



GIG
CYMRU
NHS
WALES

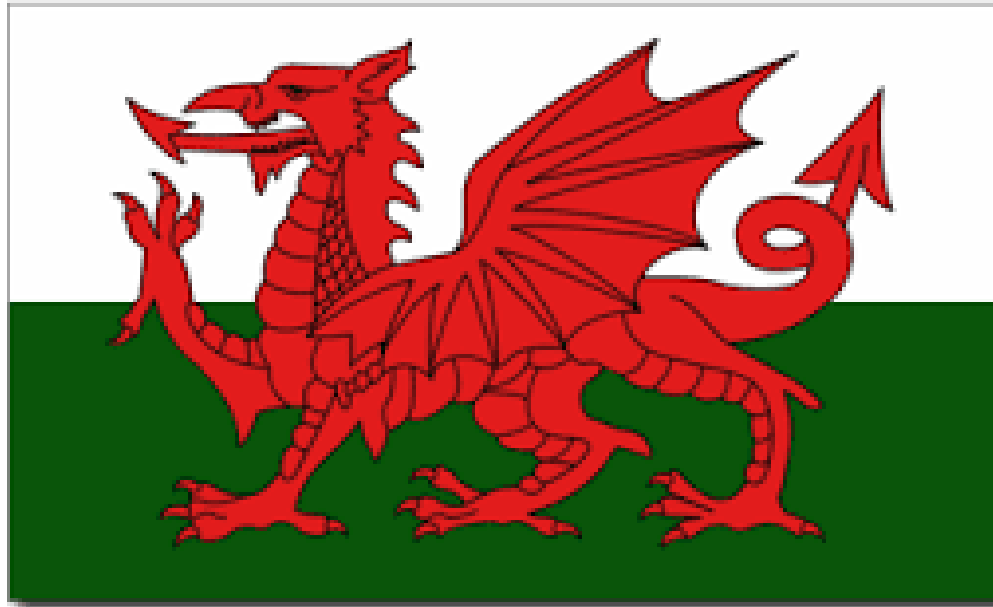
Pwyllgor Gwasanaethau Iechyd
Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)



