



CFC International
Cardio-Facio-Cutaneous Syndrome

SUPER SIBLING HANDBOOK



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About CFC Syndrome

"Your sibling is 1 in a million!"

CFC Syndrome (C - cardio F - facio C - cutaneous) is rare and the genetic change which causes it doesn't happen very often.

Genetic = genes, we have around 25,000 of these and just one change can affect the way our body works.

A change in one of these genes happened in your sibling's body: BRAF, KRAS, MAP2K1, MAP2K2 or YWHAZ.

You may have noticed some of the ways this change has affected your sibling. Perhaps they have a tube to help them eat or they use a wheelchair. They may visit the hospital regularly to see lots of different doctors and you have noted that your parents spend a lot of time caring for them.



Your Amazing Role

As a Super Sibling, you are an amazing role model who shows exceptional strength, resilience, and support to your sibling and to your family.

Sometimes you may help your parents to care for your sibling, this might mean you help them to put on their shoes or comfort them when they are feeling unwell.

There are still times to play, read or watch TV with your sibling too, but as a Super Sibling, you know that spending time doing fun things can sometimes be a challenge. Especially with all the medical needs your sibling has.

A sibling with special needs like yours will need extra care and attention from your family and at CFC International we know that this can be tough.

Feelings

It is really important to tell your parents how you are feeling.

Super Siblings can often feel sad and angry that their sibling has CFC Syndrome.

You may also feel jealous of the amount of time your parents spend with them or frustrated that your sibling cannot do things that other people do.

There may be times when your parents don't realise how you are feeling. So telling people how you feel will help them to understand.

Perhaps you would like to spend time with your parent(s) on your own sometimes or you have decided that you would rather not help care for your sibling everyday, just occasionally.

Talking things through will help the whole family to come up with a plan to make things better.

"Your feelings are normal!"

it's okay to feel



your feelings

If you aren't sure how to talk to your parents about the way you feel, you could talk to another family member first or write the way you feel down and give this note to your parents as a talking point.

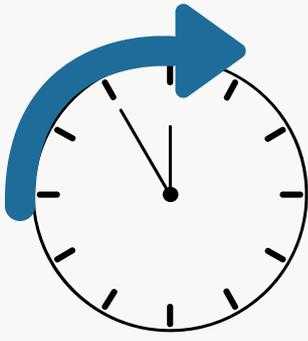
I am worried about....

Can we chat about...

Can I ask you about...

What does this mean...





The Future

Telling Friends

You might feel nervous about telling your friends about your sibling and how your life is different. It might help to tell them this "my sibling has a rare syndrome called CFC Syndrome. It affects them in lots of different ways and they have to deal with a lot of things. Maybe you might like to meet them one day.

Education for my Sibling

CFC Syndrome can mean that siblings will struggle a little more than others when it comes to education. This is because sometimes medical and mobility issues and developmental delays mean they aren't able to do school work in the way that you do.

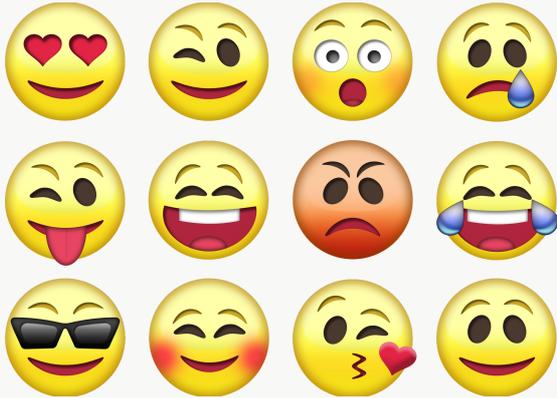
Siblings might still attend a regular school, but receive support in class or they might attend a special school if they need lots of help and support.

Communication

Sometimes siblings won't be able to communicate with others the way you do using words. Instead they might use pictures, Makaton/sign language and gestures (pointing to things). However they communicate you may find that they talk just as much as you do - just in their own way!

