

# Adult Congenital Heart Disease Syndromes and Learning Disabilities

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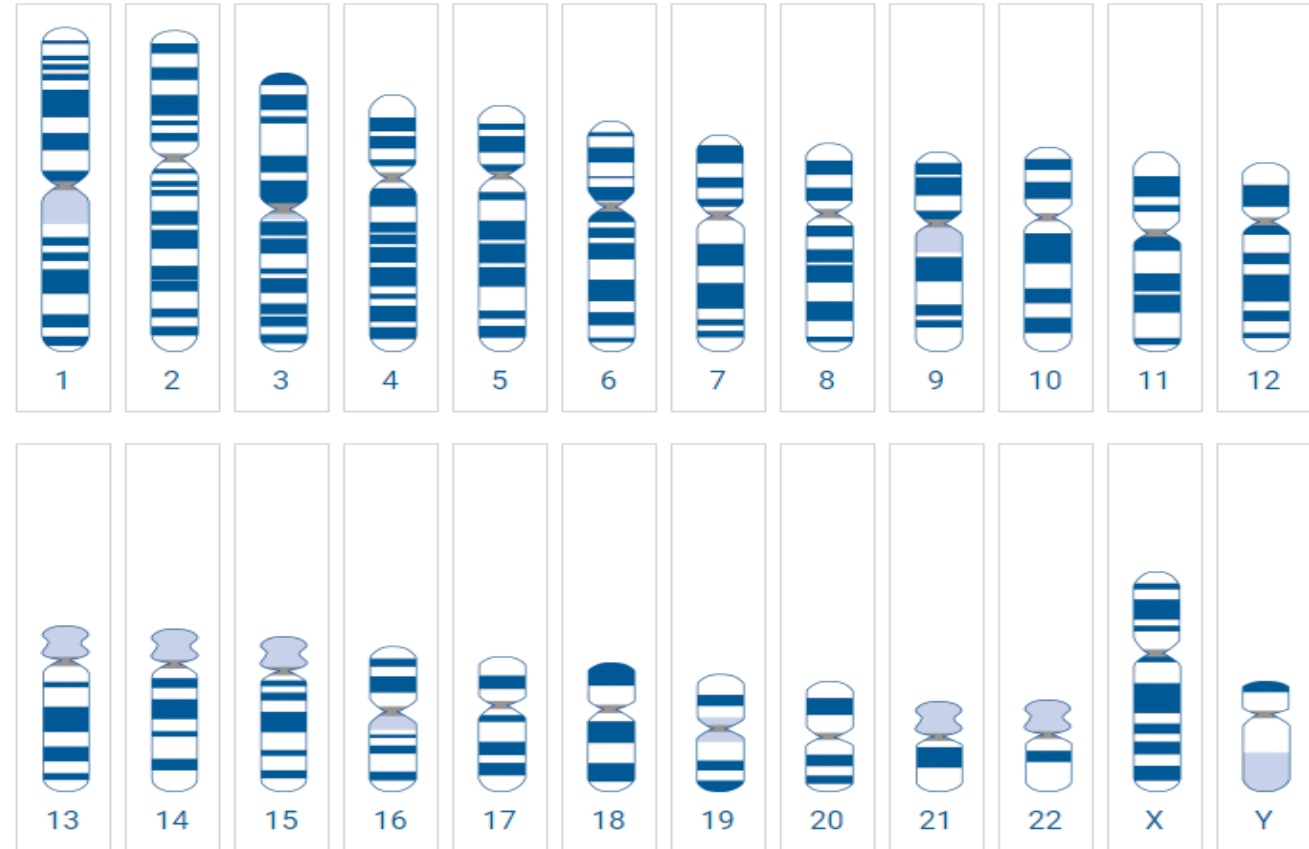
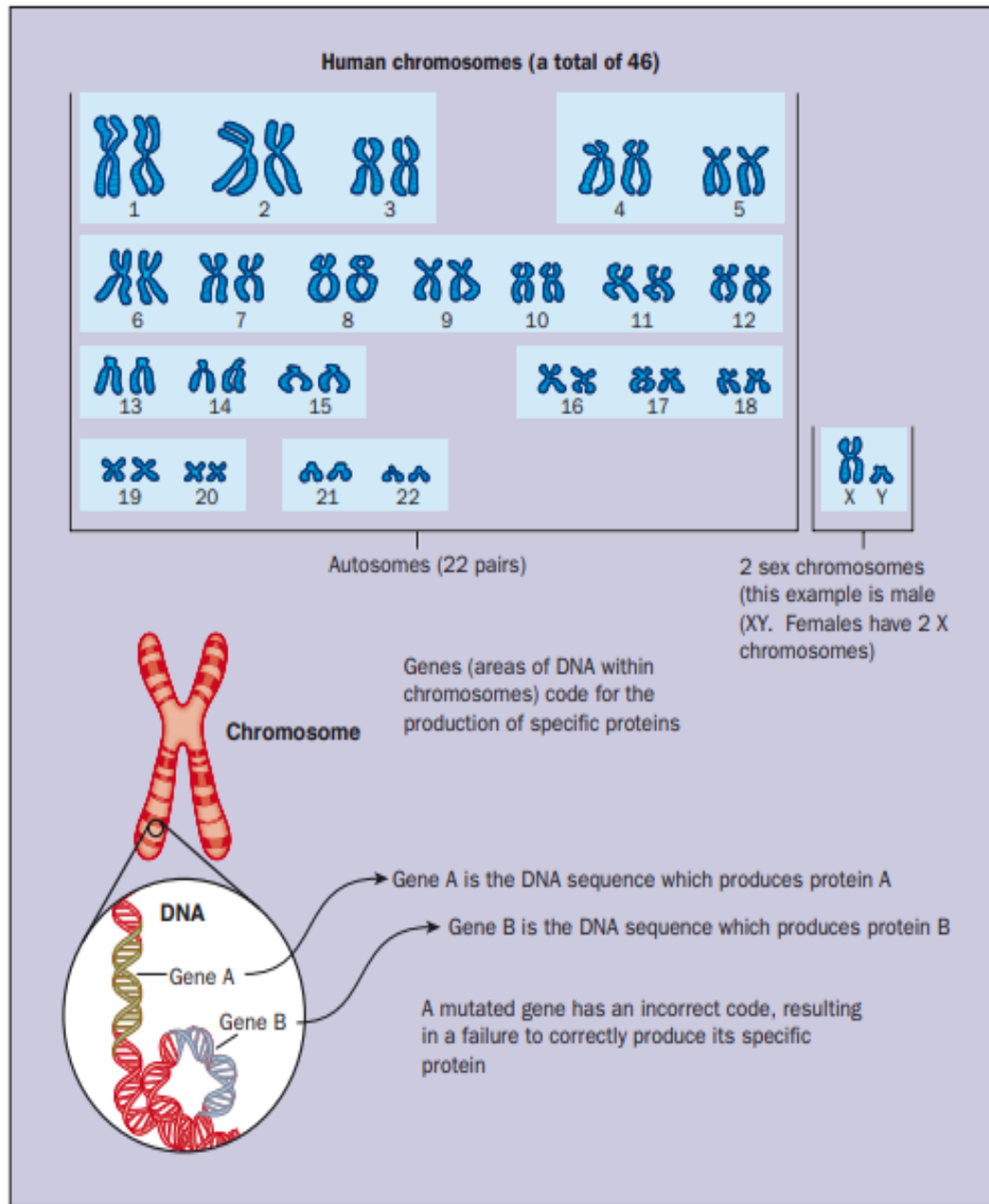
# What do I need to know?