South Wales and South West
**Congenital Heart
Disease Network**

Living with Congenital heart Disease

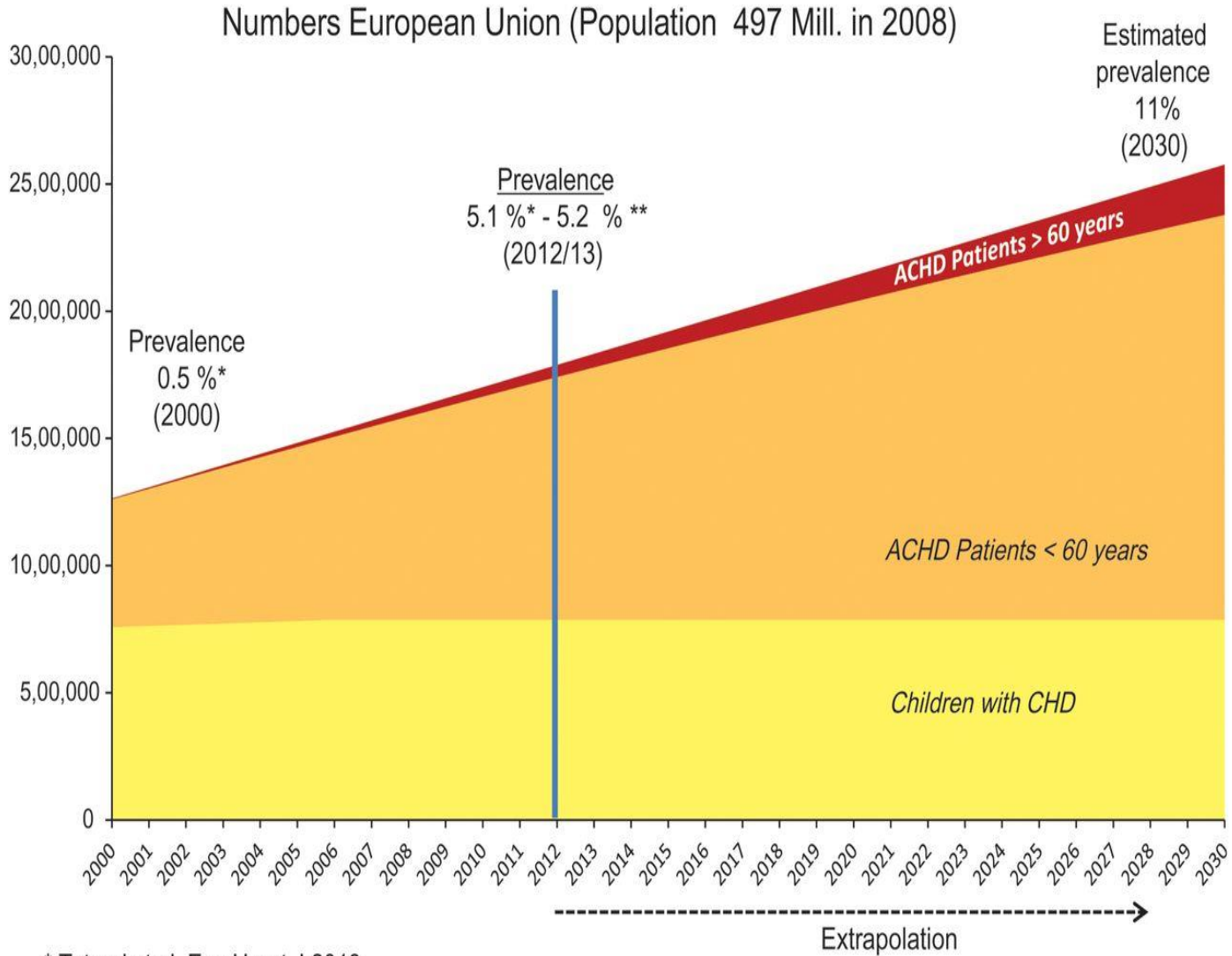
Sheena Vernon MSc
Cardiff 10/3/2018



Outline of population- it is big
Diet, alcohol, smoking,
Endocarditis
Exercise
Sex, pregnancy, contraception
Extreme sports

HISTORY OF POPULATION

- Incidence: 8 per 1000 live births
- 40 yrs ago mortality was 60%- 70% over the age of 18 years
- Success of cardiac surgery and cardiology
- 85% of CHD patients, including complex, rare and severe conditions will reach adulthood
- More adults than children with CHD



* Tutarel et al. Eur. Heart J 2013

** German Competence Network for Congenital Heart Disease (data on file)

COMMON CONGENITAL HEART DEFECTS

• Atrial Septal Defect	10%
• Ventricular Septal Defect	30%
• Tetralogy of Fallot	6%
• Transposition of the Great Arteries	4%
• Coarctation of the Aorta	7%
• Patent Ductus Arteriosus	10%
• Aortic Stenosis	6%
• Pulmonary Stenosis	7%
• Other	20%



UK

TODAY

425

people will lose
their lives to CVD

...more than
100 people
will be
younger
than **75**

7
MILLION

people fight their daily
battles with CVD

515

people will go to hospital
with a heart attack

190

people will die from
a heart attack

12 babies

will be born with
a heart defect

**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk

Updated August 2015

Risk factors

The more risk factors for coronary heart disease you have, the greater your chance of developing it. The good news is that for most risk factors, you can do something about them.



UNDERSTANDING

- **Poor understanding**
 - Condition
 - Follow-up
 - Competitive sport
 - Deterioration
 - Risk endocarditis
 - Smoking and alcohol
 - Inheritance
 - Contraception and pregnancy
- 91x17yrs



