Inherited Cardiac Conditions Resource Pack

Welcome to the Inherited Cardiac Conditions Resource Pack.

In this pack you will find links to organisations, information materials and support that is available for people living in Scotland affected by Inherited Cardiac Conditions and their families.

This resource has been developed by the Network for Inherited Cardiac Conditions Scotland (NICCS). The Network brings together a range of professionals working in healthcare and other sectors, voluntary organisations and patient representatives to support improvements in care for children and adults who have an Inherited Cardiac Condition.

Further information on the Network for Inherited Cardiac Conditions Scotland (NICCS) is available on our website **www.niccs.scot.nhs.uk** or you can email us at **nss.niccs@nhs.scot**

If you have any comments, updates or additions to this resource pack please get in touch.

Content Last Reviewed: August 2026
Next Review Planned: August 2027

This document has been prepared by Public Services Delivery Scotland (PSD Scotland) on behalf of the Network for Inherited Cardiac Conditions Scotland (NICCS). Accountable to Scottish Government, PSD Scotland works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. NICCS is a collaboration of stakeholders involved in care of inherited cardiac conditions who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway.

©PSD Scotland 2026. You can copy or reproduce the information in this resource for use within NHS Scotland and for non-commercial educational purposes under creative commons CC BY-NC 4.0 Deed | Attribution-Non Commercial 4.0 International | Creative Commons. Use of this document for commercial purposes is permitted only with the written permission of PSD Scotland.

NICCS
NETWORK FOR INHERITED CARDIAC CONDITIONS SCOTLAND

Website: www.niccs.scot.nhs.uk **Email:** nss.niccs@nhs.scot

Contents

Support	Resource	Page
Information and Support on Inherited Cardiac Conditions	Arrhythmia Alliance	3
	British Heart Foundation	4
	CardiomyopathyUK the heart muscle charity	5
	Chest Heart & Stroke Scotland	6
Information and Support on Genetic Conditions	GENETIC ALLIANCE UK	8
Medication and Long QT Syndrome	CREDIBLEMEDS®	9
Inherited Cardiac Conditions and Lifestyle Resources	NHS inform	10
Support for Children and Young People	Cardiac Risk in the Young	11
Moving from Childrens to Adult Services		12
	Scottish Transitions Forum	13
Get Involved in Shaping Cardiac Health Services		14

Information and Support on Inherited Cardiac Conditions

Arrhythmia Alliance (A-A) is a coalition of charities, patient groups, patients, carers, medical groups and allied professionals who work together to promote timely and effective diagnosis and treatment of arrhythmias.

If you have, or are suspected of having, cardiac arrhythmia then Arrhythmia Alliance offers you a full range of resources including:

- Patient Information booklets covering all aspects of arrhythmia care, diagnosis and treatment.
- Information fact sheets which summarise key topics related to heart rhythm disorders.
- Information checklists covering all aspects of arrhythmia care, diagnosis and treatment. These checklists help provide patients with practical information and to help them prepare for GP and hospital visits.
- Patient information video covering all aspects of arrhythmia care, diagnosis and treatment.
- Information sheets and booklets specifically for children including how the heart works, how to take a pulse and implantable devices.

The patient resources are available at:
https://heartrhythmalliance.org/aa/uk/resources/arrhythmia-alliance-patient-resources

The website provides:

- links to organisations, charities, patient groups and healthcare bodies who work to improve diagnosis, care and treatment of cardiac arrhythmias.
- free education event for patients
- information on support groups.

Further information

Website: www.heartrhythmalliance.org
Telephone: 01789 867 501
Email: info@heartrhythmalliance.org

British Heart Foundation

The British Heart Foundation's vision is a world free from the fear of heart and circulatory diseases. We raise money to research cures and treatments, so we can beat heartbreak forever.

