

Factsheet



Talking to Doctors

The aim of this factsheet is to help parents and carers to prepare for a doctor's appointment.

There can be a great deal of information provided during an appointment. By preparing a few things you will have a better chance of understanding the information you are given and will be able to ask informed questions.

Prepare yourself for the appointment

You may find it helpful to write down a list of questions that you can bring to the appointment. This may seem obvious, but it can be very easy to forget to ask your questions during the appointment. You may also want to bring a pen and paper with you to take some notes. Any notes you take will help you to remember the details discussed during the appointment.

Prepare your child for the appointment

Depending on the age of your child, you may want to prepare them for the appointment.

If you have a young child, you may want to check they understand what words and phrases like 'breathless' or 'keeping up with your friends' mean. This will help them to reply to the doctor's questions. You can also use a CHF Molly's Dolly to help prepare your child for their appointment. During the appointment the doctor can use the Molly's Dolly to demonstrate any tests/examinations, which may help to reduce the child's anxiety. If your child is older, ask them to think about any questions they may want to ask the

doctor. Older children, especially teenagers, may have questions that they are embarrassed to ask the doctor in front of you. If your child is in their teens, ask them if they would like to talk to the doctor alone.

Take someone else with you

As a great deal of information can be shared during appointments, it is often very helpful to have another adult with you. It can be hard to remember everything that is said during an appointment and having someone to support you will be helpful, especially when you are stressed. Why not ask a family member or a trusted friend to come with you? It may also be helpful to ask them to take notes during the appointment.

If you are unfamiliar with the English language, you can ask for an interpreter to attend the appointment. If you have communication problems, you can ask for a communication support worker to attend the appointment.

Remember:

- There are no stupid questions.
- Make sure you understand everything, if not, ask again.
- Do not worry that you are taking up too much of the doctor's time, it is important that you get all the information you need.
- Be assertive if necessary, but never aggressive.



Finding out your child has a heart condition can be very upsetting. It can be hard to take everything in that you are being told. If you think of more questions after your appointment, book another appointment with the doctor, or ask to speak to them on the phone or via email. Alternatively, you can get in touch with your cardiac liaison nurse.

Some examples of questions you may want to ask are shown below:

- What is the name of my child's heart condition? (Write it down)
- Where is the best place to treat this condition? (Find out if there is a specialist paediatric cardiac unit that deals with this condition)
- What treatment does the doctor recommend?
- Will my child need an operation?

Discussing further tests

If the doctor wants to do further tests on your child, you may want to ask the following questions:

- What are the tests for?
- What will happen during the tests?
- When and where will the tests be carried out?
- How accurate are the tests?
- When will the results be available?
- How often will these tests be needed?
- Who do I contact if I have more questions?

Discussing new medication

It may be useful to bring a list of your child's medication (include any food supplements, vitamins etc.) to the appointment. Some parents find it easier to bring medicines to a doctor's appointment rather than make a list. If the doctor is suggesting putting your child on medication, you may want to ask the following questions:

- For how long will my child have to take this medication?
- What are the possible side effects of this medication and how common are they?
- Are there any foods, other medicines or activities my child should avoid while taking this medication?
- What happens if this medication does not work?
- What happens if we miss a dose?
- Is there anything else that should be avoided?

Discussing an operation

All operations carry some risk. If the doctor is suggesting your child needs an operation, it is important that you understand what these risks are before you decide whether or not to give your consent (permission).

Some of the questions you may want to ask in this situation are shown below:

- How will the operation benefit my child?
- What are the risks involved in this operation?
- What is likely to happen if the operation is not done?
- Are there any alternatives to performing this operation?
- Who will be doing the operation?
- How long does the operation generally take?
- What are the success rates for this surgeon and this operation?
- How long will it take for my child to get back to their normal routine after the operation?
- Will my child be left with a scar?
- Is my child likely to need further operations or treatment after this operation?
- What are the long-term effects?



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Discussing what happens next

Make sure you understand the next steps after the appointment.

Here are some questions that may be helpful:

- What happens next?
- Do I need to come back and see you? If so, when?
- Who do I contact if things get worse?
- Do you have any written information?
- Where can I go for more information?
- Is there a support group or any other source of help?
- Where can I find more reliable information?
- Try to book your next appointment and make sure to put it in your calendar.

Before you leave an appointment, check that you will be receiving a detailed letter about what was discussed with your doctor. Your GP should also get a copy of this letter. You should also make sure that you understand what has been discussed.

If a cardiac liaison nurse has been appointed to you, make sure to contact them with any health-related questions about your child.

About this document:

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To inform CHF of a comment or suggestion, please contact us via info@chfed.org.uk or Tel: 0300 561 0065.



General checklist

- Plan in advance how to get to the appointment and leave enough time for possible delays.
- Have a list of questions with you.
- Take a pen and paper with you.
- Take a list of all medicines (including dosage and concentration) that your child is currently prescribed along to your appointment.
- Repeating what the doctor has said to you will help you to make sure that you have fully understood what they tried to explain. For example, "So you are saying that if my child will take drug X, then Y will happen?".
- If you do not fully understand what the doctor is saying, ask them politely to explain it again until you understand what he is trying to explain, "Can you please repeat this?".
- If there are any words that you do not understand, write them down, so you can look them up later.
- When talking about the heart, it is often helpful if the doctor draws you a diagram, they will be more than happy to do this, just ask them to draw a sketch.
- Make sure that you understand what will happen next after you leave the appointment.

If you are unsure about anything please call CHF on 0300 561 0065.

Evidence and sources of information for this CHF information sheet can be obtained at:

(1) National Institute for Health & Care Excellence. Structural Heart Defects Overview. London: NICE; 2017. Available at:

<https://pathways.nice.org.uk/pathways/structural-heart-defects>

(2) NHS Choices. Congenital Heart Disease. London: NHS; 2017. Available at:

www.nhs.uk/conditions/congenital-heart-disease/pages/Introduction.aspx

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