Journal

This page can be photocopied as many times as you like.



Today's Date

Today I am feeling....

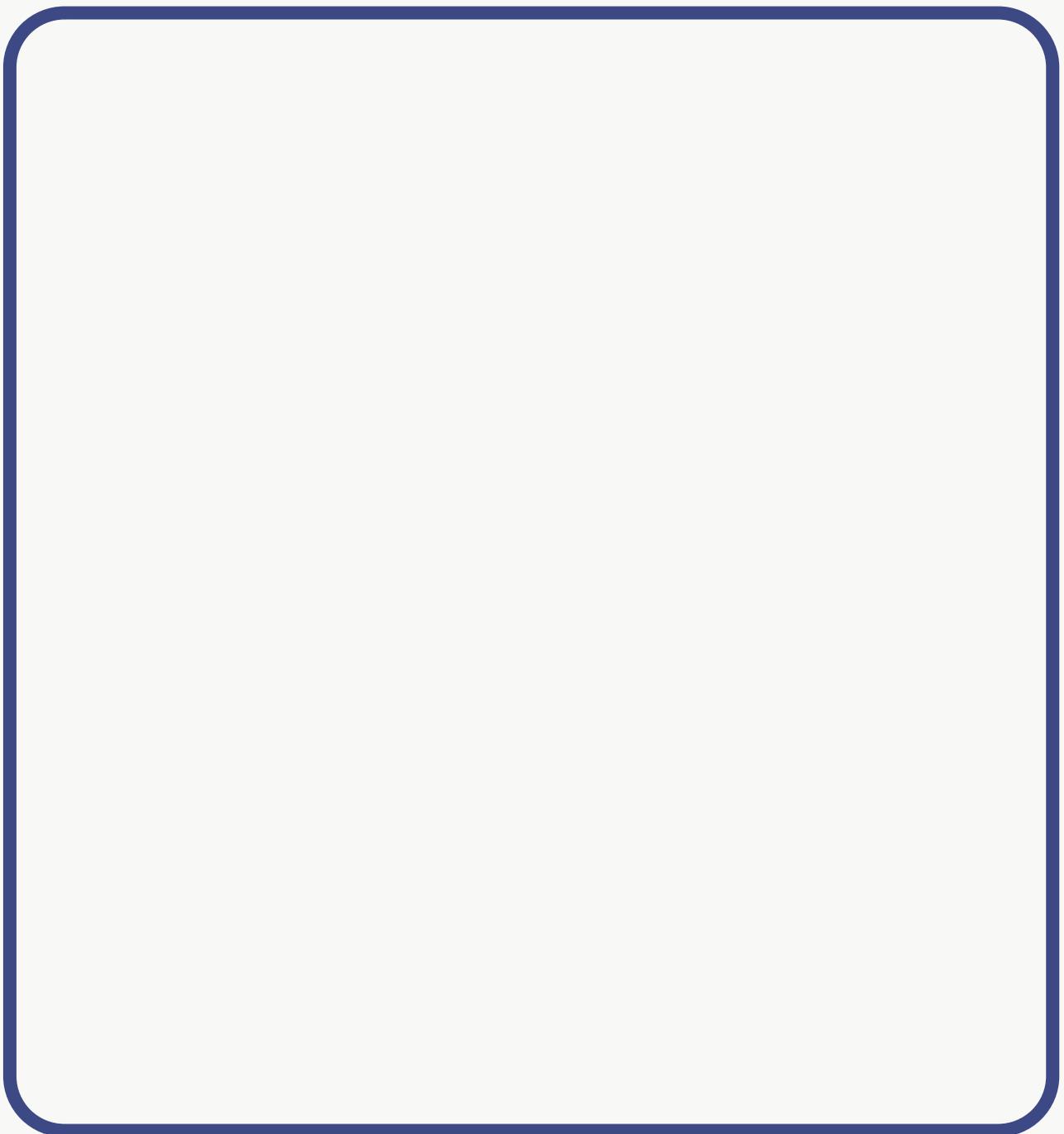
Doodle time!