The website has specific information and support relating to Inherited Cardiac Conditions. Information includes signs and symptoms, different conditions, genetic testing and treatment options. This can be found at: www.bhf.org.uk/informationsupport/conditions/inherited-heart-conditions

A range of information booklets are available to download or order to support people with Inherited heart conditions at: www.bhf.org.uk/informationsupport/publications

Genetic Information Service

The Genetic Information Service (GIS) can give you information and support about inherited heart and circulatory conditions. The GIS cardiac nurses can also help you understand why you, or a family member, might need to be assessed at a specialist clinic. They may be able to support your referral to a clinic too. You can speak to the specially trained GIS nurses confidentially.

Find out more at:
www.bhf.org.uk/informationsupport/support/genetic-information-service

Heart Helpline

The helplines cardiac nurses can help with lots of queries and concerns about heart and circulatory diseases, and their risk factors. Some of common queries include understanding medications and their side effects, improving diet and lifestyle and managing new and existing diagnosis.

You can contact the Heart Helpline by telephone, emailing or via the website. Find out more at: www.bhf.org.uk/informationsupport/heart-helpline

Support Groups

The organisation provides online and local support groups for patients and carers to share knowledge, experiences and support with each other. Find out more at: www.bhf.org.uk/informationsupport/support/support-groups

Further information

Website: **www.bhf.org.uk**
Telephone: **0300 330 3322**

If you have, or are suspected of having, an inherited cardiomyopathy or myocarditis then Cardiomyopathy UK offers you a full range of resources. Others with inherited arrhythmias will find helpful information here too: www.cardiomyopathy.org

Support available includes:

- Cardiomyopathy Support Nurse on line and telephone advice, Mon-Fri 9am-4pm
- Peer to peer telephone support from patients just like you
- Tailored advice on how to claim PIP and other benefits
- A friendly closed FACEBOOK group where you can share your worries and concerns with folk who are already on the journey.
- Zoom and in-person Support Groups, both geographical and by type of cardiomyopathy
- A Youth Hub for young people aged 16 -24 who have cardiomyopathy.

There are also a range of articles and information available to download or order via post including:

- Each of the individual types of cardiomyopathies and myocarditis
- All about your medications
- About the heart, and heart failure
- Arrythmias
- Genetic testing, and an introduction to genetics
- Exercise advice
- Each type of device you may be offered
- Living with breathlessness
- Driving; how the rules work for you
- Travel and insurance
- Returning to work; your rights, and advice
- Impact on carers; and support for parents
- Emotional health, including resources and further information plus much more; if you've another concern, the chances are there is an information sheet that covers it.

Further information

Website: www.cardiomyopathy.org
Telephone (Office): 01494 791224
Genetic and Nurse Helpline: 0800 018 1024
Email: contact@cardiomyopathy.org

Scotland's health charity supporting people and their families across Scotland with chest, heart and stroke conditions. Chest, Heart & Stroke Scotland want to make sure life living with a chest or heart condition or after a stroke is a life lived to the full. They will fight for better health for everyone and work to make sure there is help and support in every community.

Chest Heart & Stroke Scotland are there to support you after you return home from hospital with a heart condition. Understanding your condition and learning how to manage it well at home can help you live life to the full.

Patient Information

Whether you have recently been diagnosed, have been living with a heart condition for years, or care for someone who has a heart condition, their guides will help you find out more about your condition and the support available to you.

There is a range of information available on the heart information section on the website. This includes information on common heart conditions, living with a heart condition and looking after yourself.

www.chss.org.uk/heart-information-support/

Patient and Carer Education

The website has a range of educational resources suitable for both patients and carers, which include everything from practical information about your condition to ways you can find support and resources to help you live life to the full.

Our e-learning resources will help you learn more about chest, heart and stroke conditions and empower you to self-manage your condition at home.

www.chss.org.uk/services/patient-carer-education/

Peer support groups

Meeting others and sharing experiences can make a huge difference for some people. Chest Heart & Stroke Scotland has support groups all over Scotland for people living with chest, heart and stroke conditions, and their carers.

To find out if there is a support group in your area, call the CHSS Advice Line nurses on 0808 801 0899 or email adviceline@chss.org.uk.

