

Advice for heart siblings about talking about your family situation

Supporting and helping your sibling with medical and social needs can be rewarding and fun, but it can also be hard work and you need to look after yourself too. Doctors, nurses, teachers and other professionals might not understand that you play an important part in supporting your brother or sister so we have a few suggestions from organisations and other young people about talking about your situation:

Talking to your sibling

- Don't be afraid to ask questions if your sibling is old enough to talk about their heart. Share with them your fears or anxieties if you can, they will have some that they might share back.
- Find out why they can't do what you want them to or how they would like to take part - if you just "think" they can't or won't want to, you might miss out on lots of fun!

Talking to your parents/carers

- Ask questions about your sibling's condition or the medical treatment they are having, especially if you are worrying about it - often the answers will be much more positive than you think.
- Let your parents/carers know who you would like to have as your "go to" contacts, these could be family members or friends that you stay with if your sister/brother needs to be in hospital or the people you go to when things are tough.
- Make time to have fun with your parents - remember that they might have to spend a lot of time with your sibling but they also might like the suggestion of a movie night, arts and craft hour or a snack in the local cafe.
- Always be honest: *"Dad I cannot go to the hospital on Friday because I have football" is better than going and being unhappy, I used to make up all kinds of reasons why I couldn't go to hospital and I didn't want to tell my parents they were missing something, but once I started to be honest things got a lot easier"*

Talking to a professional who is there to support you, if you need to

- As a heart sibling, you'll often have to deal with medical appointments and speak to doctors and nurses, remember these people are here to help.
- Remind the medical or professional team to breakdown information or give it to you in simple language - no hospital or medical abbreviations or long words.
- If you have questions about the medical condition that you want to ask why not attend an appointment with your sibling? If they are happy for you to be there and ask, the professional team will be happy to help.
- Ask what is there for you - if you are in hospital with your sister or brother there might be

some clubs or activities going on through local groups or charities (like ECHO), find out if anything is happening on the days you visit.

- National and local charities offer information about mental health support and young carers groups, so do ask about this if you'd like to speak to them.
- Practice critical conversations and don't be afraid to speak up and ask questions or raise concerns.

Talking to your teachers at school

- Let your teacher know if your sibling is unwell or needs extra support.
- Ask your parents to inform the school if your home life becomes disrupted.
- Make quiet time for homework - if you need support ask, don't fall behind if you can help it.
- If your parents can't make the important meeting at school or see that end of year play ask your school if they can video it - that way you get to show your sibling and parents your play. Your parents will find this very useful and be pleased they can still be part of your achievements.
- Time off - If you need to take time off because your sibling is having heart surgery or treatment and you need to be at the hospital or with relatives talk to your school as early as possible to make arrangements.
- The Children's Society has an interesting report '[Hidden from View](#)' that looks into young carers missing vital time from school and training, it might be a good idea to share this with your teachers if you feel it explains what you are going through.
- Understand why you cannot attend every medical appointment with your sibling - you are important too and so is your school work or training.

The positives acquired by siblings such as tolerance, patience and kindness are rarely acknowledged or celebrated by schools.

SIBS

Am I a young Carer?

The official definition of a young carer is 'a person aged under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work).' Children and Families Act 2014 Section 96.

Sibling young carers are forced to grow up early and can often miss out on the same opportunities as other children because they care for brothers and sisters who are disabled or chronically ill.

In April 2014, two new laws, the Children and Families Act 2014 and the Care Act 2014, came into effect with regards to young carers and their families, particularly around the right to an assessment of their needs for support. The rights afforded to young carers 'will be extended to all young carers under the age of 18 regardless of who they care for, what type of care they provide or how often they provide it.' - The Care Act and Whole Family Approaches, 2015.

Find local and national support for young carers:

SIBS

SIBS is a charity dedicated to supporting brothers and sisters of children with disabilities. They have lots of information and different types of support for siblings.

Young Minds

Young Minds is a charity committed to improving the emotional wellbeing and mental health of children and young people, they offer different types of help and support.

Over the Wall

Over the Wall is a charity offering respite holidays for siblings to get away and meet other siblings in a relaxed and fun environment, more information is available [here](#).