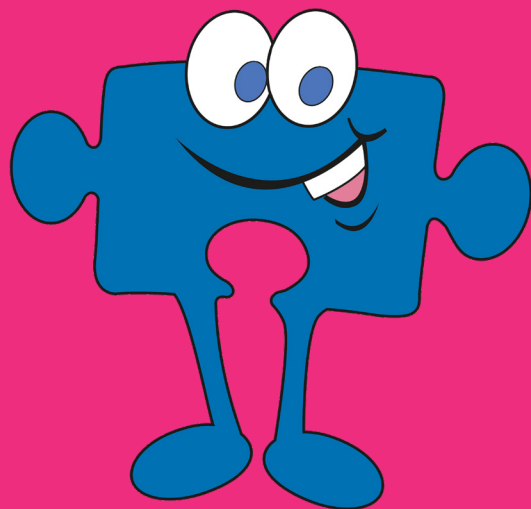


# LHM Kidz

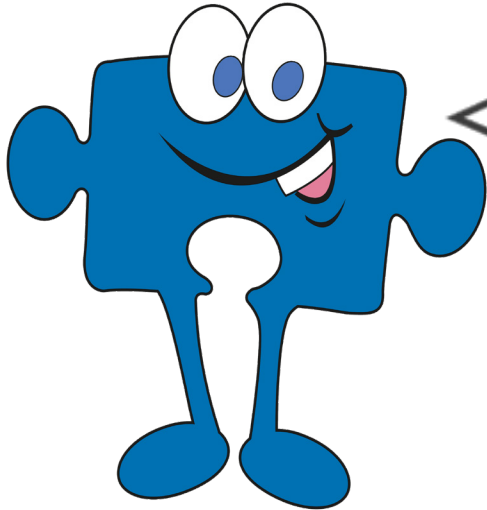
I have a special heart  
What does that mean?

Let's discover  
about your  
special heart  
together!



*Specially created for our young members*

# What does having a special heart really mean?



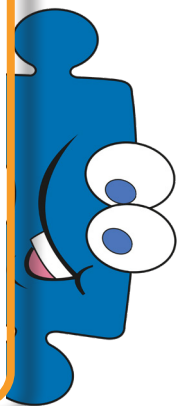
So now you know you have a special heart condition, can you remember what it's called?

---

Have you tried saying it out loud?  
I find it REALLY difficult to say!

Now, what does having a special heart really mean?

What do you think?  
Write your thoughts in the box below.



Did you think of any of these?

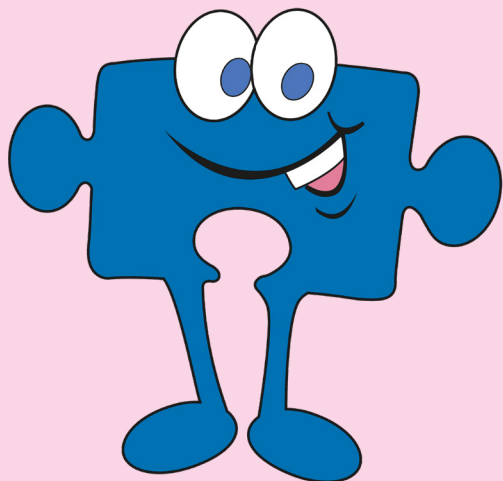
If not, take a little look at them now. Tick the ones that apply to you.

I get more tired than my friends

WHY?

When you have a special heart it means that blood doesn't move around your body as easily as children with normal hearts. Blood carries oxygen, food and water around the body which your cells then turn into energy. Because your heart has to work very hard to get blood and oxygen around your body making energy can be difficult and so you get tired. To look at it simply you probably have about half the energy of your friends.