Chest Heart & Stroke Scotland Advice Line

A free, confidential Advice Line service, run by health professionals, provides support, information and health advice for people living with chest, heart and stroke conditions.

The Advice Line also provides support, information and advice to families, friends, carers, and health and social care professionals across Scotland.

Telephone: 0808 801 0899 (free from landlines and mobiles)
Email: adviceline@chss.org.uk
Text: ADVICE to 66777 (standard rates apply)

The service is open **Monday to Friday from 9:30am to 4pm**.

Find out more: www.chss.org.uk/services/chest-heart-stroke-scotland-advice-line/

Further information

Website: www.chss.org.uk
Telephone: 0131 225 6963

Information and Support on Genetic Conditions

Genetic Alliance UK work on a variety of issues that families and individuals with genetic conditions face. They provide information, support families and influence the services needed by these patients. They also work to add patient voice into debates that matter to our community.

Genetic Alliance UK Website - geneticalliance.org.uk/

Rare Resources for Scotland

A project run by Genetic Alliance UK for families in Scotland with the aim of improving access to high quality information and support for people living with rare, genetic and undiagnosed conditions in Scotland.

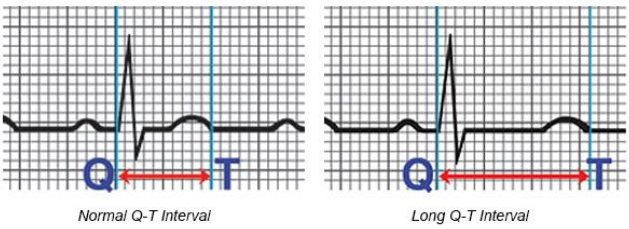
A collection of helpful information guides is available for families, adults and health care professionals. The website also includes a Rare Resources Directory which contains links and contact details for a variety of sources of support available in Scotland.

geneticalliance.org.uk/information/living-with-a-genetic-condition/rare-resources/

Further information

Website: geneticalliance.org.uk
Email: contactus@geneticalliance.org.uk
Telephone: 0300 124 0441 (voicemail only)

Medication and Long QT Syndrome



Long QT is a syndrome which can cause a disturbance in the electrical system of the heart, whilst the mechanical function of the heart can remain completely normal. It is often the result of inheriting an abnormal gene which causes an imbalance in molecules that control the electrical impulses of the heart. Long QT may result in a very fast abnormal heart rhythm (known as an arrhythmia).

There are many medications which might affect the heart rhythm in patients with Long QT Syndrome. These include some over-the-counter cough or cold remedies (decongestants) and some antibiotics. Other drugs that might affect the QT interval include some antidepressants, some treatments for fungal infections, and drugs for heart rhythm disorders.

If you are prescribed any medicines, always check with your doctor and pharmacist that it is safe for a patient with LQTS to take these medicines. Some herbal remedies are also to be avoided (e.g. St John's Wort). Please take care with herbal remedies and ask your doctor for specific advice.

A list of drugs currently known to affect long QT is available on the website www.crediblemeds.org A mobile app is also available to download.

This list will not be exhaustive as newer drugs are becoming more available. Always inform anyone who is prescribing you medication that you have LQTS as there may be newer drugs on the market which may have not have been added to the website.

Inherited Cardiac Conditions and Lifestyle Resources

NHS Inform is Scotland's national health information service. Their aim is to provide people in Scotland with accurate and relevant information to help them make informed decisions about their own health and the health of the people they care for.

NHS Inform has a section providing more information on inherited heart conditions including the signs and symptoms, treatment options and areas of further support.
www.nhsinform.scot/illnesses-and-conditions/cardiovascular-disease/heart-disease/inherited-heart-conditions/

NHS Inform also include information to support people to look after your mental and physical wellbeing with advice on stopping smoking, eating well and how to get enough exercise.
https://www.nhsinform.scot/healthy-living

Support for Children and Young People

Cardiac Risk in the Young aims to prevent young sudden cardiac deaths through awareness, screening and research, and supporting affected families.

They offer dedicated bereavement support to support families after the tragedy of a young sudden cardiac death of a person aged 35 or under.