DIET

- Healthy low fat
- CVS risk factors
- Junk food
- Cholesterol

**5-A-DAY WITH
HEART
MATTERS**



ALCOHOL

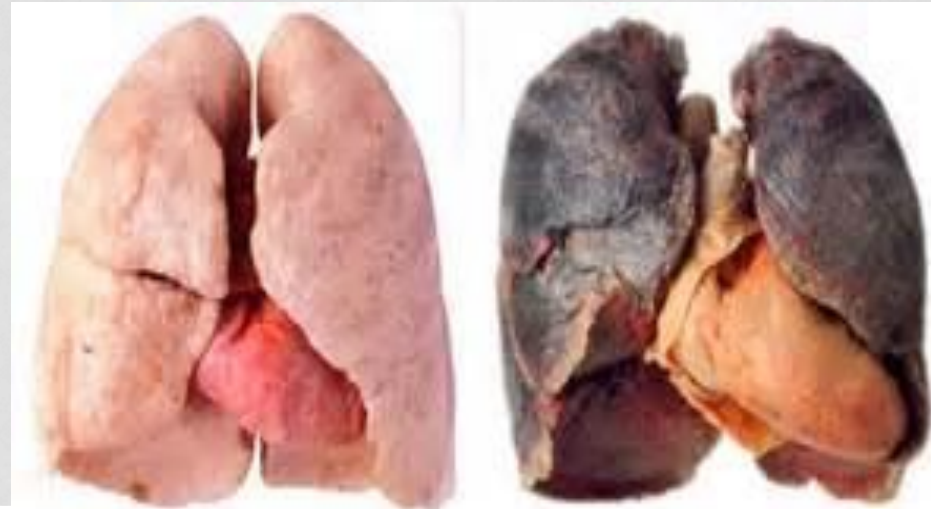
- Poor understanding safe drinking
- Stimulant drinks
- HR ↑, BP ↑
- Effects of excessive drinking INR
- Recreational drugs



SMOKING

- 10 million adults in UK smoke
21% men and 19% women.
- Two-thirds start before the age
of 18
- Causes 80% of deaths from
lung cancer
- 80% of deaths from
bronchitis+emphysema
- 17% of deaths from heart
disease
- £2.7 billion pa treating
diseases caused by smoking

- HR ↑
- ↓O₂ RR ↑
- ↑BP
- ↑Toxins 4000
- Damage vessels
- ↑risk of MI, CVA +clotting
- ↑respiratory disease
- ↑ cancer



INFECTIVE ENDOCARDITIS

- Infection of the lining of the heart + valves
micro-organisms from poor dental hygiene,
dental intervention, piercing, tattoos, minor
procedures.
- Flu like symptoms more than 5 days.
- Blood cultures, echo, ecg, cxr,
weight, urinalysis.
- IV antibiotics for 4-6 weeks.
- Change in antibiotic prophylaxis
- Education



INFECTIVE ENDOCARDITIS

- Symptoms and change in prophylaxis
- High risk lesions. Dentist.



ESC GUIDELINES

European Heart Journal Advance Access published August 27, 2010



European Heart Journal
doi:10.1093/eurheartj/ehq319

ESC GUIDELINES



ESC Guidelines for the management of grown-up congenital heart disease (new version 2010)

The Task Force on the Management of Grown-up Congenital Heart Disease of the European Society of Cardiology (ESC)

Endorsed by the Association for European Paediatric Cardiology (AEPCC)

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The disclosure forms of the authors and reviewers are available on the ESC website www.escardio.org/guidelines

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Councils: Cardiology Practice, Council on Primary Care, Cardiovascular Imaging, Cardiovascular Nursing and Allied Professions (CCNAP)
Working Groups: Grown-up Congenital Heart Disease, Pulmonary Circulation and Right Ventricular Function, Valvular Heart Disease, Cardiovascular Surgery, Thrombosis, Acute Cardiac Care

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ESC GUIDELINES



2015 ESC Guidelines for the management of infective endocarditis

The Task Force for the Management of Infective Endocarditis of the European Society of Cardiology (ESC)

Endorsed by: European Association for Cardio-Thoracic Surgery (EACTS), the European Association of Nuclear Medicine (EANM)

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ESC entities having participated in the development of this document:

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ESC Councils: Council for Cardiology Practice (CCP), Council on Cardiovascular Nursing and Allied Professions (CCNAP), Council on Cardiovascular Primary Care (CCPC)

ESC Working Groups: Cardiovascular Pharmacotherapy, Cardiovascular Surgery, Grown-up Congenital Heart Disease, Myocardial and Pericardial Diseases, Pulmonary Circulation and Right Ventricular Function, Thrombosis, Valvular Heart Disease