## ENERGY

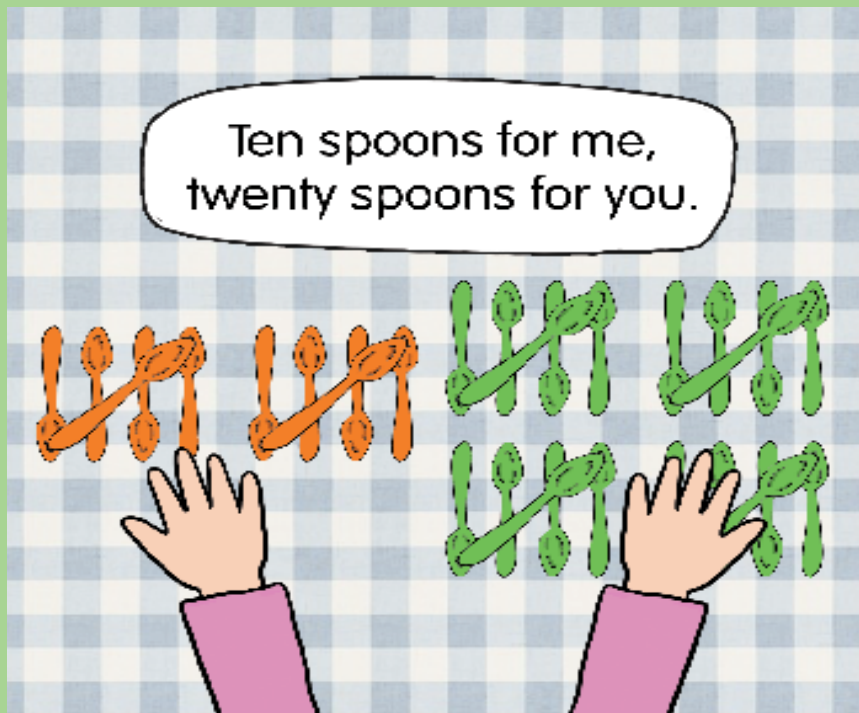


Have you ever wondered how you have the energy to do everything during the day? Do you ever feel like you get more tired and out of breath than your friends?

The energy we need every day is made inside our body using a mixture of food, drink and oxygen. Energy is made in the cells in our body from the food, water and oxygen in our blood and moved around the body by the heart. Every part of our body needs energy to work properly. Our brains need energy to think, our lungs need energy to breathe, and our muscles need energy to walk, climb the stairs and run; we even need energy to eat our meals.

When you have a special heart (a single ventricle heart condition), you can't make as much energy as your friends because you may have less oxygen in your blood and only one of the two heart pumps needed to move it around the body.

It is normal for your energy to get less and less throughout the day, so most people understand that. What is harder to explain is how children with a special heart use a lot more energy doing the same day to day activities. To make that easier to understand we use spoons to explain.



Your friends probably have 20 spoons of energy to use every day. If you have a complicated heart condition, you probably have around half that amount. So, ten spoons of energy to use every day.



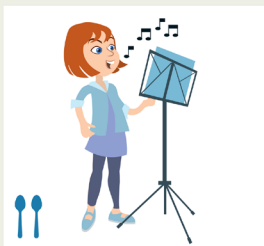
It is important to think about where you are going to use your energy every day. Everything you do needs energy: getting dressed in the morning, packing your school bag, walking to school and even concentrating and following instructions. If you have PE, a swimming lesson or an after-school activity, you may need to plan the rest of the day to have enough energy to enjoy the fun.

To help you balance your energy levels Little Hearts Matter has produced an energy timetable and an energy poster so you can try to figure out how much energy your days activities need. If you have a big party coming up you may want to have a quiet morning chilling out so you can save your energy. Have a look at our LHM Kidz Heart Gang Comic, issue 2. Tillie and Isaac have this exact problem, have a read and see how they handle it.

# Managing your energy with spoons



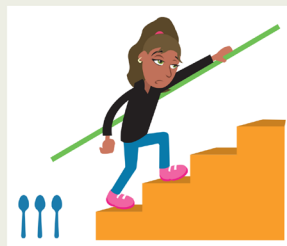
Having a healthy heart means that you start each day with 20 spoons of energy. When you have half a working heart you wake up with only 10 spoons of energy. What will you choose to do with your 10 spoons?