They offer personalised help, support, and information to young people, between the ages of 12 and 35 who have been diagnosed with a life-threatening cardiac condition

Website: www.c-r-y.org.uk
Telephone: 01737 363222

Cardiomyopathy UK have developed information on cardiomyopathy in children and young people. There is also information for parents and carers.

Find out more:
www.cardiomyopathy.org/living-cardiomyopathy/families-and-young-people

Moving from Childrens to Adult Services

In healthcare, the word transition is used to describe the process of preparing, planning and moving from children's to adult services. We understand that moving away from a team of doctors and nurses that you have been with for many years can be scary but hopefully, by getting involved in the transition process, you will feel more confident and happier about the move.

Ready Steady Go



To support you through transition, services are encouraged to use the **Ready Steady Go** transition programme.

Ready Steady Go is for you, if you or your child, is over 11 years old with a long-term condition.

Ready Steady Go will help you gain the knowledge and skills to manage your condition. It improves long-term outcomes and helps you gain the confidence and skills to move to adult services.

Ask your team about the **Ready Steady Go** programme or find out more at:

www.readysteadygo.net/rsg.html

Scottish Transitions Forum

The Scottish Transitions Forum's aim is to improve the experiences of young people (14-25) who require additional support who are making the transition to young adult life.

The objectives of the Scottish Transitions Forum are to:

- Support joined up working across all services
- Continually improve knowledge, motivation and practice
- Inform and empower young people and their carers

Find out more at: scottishtransitions.org.uk



The Scottish Transition Forum's 'Principles of Good Transitions 3' provides a framework to inform, structure and encourage the continual improvement of support for young people with additional needs between the ages of 14 and 25 who are making the transition to young adult life.

The Principles of Good Transitions 3 is available at arcscotland.org.uk/resource/principles-of-good-transitions-3

Get Involved in Shaping Cardiac Health Services

NICCS
NETWORK FOR INHERITED CARDIAC CONDITIONS SCOTLAND

Patient Engagement Group

The Network for Inherited Cardiac Conditions work closely with people and families with these conditions to find out what matters most to them and to see what more we can do. One of the ways we do this is meeting with our patient group which includes people with an ICC, family members and heart charities. This group helps us to plan information events, develop patient information and patient surveys.

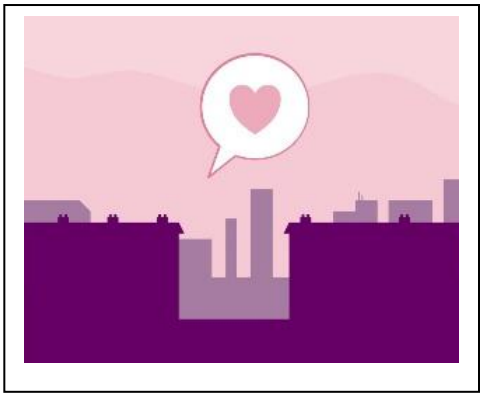
You can get involved in our work in different ways, such as:

- Coming along to network meetings
- Commenting on the information we develop
- Telling us about the care that you get
- Suggesting how we can better support you
- Joining our mailing list to find out what we are doing

You can tell us how you want to get involved and what support you would find helpful by scanning the QR code or visiting: https://forms.office.com/r/7cyyAC2D2C

Further information
Website: www.niccs.scot.nhs.uk
Email: nss.niccs@nhs.scot

Heart Disease Lived Experience Network



To support the implementation of the Scottish Government's Heart Disease Action Plan, the ALLIANCE, Chest Heart & Stroke Scotland, and British Heart Foundation have set up a Heart Disease Lived Experience Network and Reference Group to directly hear about people's individual experiences. The aim of this network is to ensure people are at the centre, that their voices, expertise, and rights drive policy and sit at the heart of design, delivery and improvement of support and services.

Further information
Website: www.alliance-scotland.org.uk/lived-experience/networks/heart-disease-network/
Email: info@alliance-scotland.org.uk
Telephone: 0141 404 0231