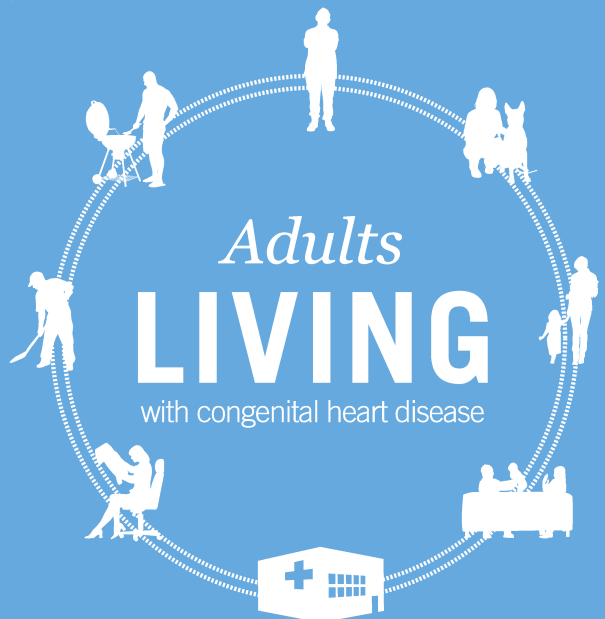


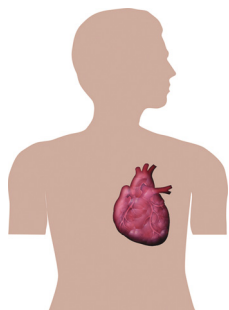
Making life better for adults with congenital heart disease

An Easy Read Leaflet
May 2012



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What congenital heart disease is

Congenital heart disease is when you are born with something wrong with your heart.

There are lots of adults living with this disease in England.



Having **congenital heart disease** can change a lot of things in your life. People who have it need lots of advice, support and care.



What this leaflet is about

We are the **NHS**. We are in charge of providing health services in the UK.

We have written this leaflet to find out your views on changes to services for adults with **congenital heart disease**.



We want to make sure good support and care happens for everyone – no matter who they are or where they live.



What the NHS is doing

We spoke to patients, their families and people who work in the NHS.

We found that there can be big differences in the support and care adults with **congenital heart disease** are getting.



Some patients said they

- get very good care but think things could still be better
- wanted to get more advice about how to live with **congenital heart disease**



We want to change this. We want all adults who live with this condition to

- be safe in things they do
- live a long and healthy life
- get the best care and treatment



More about adult congenital heart disease

People are born with **congenital heart disease**. Adult **congenital heart disease** affects adults over 16 and is a rare condition. This means that not many people have it.



Some people do not know they have it until they are adults.

Treatment and medicine is now a lot better. This means more people with **congenital heart disease** can live a longer life.



Looking at services

We want to look at services that help adults who need care and support through their lives. We want to look at what is happening for people now and what could happen in the future.



So far, we have looked at things to do with

- learning, working and going out with friends



- relationships, family and having children
- other things to do with keeping well and having a healthy life



The **NHS** needs to give as much support and advice on these things as possible. It is possible for adults with **congenital heart disease** to do everything that other people do. The more they know about the condition, the better they can deal with things.



Looking after your body and heart

Looking after your body and heart is important for everyone. Keeping fit and eating well is very important for adults with **congenital heart disease** too. You can get advice on the right kind of exercise that is good for your heart.



It is important to keep your teeth clean and looked after too. Not doing this could damage your heart.



Growing up with heart disease

It can be hard for people growing up with **congenital heart disease**. Moving from being a teenager to an adult can be one of the hardest times for people. It can make them feel lonely and not part of things.



Services need to be right for the age of the person who is using them. For example, teenagers need to use services and get support that is right for them. This might not be the same service as for an adult.



Feeling good about yourself and being happy

Having a condition like this can make you feel different. Lots of people told us that they worried a lot about their health and found things hard.



Getting support with mental health and how you feel can be very helpful too. For example, having **counselling** can help a lot. **Counselling** is when you sit and talk to someone about how you feel.



Getting older

Getting older can mean that people start to have new things wrong with them. Some people with **congenital heart disease** can get other conditions as they get older too.

We want to make sure that older people get the right care and support. We want them to get the services that would help them as things change.

Moving from children to adult services

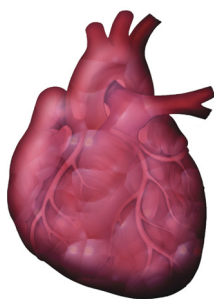


It can be hard for people to move from children's services to adult services. Some people do not get the care and support they need.



Transition clinics have been set up in some parts of the country to deal with this. **Transition clinics** are services that give special help and support to people moving between services.