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EXERCISE

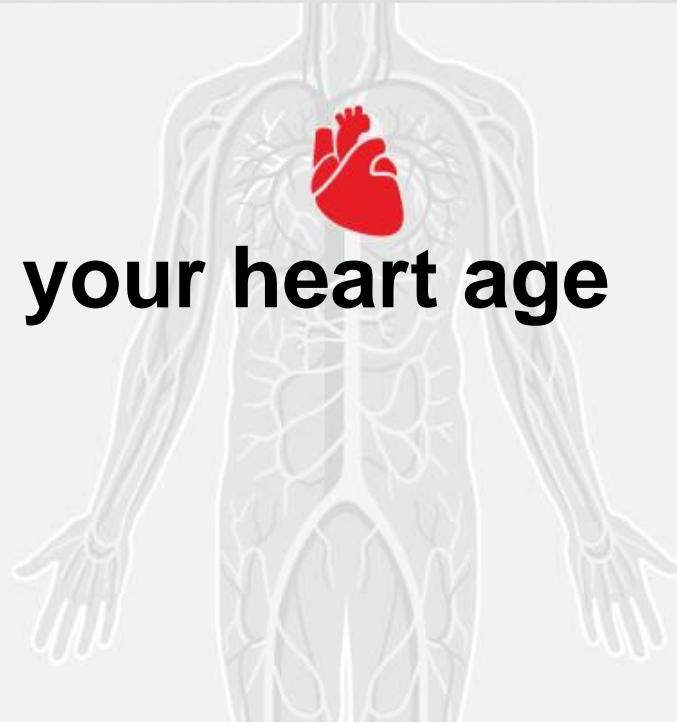
- Encourage exercise
- Isotonic (dynamic or CVS exercise) e.g. jogging or swimming
- Isometric (static) e.g. weight lifting and gym
- Depends on condition/ exercise on prescription
- Based on haemodynamics, arrhythmia
- Avoid intense physical activity, competitive, contact sport and weight lifting with mod to severe lesions
- Sudden death is v rare
- Guidelines

www.nhs.uk  **choices**

Task force 8 Sport ESC



Check your heart age



SEX

- ‘Activity is reasonable’ ? Complex
- Sexual dysfunction, anxiety, depression
- Medication affects sex drive
- Drugs for erectile dysfunction: avoid with nitrates
- Poor contraception 28%
- Pregnancy/MDT/genetic counselling
- Study shows sexual functioning is impaired
- Information about sexuality, pregnancy, delivery and heredity should given at young age



[Opić P¹](#), [Roos-Hesselink JW](#), [Cuypers JA](#), 2012

PREGNANCY

- Planned pregnancy
- Pre-pregnancy counselling
- Inheritance



PREGNANCY

- Symptom free before pregnancy, normal pregnancy
- Circulating vol. doubles
- Increased concern due to heart failure, arrhythmias, thromboembolus, reduced oxygen to the baby.
- Saturations less than 80% advised not to become pregnant.
- In Eisenmengers Syndrome high risk

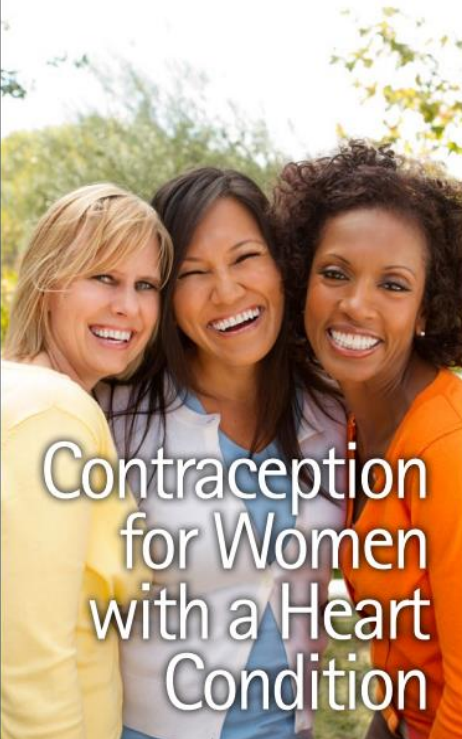
CONTRACEPTION

- Most women regular methods
- Think carefully
- Cyanosed risk of thrombosis, the combined pill may predispose to thrombosis.
- Progesterone only pill Cerazette.
- Injection may cause bruising for the patients on Warfarin
- Low progesterone Implanon
- IUD theoretical risk of infection
- Sterilization high risk/prognosis



RESOURCES

The Somerville Foundation
Supporting young people and adults
born with a heart condition



Contraception
for Women
with a Heart
Condition

The image shows three women of diverse ethnicities smiling and hugging each other. The woman on the left has blonde hair and is wearing a yellow top. The woman in the middle has dark hair and is wearing a blue top. The woman on the right has dark curly hair and is wearing an orange top. They are outdoors with green foliage in the background.