Notes

Journal

For those who prefer to 'do their own thing', here is an alternative blank space to make your own.

Today's Date _____

A large, empty rounded rectangular box with a dark blue border, intended for journaling. The box is centered on the page and occupies most of the lower half of the page.

What does that mean?

Term	Explanation
Cardio	the 'C' in CFC syndrome means the heart
Communication	how you talk or communicate to someone
Congenital heart condition	a problem with the heart, like a hole or leaky valves
Cutaneous	the other 'C' in CFC Syndrome means the skin
De novo	this means new, not happened before
Facio	the 'F' in CFC Syndrome means facial features
Gastro	anything to do with the stomach and digestive system

What does that mean?

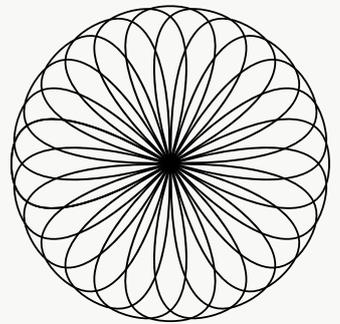
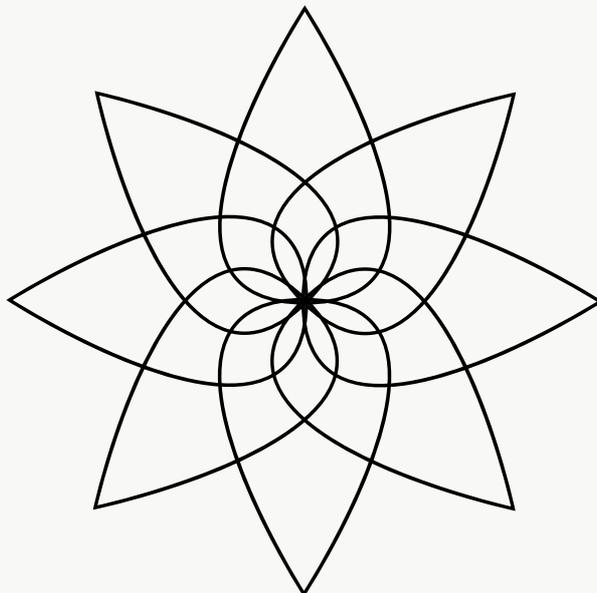
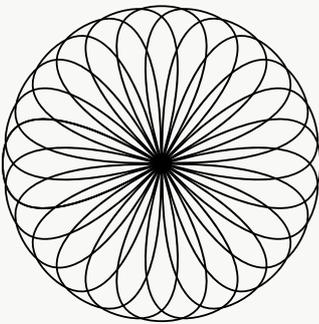
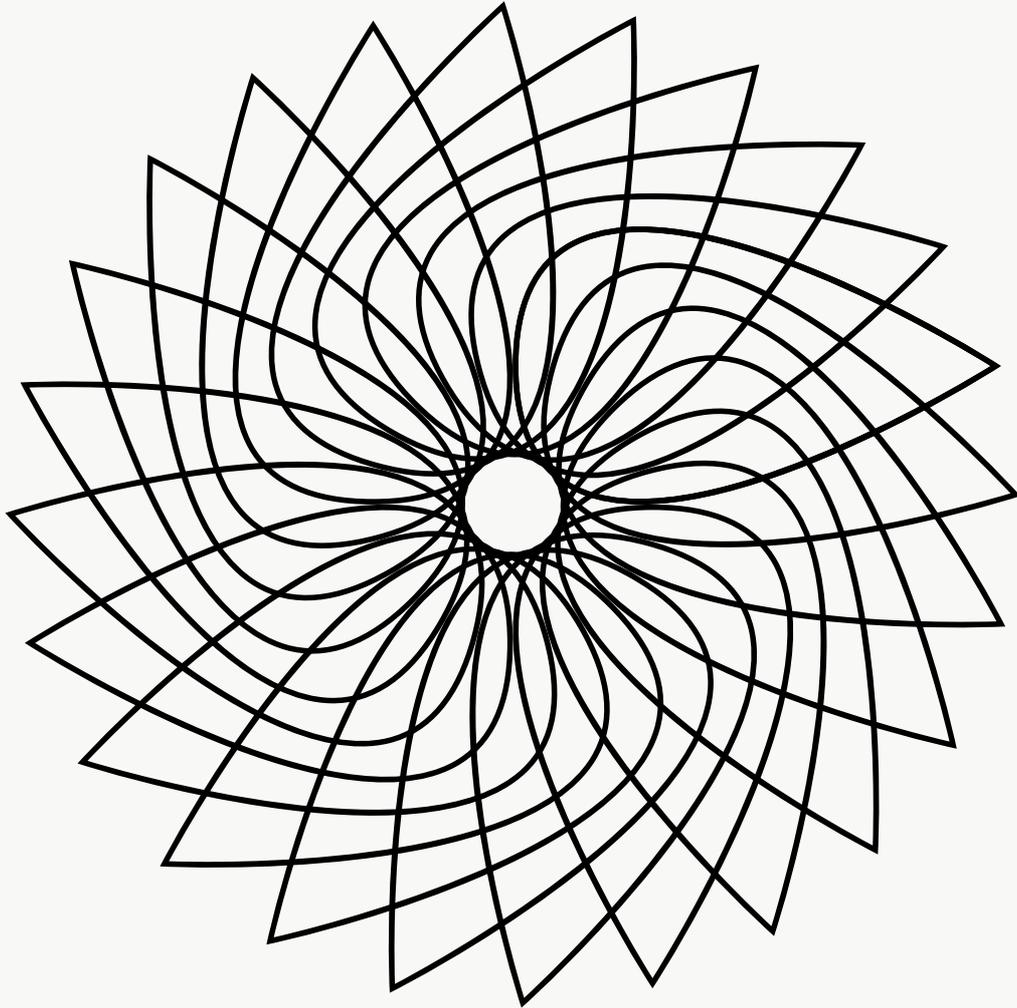
Term	Explanation
Genes	units passed down from your parents that determine your traits, like eye and hair colour
Journal	a diary or record
Makaton	a language using signs alongside speech and symbols
Medical	treatment and care from a doctor
Mobility	how you move around
Pharmacist	person who is qualified to give you the medicine written on a prescription
Prescription	a note from a doctor telling you what medicine to take and when, to be given to a pharmacist