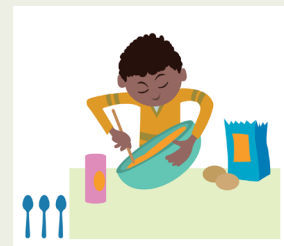
Drama/singing lessons



Getting out of bed



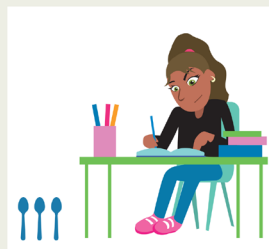
Climbing stairs



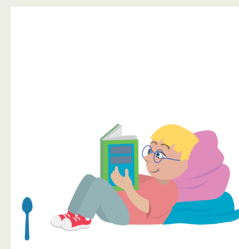
Cooking a meal



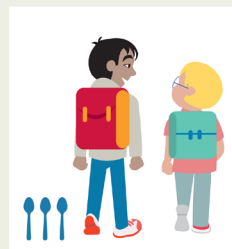
Social event with friends



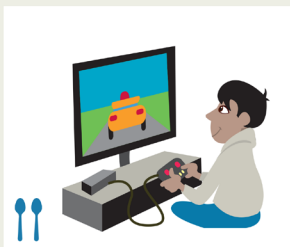
Lessons and homework



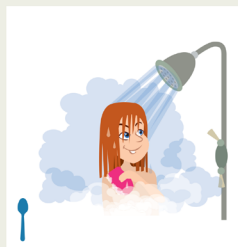
Reading a book



Walking to school



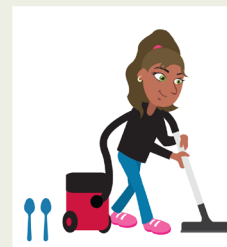
Playing computer games



Taking a shower

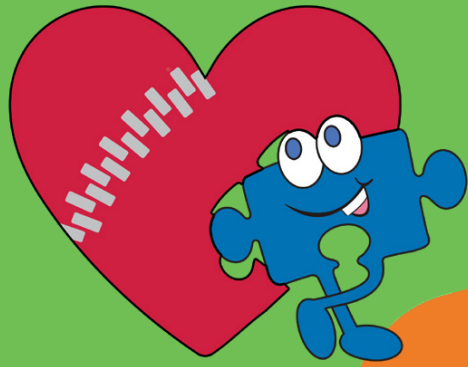


Going shopping



Tidying your room

Remember if you use more than your 10 spoons you are borrowing from tomorrow, so you may wake up with less. You can top up your energy by having a rest, nap or snack throughout the day.



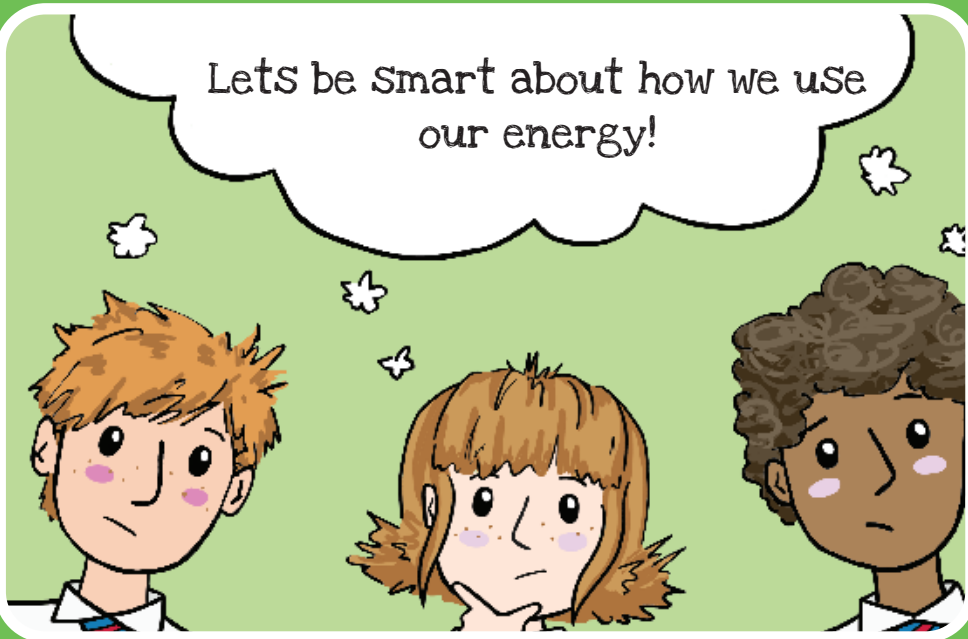
# My day in Sp



Activity:

Spoons -/+

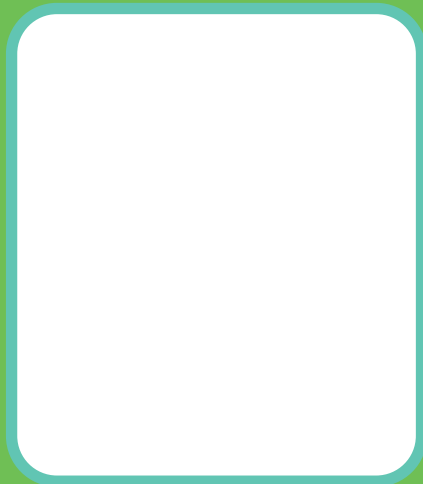
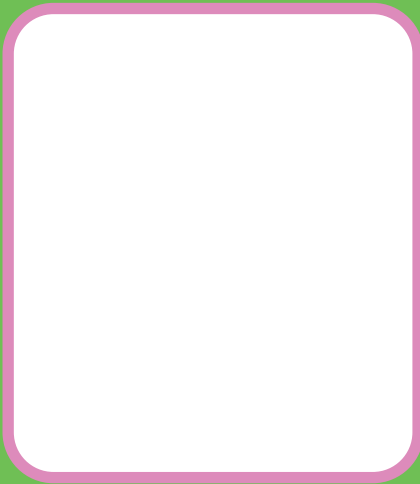
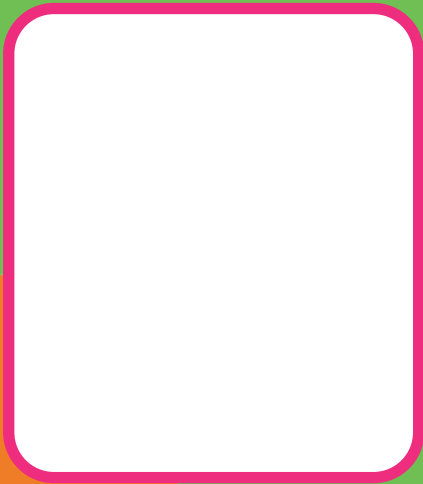
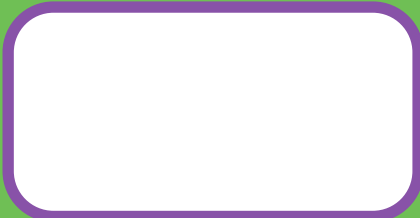
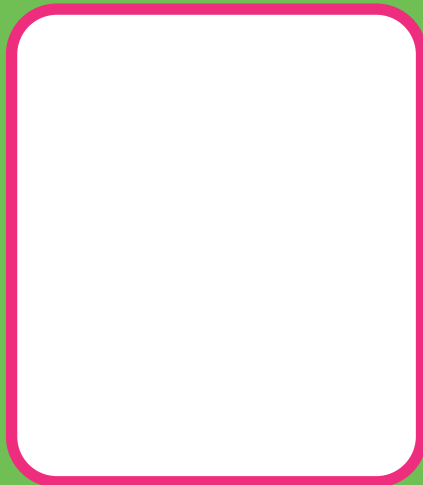
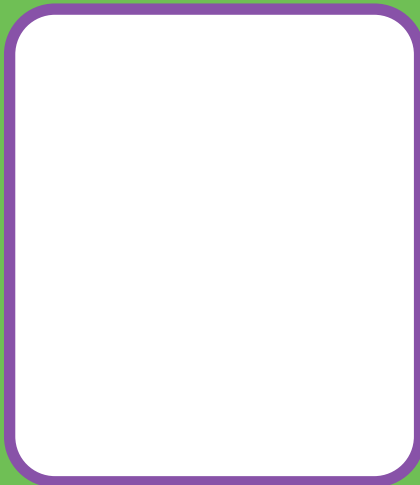
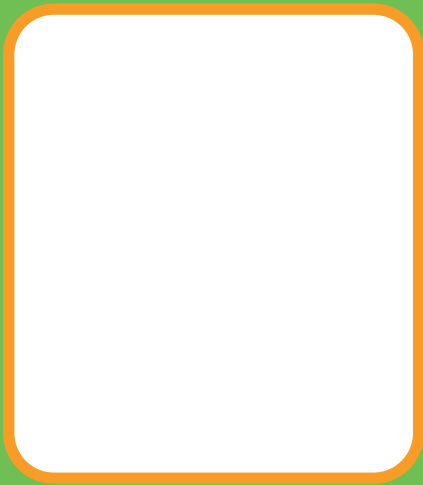
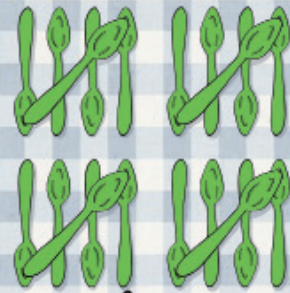
Lets be smart about how we use our energy!

