

# CDH & me!

## How does CDH affect me?

Even though my diaphragm has been repaired I may have ongoing health or other issues/challenges. The Condition isn't that well understood and each person is affected differently. CDH UK is a registered charity and a very good resource and support for anyone affected by CDH and they have put this infographic together to help me and you. It isn't my medical history but an insight into the condition and what I may experience or have experienced.

## How you can help

Check with my Parents/Guardian that my information and medication requirements are up to date and correct. Be aware of any side effects I may suffer from medications, or medical devices that I wear or use.

Be familiar with my Parents/Guardians wishes and concerns. Know what to do or who to contact in an emergency.

Support me with extra learning, patience and understanding to help me catch up and reach my potential.

Treat me like everyone else where you can. Read the CDH UK 'An Introduction to CDH' Booklet and the Parent/Guardian Personal Detail Form provided by my Parents/Guardian.

**And remember there are Olympians who were born with a CDH!**

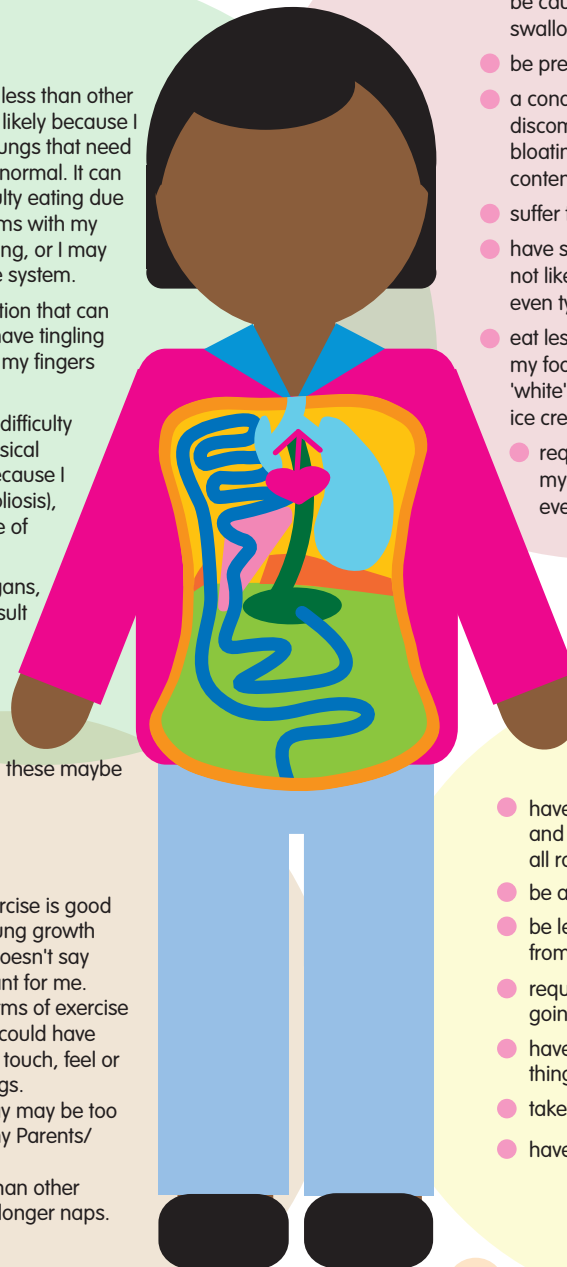
## Physical

### I may.....

- be shorter in height or weigh less than other children my age. This is most likely because I have smaller, compromised lungs that need and burn more calories than normal. It can also be because I have difficulty eating due to sensory or physical problems with my mouth, swallowing or breathing, or I may have issues with my digestive system.
- have difficulty with my circulation that can make me look pale, tired or have tingling sensations and numbness in my fingers and toes when it is colder.
- walk slower, differently, have difficulty with my balance or other physical activities and this could be because I have a curve in my spine (Scoliosis), poor muscle tone, or because of my smaller lungs.
- have problems with other organs, my bones or muscles as a result of CDH or an associated syndrome.
- breath differently and may require oxygen therapy.
- I have scars from my surgery, these maybe small or large.

## Exercise & Play

Research has shown that exercise is good for helping to develop good lung growth and so providing my Doctor doesn't say otherwise, exercise is important for me. I may struggle with certain forms of exercise or be slower than others, or I could have sensory issues and not like to touch, feel or be in contact with certain things. Some forms of exercise or play may be too rough for me so check with my Parents/Guardians first. I may tire much more easily than other children and require more or longer naps.



## Eating & Diet

### I may.....

- have problems with eating that could be caused by problems with my mouth, swallowing or digestive system.
- be prescribed a specialist diet.
- a condition called reflux that could result in discomfort, tummy pain, excess wind, bloating or I may bring up bits of stomach content or even vomit.
- suffer from food allergies or intolerances.
- have sensory issues which mean that I may not like certain textures of food or cutlery or even types of material or drinking vessels.
- eat less, slowly or not chew properly, pick at my food, or only like certain types of food like 'white' foods such as potato, pasta, cheese, ice cream.
- require tube feeding directly into my stomach, intestines or even a vein.

## Development

### I may.....

- have spent a lot of time in hospital and this could have affected my general all round physical and mental development.
- be a bit slower to learn and understand.
- be less confident and need more reassurance from teachers and other children.
- require more help with things like dressing and going to the toilet.
- have trust issues and be more wary of new things or experiences.
- take longer to settle into new surroundings.
- have an Autistic Spectrum Disorder (ASD)

## Other things to be aware of

- Hearing or sight problems and this could be the reason for any developmental delays.
- Any side effects I may suffer from medications or medical devices that I wear or use.
- More absences than my peers due to illness.
- Longer or worse symptoms with childhood ailments that could put me in hospital.
- Tummy aches or other symptoms that may not be imaginary and could be a sign that something is going on inside.

Finally, I could have been affected psychologically by my health experiences, so please be patient with me and understand my limitations.



**cdh UK** The Congenital Diaphragmatic Hernia Charity

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cdhuk.org.uk**

CDH UK is a registered charity in England and Wales (no. 1106065) and registered in Scotland (no. SC042410).  
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