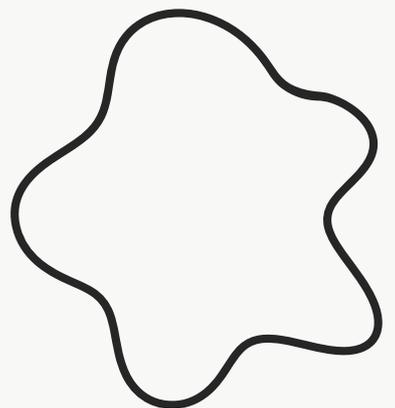
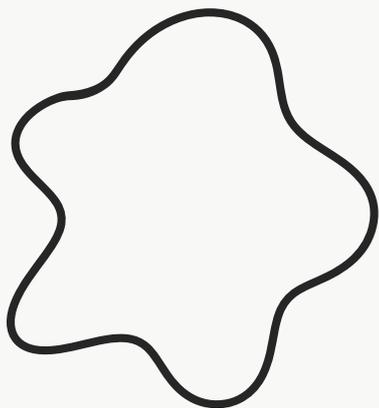
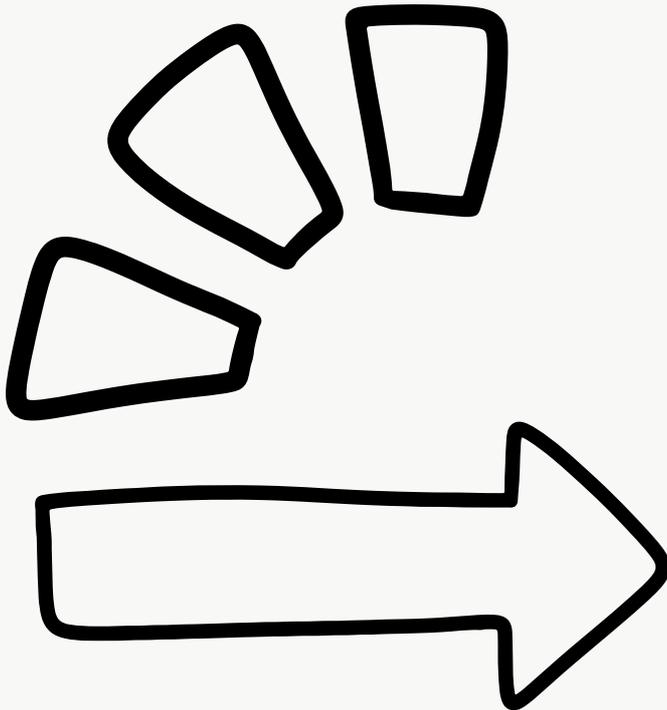
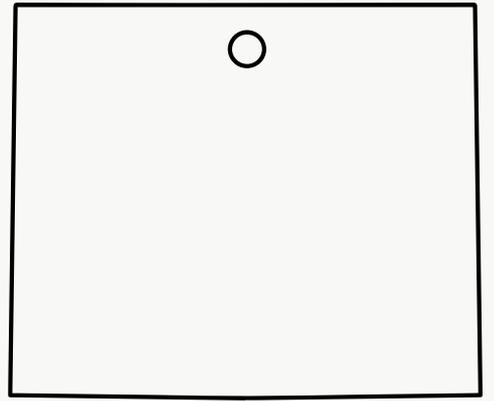
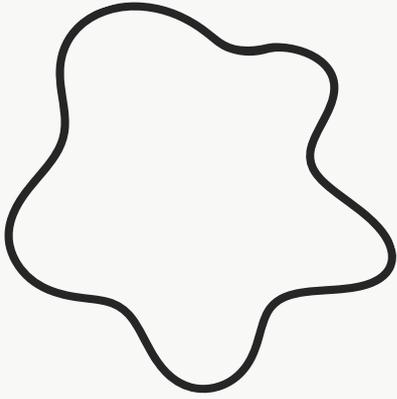
What does that mean?

