare assistant I have many hobbies. I love to sing. I'm also a YouTuber, making beauty, challenge and vlog videos nearly weekly and some have been really successful.

What is the name of your liver condition?

I have biliary atresia.

How did you get involved with CLDF?

My parents met the CLDF families' officer in hospital, shortly after I was diagnosed. They provided them with information and a listening ear and after that they became really involved and my dad became a trustee.

How has CLDF helped you?

CLDF has helped me so much. In my low points I know they're always there to talk to, when I'm ill I know they can talk to me about it. They are also a brilliant source of information about my liver disease.

What advice would you give others who have a similar condition to you?

Don't live your life having liver disease. It might be a part of you but it doesn't have to own you. No matter how sick you get you always have CLDF.

Tell us about yourself...

I enjoy fishing, playing football and video games, especially Zelda, Pokémon and Mario.

What is the name of your liver condition?

I have alpha-1 antitrypsin deficiency and I have had two liver transplants. One when I was a baby and the second when I was 19. When I heard I had to get another transplant I felt like I was going to die, I was on the waiting list for two and a half years but it's made a world of difference. I don't feel unwell anymore and I'm not yellow. I have a lot more energy than I had before, and I'm not bedridden. I don't have to live in a box.

How does having a liver condition affect your daily life?

I have to take medication day and night, and I can't play any contact sports. I also get tired very easily, and I get slight insomnia due to the side effects of my medication. A lot of my friends drink and this sometimes will prevent me going out as I don't want to go out while they are all drinking and I'm drinking water. Since my transplant I've been volunteering at CLDF to get me back into a routine and boost

my CV so I can get a job in the future when my strength is fully returned.

How did you get involved with CLDF?

My family has been involved since I was five so I feel as if CLDF have always been a part of my life.

Have you moved to adult services yet?

Yes. The biggest change compared to children's services is that the doctors come straight to the point, probably because there are more patients to be seen. My main worry with transition was being in a new place, I don't like change. But actually the people are really nice.

How has CLDF helped you?

CLDF has always been my main source of information via the CLDF website; if I've ever had a question they've always answered it. They have really supported my parents and me through my life journey.

What advice would you give others who have a similar condition to you?

If you have had a transplant, treat it well, be grateful!!! And remember to take medication. Medicine is vital and is given for a reason.

Joey, 22



"My main worry with transition was being in a new place, I don't like change. But actually the people are really nice."

"There is more to life than your liver disease."

Tell us about yourself...

I'm doing A-levels in History, Politics and English. When I'm not doing that I like playing hockey and listening to music, especially hip hop. I also enjoy public speaking; I'm a talkative people person.

What is the name of your liver condition?

I was diagnosed with primary sclerosing cholangitis at 16.

How does having a liver condition affect your life?

I find I have to explain my condition a lot. Apart from that it's just remembering to take my tablets!

How did you get involved with CLDF?

When I was at my hospital appointment, the young people's officer spoke to me about what CLDF offers. A few months later, I was off on a residential with them.

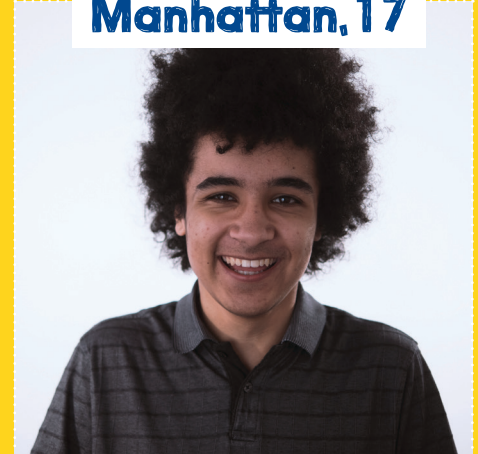
How has CLDF helped you?

I'm really happy to be involved. Before I went on Talk, Tell, Transform I didn't know much about the charity. Now I'm impressed!

What advice would you give others who have a similar condition to you?

Manage it but don't let it define you. There is more to life than your liver disease.

Manhattan, 17



Charley, 17



"I went on Closer to the Edge (now called Breakaway, a CLDF residential) and it made my life so much happier. I made friends and I got to realise that, despite what I thought, I was very much not alone."

Tell us about yourself...

I have a passion for performing arts, music, reading, baking, sport and Formula 1.

What is the name of your liver condition?

Biliary atresia.

How old were you when you were diagnosed?

I was a baby so this is all I have known.

How does having a liver condition affect your life?

Due to having an extremely weak immune system I get affected by any sick bug going around school or the family and it affects me more than others as my body can't fight the infection. I go through phases where I will get pain in my scar area from when I had surgery as a baby.

How has CLDF helped you?

Because I was only four weeks old when I was diagnosed CLDF has been a part of my life and I have always raised money for them. In 2011 I was offered a place on their Closer to the Edge (now Breakaway, a CLDF residential) and I hesitantly said yes. Before this I had no contact with any other children with a liver condition and I had no idea there was a boy who had a liver condition who actually only lived 40 minutes away from me. I went on the trip and it made my life so much happier. I made friends and I got to realise that,

despite what I thought, I was very much not alone. Even now five years on I am still in contact with some of the people I met that week.