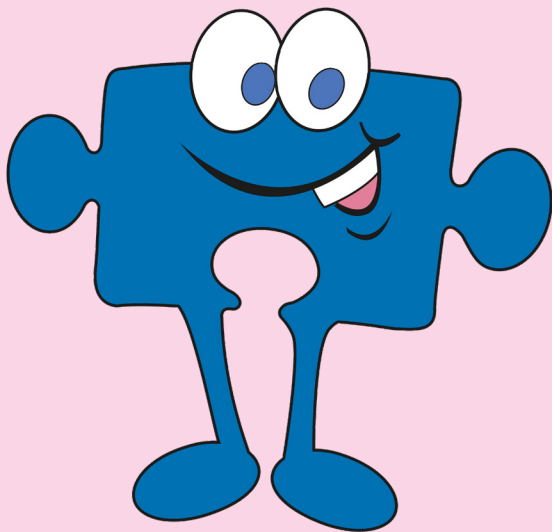




# poons!

You start your day with 10 spoons!





Eating a healthy, balanced meal can help to give you some more energy. Making sure you have a good breakfast and eating regularly throughout the day is very important.

Also sleep is very important to make sure you have enough energy. Get an early night before a big day to help give you little bit more energy. Doing this may help at some points of the day but it may still not be enough for you to do everything you want to do, so using the energy project plan is the best way to manage your day and make sure you have some energy to do the things you want, or need, to do the most.

Towards the end of the day you may feel like you have no spoons of energy left, if this happens your body may borrow some of your spoons of energy from the next day; this will help at the time but remember this means you will start the next day with fewer spoons. If this is the case make sure you plan your day with the new amount of spoons you wake up with.

Each day will bring up different challenges and sometimes you will have more energy than the day before but this tool can make sure you, your parents and teachers have a better understanding of your energy levels and why you may get more tired than others.

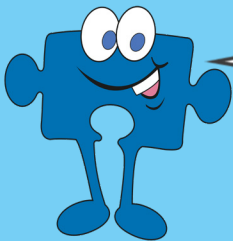


I get more out of breath than my friends

WHY?

Having a special heart means you can feel more out of breath doing everyday activities, like walking or climbing the stairs, than your friends. Everyone's heart beat and breathing rates speed up when exercising because our bodies need more energy when it's moving more. The heart beats faster and your breathing goes faster to try and get more oxygen to your moving muscles so that they can change it into energy. When you have a special heart, your heart has an extra challenge, it can't speed up as much as your friend's hearts do and you can't get more oxygen quickly. You are asking your heart to do a lot more! This can make you breathless.

Your ideas: (what do you think you could do to make things easier?)



Take regular breaks when walking or exercising. Having a short rest can help you regain your breath so you can carry on with the activity.

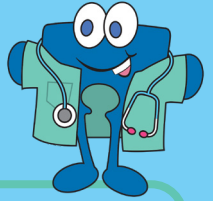
## Golden Rule!

If you are too out of breath to hold a conversation you need to take a break!

My lips go blue and I can feel very cold.



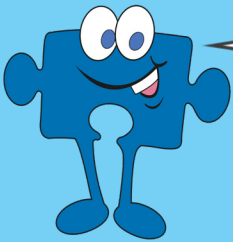
Jigzy fact:  
The word for going blue is Cyanosed.



Why?

Even people with a normal heart can go a bit blue when they get cold. That is because your heart is having to work even harder than normal to keep you warm, so it often happens when you're out in the cold or you've been swimming in a cool pool. When you have a special heart it becomes more common for your lips and skin to go a bit blue as it's a sign your blood has less oxygen and your heart is having to pump hard to keep you warm. Going a bit blue is usually not something to worry about. It's very common. If you think you are more blue than normal and perhaps a bit more breathless then talk to your heart doctor.

Your ideas:



If you notice you're going a bit blue you can help your heart by having a nice warm drink and putting on an extra layer. Take a hot water bottle on outings and if you're going swimming you can wear a wet suit to keep warm.

I have to take medication every day.