Term	Explanation
SALT	speech and language therapist
Seizures	a burst of electrical signals in the brain that wouldn't normally happen. These mess around with normal brain signals and mean the body does unexpected things, like jerking or twitching or staring into space
Sibiling	a brother or sister
Sign language	a language using just signs and gestures (no speech)
Therapy	treatment and support (for example physiotherapy or feeding therapy)

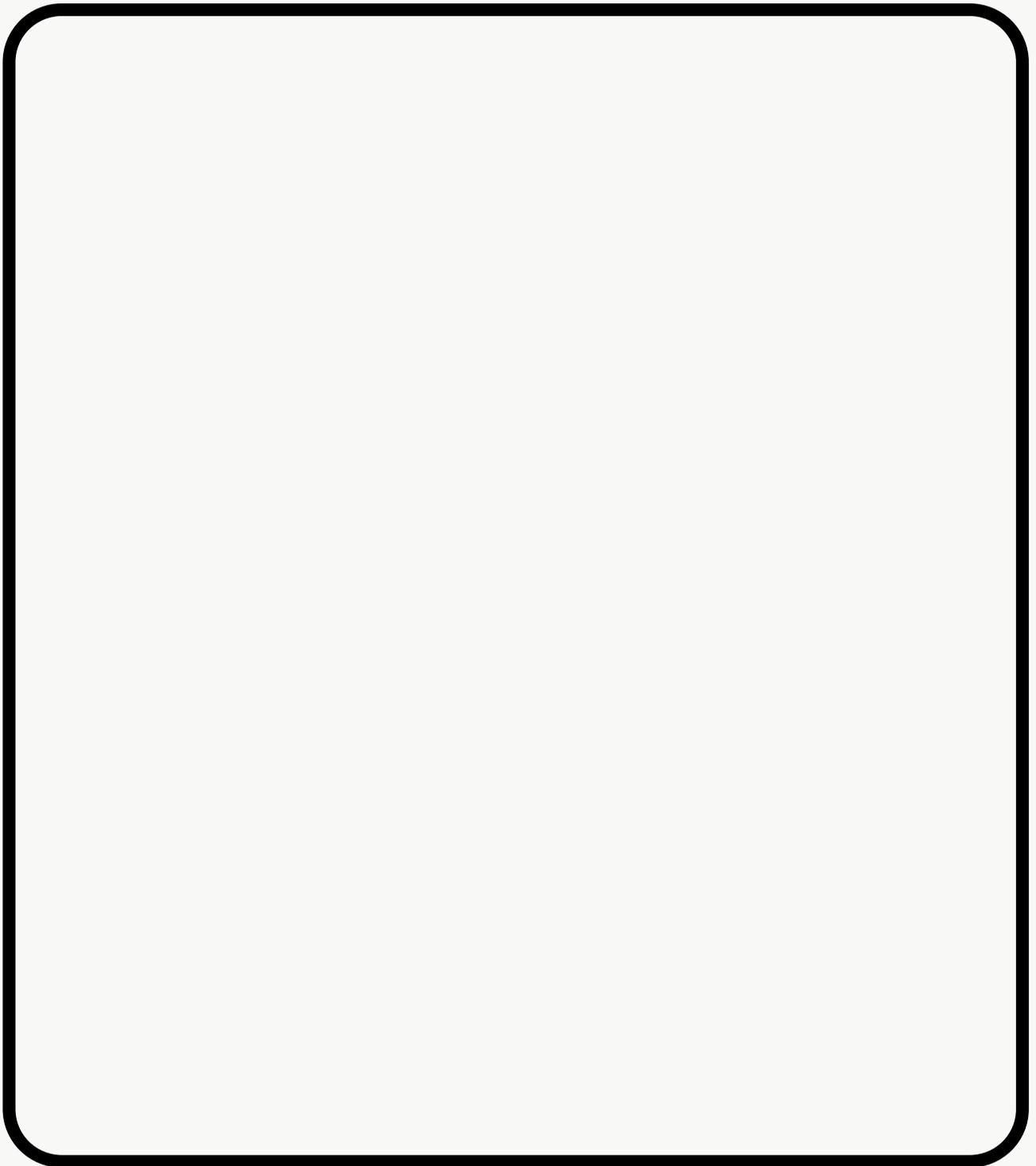
Colouring pages

(Simply print!)