## Learning disability

- Genetics is associated with molecular biology, the study of genes, genetic variation, and heredity in organisms.
- Genetic information is passed down from one generation to another.
- Adults with more complex CHD have been found to have a higher frequency of neurological comorbidities.

(Newburger et al, 2016)



**Figure 1. Human chromosomes and genetic mutation**

There are several genetic syndromes in which both CHD and learning disability occur.

They frequently have common lesions associated with their genetic make up

- |  |   |
|--|---|
| <ul style="list-style-type: none"><li>• Downs syndrome</li><li>• Williams syndrome</li><li>• Turners syndrome (Female)</li><li>• Alagille syndrome</li><li>• Noonan syndrome</li><br/><li>• Di George Syndrome 22q11.2 Deletion Syndrome</li></ul> | <ul style="list-style-type: none"><li>• Atrioventricular Septal Defect (AVSD) &amp; Ventricular Septal Defect.</li><li>• Supravalvar Aortic Stenosis. Pulmonary Arterial Stenosis.</li><li>• Aortic Stenosis and Aortopathy – Bicuspid aortic valve.</li><li>• Pulmonary stenosis. VSD</li><li>• Pulmonary stenosis with or without dysplastic pulmonary valve and hypertrophic cardiomyopathy.</li><li>• Tetralogy of Fallot, pulmonary atresia with ventricular septal defect, truncus arteriosus, interrupted aortic arch, isolated anomalies of the aortic arch, and ventricular septal defect.</li></ul> |
|--|---|

# How common is it?

- At least 10% of Adult CHD patients have some form of learning disability.
- Young adults are particularly vulnerable at this time during transfer from paediatric to adult health care settings

*(Adult Congenital Heart Disease (ACHD) Specification - NHS England, 2016)*

# Definition

A learning disability is caused by the way the brain develops.

There are many different types and most develop before a baby is born, during birth or because of a serious illness in early childhood.

A learning disability is lifelong and usually has a significant impact on a person's life.

A learning disability is a reduced intellectual ability and difficulty with everyday activities.

For example household tasks, socialising or managing money – which affects someone for their whole life.

# Capacity Assessment is required

If a patient with learning disability requires:

- Cardiac specific intervention
- Procedure in a cardiac cath lab
- Cardiac surgery

Then a capacity assessment must be carried out using Trust documentation.

If unsure contact the Learning Disability Nurse Specialist or the Adult Congenital Heart Disease CNS - Call the office on 0117 3426599



# Provide written information in an Easy Read format

WHAT TO EXPECT AT YOUR

## ANNUAL HEALTH CHECK

FOR SOMEONE WITH A  
LEARNING DISABILITY

<https://www.easyhealth.org.uk/wp-content/uploads/2020/05/What-To-Expect-During-Your-Learning-Disability-Health-Check.pdf>



**easyhealth.org.uk**





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Go for it"**

Going to hospital for an operation on your heart

# I'm gonna go for it

Andrew was born with something wrong with his heart. He went to hospital for an operation to fix it.

The operation was a great success. Andrew feels much better now his heart is fixed.



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Running time : 35 minutes.  
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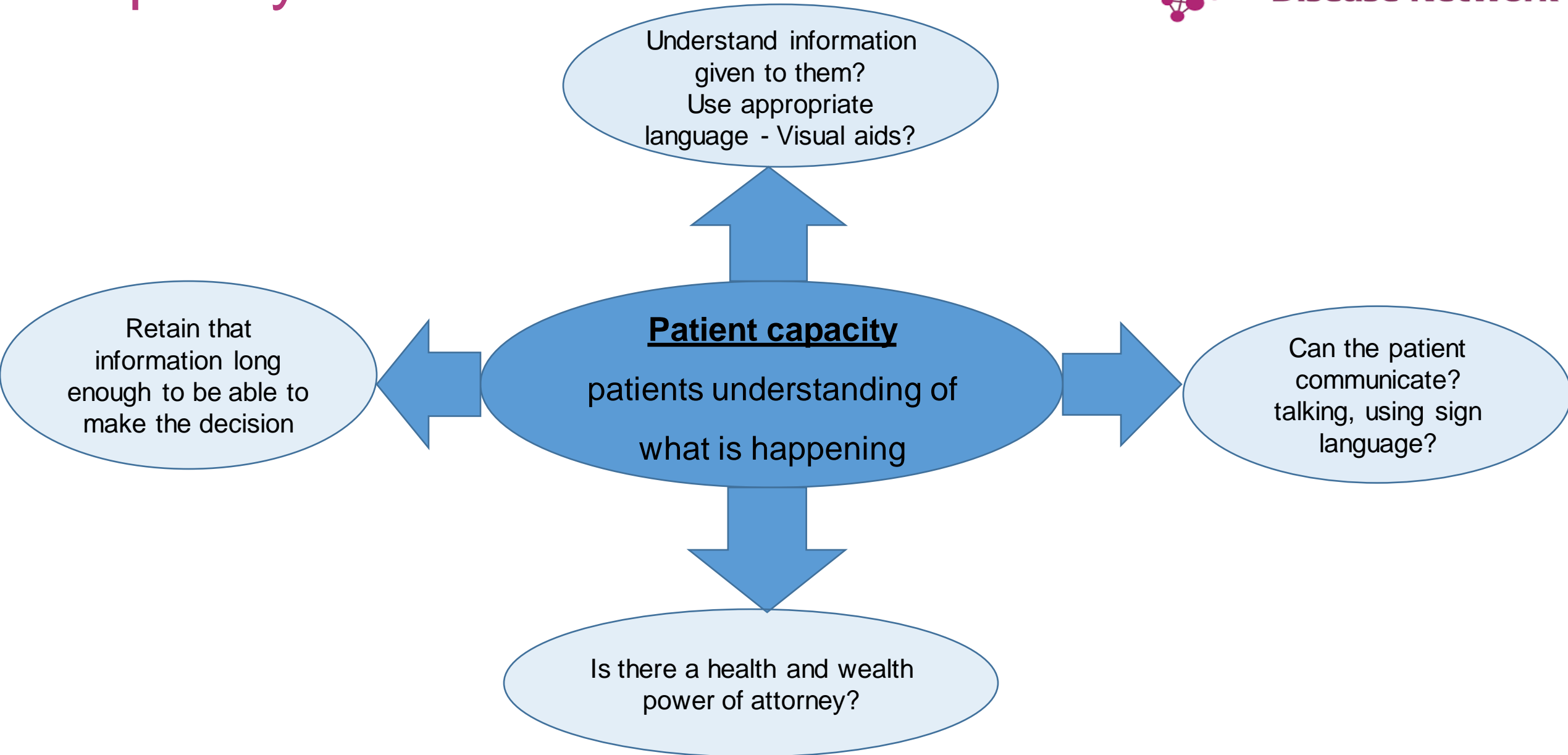