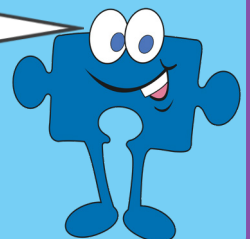


Why?

Most of our LHM kidz take medications to help their hearts. It's really important you take them as your doctor prescribes (tells you) to keep your heart as strong and healthy as possible.

Your ideas:

Your parents or carers will be responsible for your medication at the moment, but as you get older and it becomes your responsibility you can make it a part of your daily routine or set reminders on your phone so you don't forget.



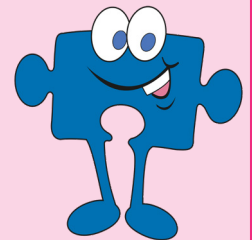
## I get more coughs and colds than my friends

### Why?

Actually, children with special hearts don't actually get MORE coughs or colds than their peers (people the same age as you) but it might feel that way because you might suffer for longer or get worse symptoms than your friends. This is because it takes a lot of energy to fight off infection (coughs and colds) and when you have a special heart it takes a bit longer because your heart is having to work really hard to get your body the energy it needs to make itself better. You may need a day or two at home in bed to recover.

### Your ideas:

Eat a healthy diet and make sure you get enough sleep. This can help you to fend off bugs and infections. You and your family may also choose to get the flu vaccine every year to give you a bit of protection from bugs.



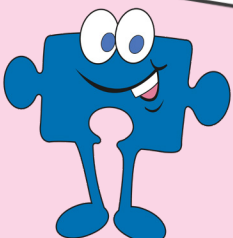
## I have to go to the hospital and the doctors a lot more than my friends

### Why?

When you have a special heart, your doctors like to do regular check-ups as a way to keep an eye on any changes. You may also need time off school for treatment. While this can be annoying as it means time off school or away from your friends it is the best way for them to keep track of any changes in your heart and make sure they are doing everything they can to keep you fit and healthy.

### Your ideas:

If you know you need time off school for testing or treatment you can ask your teacher for your school work for those days and ask your friends to reschedule meet ups for days when you can be there so you don't miss out.



## I can't join in with everything in P.E.

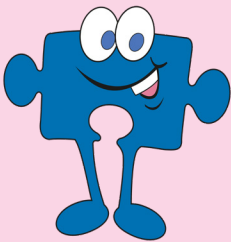
### Why?

As we've already discussed, your energy levels can be different to your peers because your heart is having to work extra hard to pump blood around your body. This means some activities can be too strenuous, like bleep tests.

Other activities, like contact sports, such as rugby, aren't advised if you're on an anti-coagulant, such as Warfarin, because if you bump yourself you are likely to bleed more than other children. Have a look at our 'Medication' booklet for more info on anti-coagulants.

There are still LOADS of things you can do, you might just need to rethink how you approach things.

### Your ideas:



Make sure your parents or carers have had a chat with your P.E teacher so they can change the lessons to suit your abilities. If you're playing cricket, perhaps you can hit the ball and have a runner so you don't have to sprint? Maybe you can join in with the skills element of a lesson and the referee when it becomes competitive? You can still always join in in some way as long as your teacher is thinking creatively.

## I feel different to my friends.

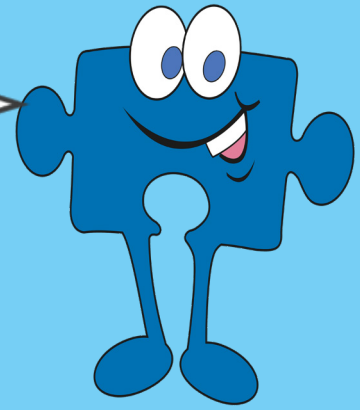
### Why?

As we get older we all start to notice differences between ourselves and our peers (school friends) and compare ourselves with others. 'They're better than me at maths,' 'They have nicer clothes than me.'

The differences can seem even more obvious when you have a special heart, because of all the things we've talked about above.

Sometimes feeling different to others can make us feel really sad and bad about ourselves.

While I know feeling different is hard I want you to remember that being different isn't always a BAD thing. You're amazing and you just need to remember that!  
When you're feeling down what can you say to yourself to make yourself feel better?