**Draw a picture of you
and your sibling(s)
having fun.**



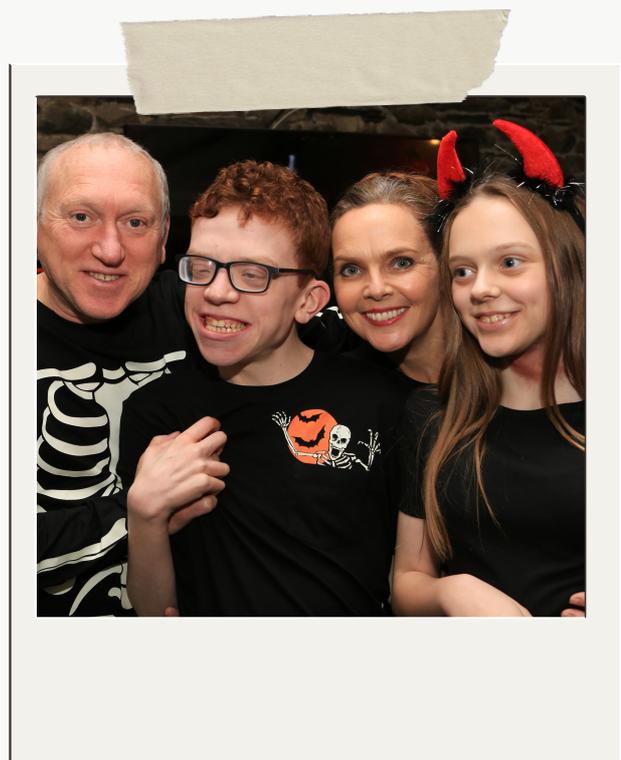
Online Resources

Find these resources online:-

Sibs (www.sibs.org.uk): A United Kingdom charity, Sibs represents the needs of disabled people. Siblings of those with life-limiting illnesses have a lifelong thirst for information, often experiencing social and emotional isolation while coping with difficult situations.

Siblings Australia, Inc. (www.siblingsaustralia.org.au): This organization is committed to improving the support available for siblings of children and adults with chronic conditions, including disability, chronic illness and mental health issues.

The Sibling Support Project (www.siblingsupport.org): This organization believes disabilities, illness and mental health issues affect the lives of all family members. Therefore, this non-profit organization aims to support the brothers and sisters of people with special needs.



Book Resources

These resources are all books:-

Living with a Brother or Sister with Special Needs: A Book for Sibs. Don Meyer and Patricia Vadasy

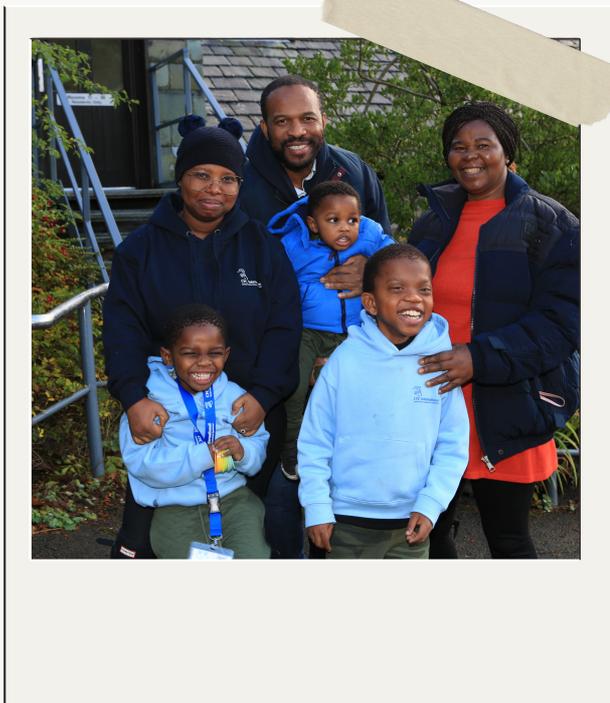
The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults With Disabilities. Don Meyer and Emily Holl

The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs. Don Meyer

Thicker Than Water: Essays by Adult Siblings of People with Disabilities. Don Meyer (Kindle Edition)

Uncommon Fathers: Reflections on Raising a Child With a Disability. Don Meyer

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs. Don Meyer



Super Sib Badges

Just to remind you how super you are! Use the image in any way you choose (ask an adult for help with any cutting out or crafting if you need it!)



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www.cfcsyndrome.org