CODE  
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DVD  
VIDEO

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# Capacity assessment





# Best Interest Meeting

If an adult does not have capacity to sign a consent form then a best interest meeting is required – this is a multidisciplinary meeting including:

- The individual carrying out the procedure;
- The patient, family member and CNS;
- If there is no family member then an **Independent Mental Capacity Advocate (IMCA)** must be present at the meeting. If you have any questions about IMCA services in Bristol please contact:

**Telephone: 0117 980 0371**

**Email: [imca@bristolmind.org.uk](mailto:imca@bristolmind.org.uk)**



# Consent form 4

- **Consent Form 4** (form for adults who are unable to consent to investigation or treatment).
- Assessment of patient's capacity (in accordance with the Mental Capacity Act)
- Best interest meeting must have taken place and documentation available.



# Reasonable Adjustments

- Every effort should be made to put in place reasonable adjustments.
- Every person is an individual – therefore, the adjustments will differ from person to person.
- Under the Equality Act 2010, all disabled people have the right to reasonable adjustments when using public services, including healthcare.

# Learning Disability Team

## Our team

Learning disabilities liaison nursing team



The service is available Monday to Friday (excluding bank holidays) 8am to 4pm

Contact number : 0117 342 1707

We have a secure voicemail so please leave a message with your details and we will get back to you.

## Members of the team:

Lorna Hayles - Team lead

Working days: Monday to Friday

Learning disability nurse

Sarah Reynolds

Working days: Monday to Tuesday

Learning disability nurse

Who can get help?



How can we help you?



Hospital passport



Accessible information



Carers





# Clinical Genetics Team BRI

Reception: 0117 342 5325 or 5324.

Clinical Genetics Department: 0117 342 5107

# References

- Carvalho CM, Lupski JR. Mechanisms underlying structural variant formation in genomic disorders. **Nat Rev Genet.** 2016; 17:224–238. doi: 10.1038/nrg.2015.25.
- <https://www.mencap.org.uk/learning-disability-explained/learning-difficulties>
- <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf>

# Useful Resources

- <https://www.england.nhs.uk/learning-disabilities/about/resources/er/>.
- <https://www.mencap.org.uk/learning-disability-explained/resources-healthcare-professionals>.
- [http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/patients-with-a-learning-disability-or-autistic-spectrum-disorder-\(asc\)/easy-read/](http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/patients-with-a-learning-disability-or-autistic-spectrum-disorder-(asc)/easy-read/).

Thank you & Questions