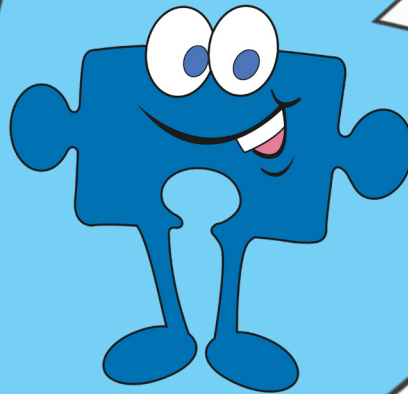
Having a special heart makes me:

I am amazing at:

When someone makes me feel bad I will say:

## Jigzy has some ideas!

I am really great at dancing and being kind to others when they need help.



My special heart makes me unique. I have a cool scar and I can tell people I was in a battle with an alligator!

My special heart is what makes me me. If you want to ask questions about it, I'll be happy to explain, but never pretend you're better than me, because you aren't.

It is normal to have moments in your life when you don't feel great about yourself. But if this is happening all the time it is important you find help. You can ask for help in a few places:

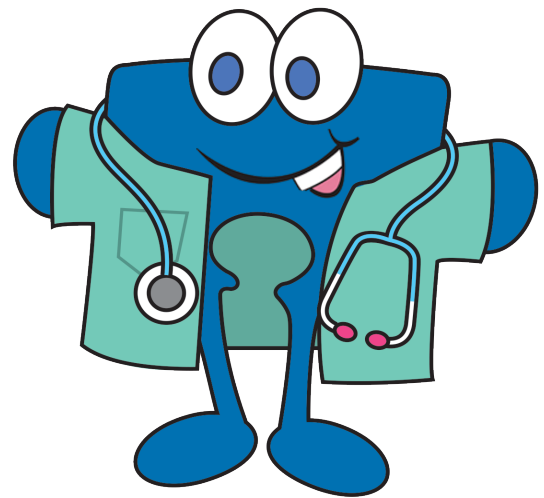
- Talk to your parents or a trusted teacher.
- Talk to us via the LHM hub. You can message Olivia privately or talk to the group.
- Call a mental health charity like Mind (0300 123 3393) or Childline (0800 1111, or have a 1 to 1 chat through their website.)



## If I am worried or have a question who should I ask?

The doctor or nurse looking after you will always be able to help or give answers if you need them. If they aren't available, you can contact the team at LHM and we will help find the answers for you. email Olivia, your LHM Kidz lead at [olivia@lhm.org.uk](mailto:olivia@lhm.org.uk)  
Also, you can always have a chat on the LHM hub, some of our other members might be able to help.

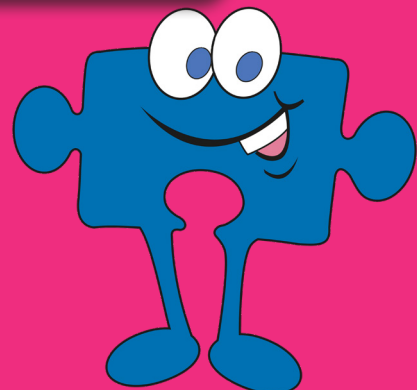
Well done! Now you're starting to understand what effects your special heart has on your body and energy levels! That's HUGE! If you feel like learning more check out some of the other LHM Kidz info packs we have available on your LHM Kidz webpage!

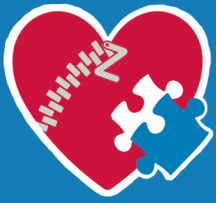


### LHM Kidz info available:

- My heart
- My medication
- Hospitals do a lot of tests, what do they all do?

Jigzy is always working hard to bring you new information and content for your LHM Kidz webpage, so keep checking back to see what's new. If there is anything you would like to see in future please email [olivia@lhm.org.uk](mailto:olivia@lhm.org.uk) to share your ideas!





# LHM Kidz Youth Hub App



We have created a safe online space for all of our youth members living with half a heart. Here you can chat with Olivia, our youth mentors AND your LHM friends.

we have created three chat groups;

- LHM KIDZ - for our 7-11 year old members
- LHM JUNIORS - for our 12-14 year olds members
- LHM SENIORS - for our 15-17 year old members



You'll be able to access our online calendar and online youth groups to chat about life topics, or just chill and play games.

Just scan the QR code, create a profile and away you go!



## Little Hearts Matter

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Littleheartsmatter



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