Sadly, when I went into secondary school things went downhill for me again as my medical health and mental health became very strained. Once again CLDF seemed to have given me a miracle and I went on Talk, Tell, Transform. That week was a big turning point in my life as it was the first time I truly accepted my scar and my condition. I knew from that point on I wanted to become a young ambassador as soon as I was old enough and raise as much awareness as possible. I wanted to be able to help other young children as others have done for me.

What advice would you give others who have a similar condition to you?

Get involved! CLDF has helped me as the people running the charity and the other young people involved have given me endless amounts of support, friendship and care. Without CLDF I would not be where I am now and I wouldn't have the confidence to show my scar or even talk about my medical conditions to others. But now I can do talks in schools without any fear of judgment as I know I will always have the other young people I've met to support me.

Josh, 17



Tell us about yourself...

I enjoy athletics, especially discus throwing. I also like watching TV and Netflix, and playing PS4 games.

What is the name of your liver condition?

I have biliary atresia and received a liver transplant when I was 7 and another when I was 13.

How does having a liver condition affect your daily life?

Taking medicines is just one more thing I need to think about during my daily life and activities.

How did you get involved with CLDF?

My mum has always received information from CLDF but I didn't get involved until I went on Closer to the Edge (now Breakaway) in 2013.

Have you moved to adult services yet?

Yes – it's just a different atmosphere really. There's no brightly coloured rooms or anything to occupy you while you're waiting to be seen. You could say that the place is a bit dull but the staff are nice.

How has CLDF helped you?

The events have been a great opportunity. I enjoyed Breakaway the most and the National Conference which takes place every two years has been a real help to me and my family.

What advice would you give others with the same condition as you?

Confide in other people who you meet with similar conditions and the support team at CLDF also. Relax a little, don't worry you will be fine – you will grow. Your scars will give you a story and you will miss them when they start to fade.

**"Relax a little,
don't worry you
will be fine – you
will grow. Your
scars will give you
a story and you
will miss them
when they start
to fade."**

Want to find out more about what CLDF can offer you?

Here is an overview of CLDF's services; we're here for you from the day you turn 11 up to the age of 25 years old.

CLDF Breakaway

This event is a four-day outdoor adventure week for 12- to 15-year-olds, including a 24-hour woodland survival experience.

Talk, Tell, Transform

This is a unique five-day digital storytelling project that brings 16- to 18-year-olds together to learn skills in film making, as well as sharing with others their experience of living with a liver condition. Past stories can be viewed on CLDF's YouTube channel (youtube.com/CLDFonline).

CLDF Weekender

This event is aimed at 16- to 24-year-olds from across the UK to learn, share, and connect with other young adults with a liver condition.

Join HIVE

Hive is our safe online community where young people aged 13–24 with a liver condition can exchange stories and make friends. Visit CLDFHIVE.co.uk.

CLDF: My Liver App

A mobile app to help prepare teenagers for the transition into adult services. Including medication reminders, hospital contacts and a guide to moving to adult services. This is available on the Apple App and Google Play stores for you to download at any time.

CLDF's National Conference

Every two years CLDF hosts a conference for all the family. Whilst parents can listen to talks from experts discussing childhood liver disease, young people can meet with others and have a fun day out. Those 16+ can also volunteer on the day.

Telephone, email, and online support – We are here should you have a question, a problem, or just need someone to listen. You can call us on our direct line **0121 212 6024** or on our Young People's team mobile **07928 131955**. You can also text or send a WhatsApp message, email us at youngpeople@childliverdisease.org or contact us through Facebook – just search '**CLDF Young People's Team**'.

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What is Children's Liver Disease Foundation (CLDF)?

CLDF is the UK's leading organisation dedicated to fighting all childhood liver diseases.

CLDF provides information and support services to young people up to the age of 25 with liver conditions and their families, funds vital research into childhood liver disease and is a voice for everyone affected.

Are you a young person with a liver condition?

CLDF's Young People's team is here for you, whether you want to talk about issues affecting you, meet and share with others, or just belong to a group which cares, knows what it's like and is fighting to make a difference. You are not alone.

Get in touch:

Phone 0121 212 6024

Email youngpeople@childliverdisease.org

CLDF has a social media platform called HIVE for 13–24 year olds with a liver disease/transplant to make new friends, connect and share stories www.cldfhive.co.uk.

Would you like to help us support the fight against childhood liver disease?

All of **CLDF's** work is funded entirely through voluntary donations and fundraising. Please help us to continue to support young people, families and adults diagnosed in childhood now and in the future. To find out more about fundraising and how you can join the fight against childhood liver disease you can visit: www.childliverdisease.org/get-involved. Alternatively, you can contact the Fundraising Team by email fundraising@childliverdisease.org or call **0121 212 6022**.

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