But this is not happening everywhere. We need to make sure that the right services and support are there for everyone who needs them.



Having enough services for people

More people are starting to need **specialist care** to help them with adult **congenital heart disease**. We want to make sure this happens in a good way and the right services are there for people.

We want



- doctors to have enough time to be with their patients
- women with **congenital heart disease** who have babies to get the care they need
- adults with **congenital heart disease** and other conditions to get the care they need



People who work in **specialist care** need to work together. This would help everyone get the right care and services.



Training staff

The **NHS** needs to train staff so they know how to take care of adults with **congenital heart disease**. This would mean getting the right training. It can be better if adults with **congenital heart disease** are treated as part of a specialist service.

It is our job to make these things happen.

How services work



A group of experts have thought of better ways that services can work. They hope their ideas for services would help more adults get the best possible care and support.

We want to know what you think about these ideas.

The services would work in different ways to deliver care. This would happen at **specialist centres** and in local centres too. **Specialist centres** are places where people can get special treatment.

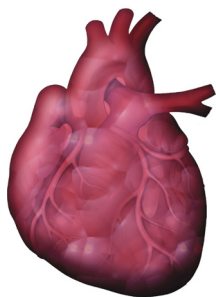
We want adults to get the best care possible and get as much support as they can.





Changes we want to make

- **local centres** would be in charge of everyday care. This is where people would still go for regular checks on their health
- **intermediate centres** would be in charge of things to do with the heart that do not need surgery
- **specialist centres** would be in charge of things to do with surgery. We want to have a smaller number of specialist centres with bigger teams of heart surgeons. We think this will help people get the best care by surgeons who have lots of practice with congenital heart disease
- we want to make it easier for children and teenagers to move into getting the care they need as adults. We think the best way for this to happen is to have specialist nurses to help people move between services



We want your views. You can read more about the services by going to www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease



Getting care closer to home

We want patients to get the best care they can close to where they live. This would stop patients having to travel to a specialist centre all of the time.



Patients should have a care plan to make sure they get the right care. Their doctors should know as much as possible about them so they can get this.



If there is an emergency, then a specialist heart doctor who knows a lot about **congenital heart disease** should be able to help.



We want families to be able to stay near to specialist centres if they need to. Adults with **congenital heart disease** and a learning disability might need to have their carers and family close to them. These people would need somewhere to stay too.



Linking services together

We want to link up doctors, nurses and specialist centres and get them working together. This would help adults with **congenital heart disease** get the best care and support.



More adults are living with **congenital heart disease**. This means that some nurses and doctors would have to work very hard to care for patients.

We want patients to have a nurse that they know well to take care of them. This helps the patient get the right care and advice.



We want better support and information for partners, families and carers. This would help people know where to go to get the right advice.

Specialist centres should have the best information for patients so that everyone knows about support they can get.

Heart charities can help to do this too.

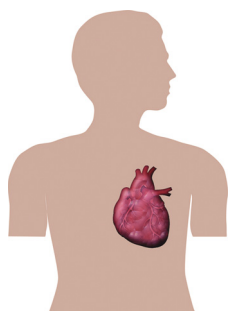




Adults with Down's Syndrome

Down's Syndrome is a condition you are born with. Almost half of people who have **Down's Syndrome** are born with heart problems.

It is very important that these people know as much as they can about adult **congenital heart disease**. They should get the right emotional support too – this means getting support to do with how they feel.



Doing things in a good way

The NHS asked a special group to work together to write down the best way to give care and advice on everything about adults with **congenital heart disease**.





As part of their work, they wrote a list about the best kind of care and support people with congenital heart problems need.

You can read more about this list by going to

<http://www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease>



What happens next

The **NHS** will ask another group that know a lot about **congenital heart disease** to work with them.

The group would visit different hospitals to find out if they are following the right standards in things to do with **congenital heart disease**.



We want you to tell us what you think about the standards. The things you tell us would help the plan develop.

Over the next few months, we are working on a plan to make things better for adults with **congenital heart disease**.



You can tell us what you think by

Writing to us at:

**Christy Rowley
NHS Specialised Commissioning Team
2nd floor
Southside
105 Victoria Street
London SW1E 6QT**



E-mailing us at

adultheart@nsscg.nhs.uk

You can read about the list we are putting together to make sure people get the right care, on this website
www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease



For more information, you can

Telephone 0207 025 7520

Or email

nhsspecialisedservices@grayling.com



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- **Down's Heart Group**

Organisations involved in the review



BRITISH CONGENITAL CARDIAC ASSOCIATION



British Cardiovascular Society



children's heart
FEDERATION



Royal College
of Nursing®



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Bringing to life the best in women's health care