The Somerville Foundation
Supporting young people and adults
born with a heart condition



GUCH
and Pregnancy

The image shows a pregnant woman in profile, wearing a white sleeveless dress, standing in a grassy field. She is looking down at her belly with a gentle smile. The background is a soft-focus green field.

EXTREME SPORTS

- Bungee jumping
- Skiing
- Parachute
- High altitude/hypoxia
- Warfarin
- Diving HR↓
- ↑ pul oedema
- ↑air embolism
- ↑decompression R-L



THEME PARK RIDES



- HR
- BP↑
- BP↓
- Avoid dogems
- Warfarin

FLYING

- Oxygen
- Wheelchair
- Hydrated
- DVT Prophylaxis/
- Aspirin
- Infection
- Clinic letter
- Travel insurance



RECREATIONAL DRUGS

- Ecstasy and speed arrhythmias
- BZP arrhythmias
- Ketamine slows down HR
- Advise against
- IV endocarditis



RISK TAKING

- Smoking, alcohol
- Substance abuse
- Risky sexual behaviour
- Non-adherence/DNA
- Extreme sport
- Cyanosis
- Social problems
- Depression
- Anger



NSF 2006

Tong E and Kools S 2004

COAGUCHEK

- INR test



CoaguChek®

SCARS

- Scars
- Body image
- Camouflage make-up



DRIVING



<https://www.gov.uk/contact-the-dvla>

ADVICE LINE

- Admission, surgery, intervention, pregnancy, learning disability, TYA
- Advice for HC professionals
- **Lifestyle**
- Long haul flights/ travel
- Employment issues/benefits
- Meds and warfarin
- INR – CoaguChek



SOCIAL ISSUES

- Interrupted Education
- Peer Pressure
- Employment Difficulties
- Insurance Problems
- Benefits complicated
- Mild 50% rejection
- Moderate 400%



CAREERS AND EMPLOYMENT

- Employment advice and support
- Only 10% are totally disabled
- Intellectual limitations
- Isolation and low self esteem
- **National Careers Service**
- www.direct.gov.uk/youngpeople
- Life Insurance
- Mortgage and buying a house
- Variable loading
- Travel insurance shop around



SUPPORT

- Somerville Foundation
- Newsletter / leaflets
- Telephone help line
- Support groups/mental health
- Financial support
- Workshops / conferences
- Web Sites
- BHF Lifestyle advice





The American Heart Association's Diet and Lifestyle Recommendations

www.heart.org



Royal College
of Nursing

To support adult
standards guidelines
from RCN for nursing
published



RCN COMPETENCES

Adult congenital heart disease nursing

RCN guidance on roles, career pathways and competence development



GUIDELINES

- European Society of Cardiology's guidelines on the “Management of Grown Up Congenital Heart Disease” 2010
- The British Cardiac Society Working Party on Grown-up congenital heart disease (GUCH). September 2002.
- The 32nd Bethesda conference: Care of the Adult with Congenital Heart Disease JACC Vol 37, 2001.
- The Canadian Cardiovascular Society's Consensus Conference update 2001 update
- AHA.

THANK YOU



OUTPATIENTS





WORK LOAD

- In-patient and out patient issues
- Surgery, cardiology, medical admissions, arrhythmias, endocarditis, heart failure.
- Learning disability work
- Pregnancy/contraception
- Teenage and young adult clinic
- End of life care
- Pulmonary hypertension
- Lifestyle, endocarditis prophylaxis
- Medication e.g. Warfarin
- Telephone Advice 1500 calls pa

PSYCHOLOGICAL ASPECTS OF CARE

- Patient characteristics – 2 groups
- Teenagers and parents
- LD 10% Capacity assessment and BIM
- Fears, phobias, anger and depression
- ***Emotional and Mental Health Resources***

PHYSICAL ASPECTS OF CARE

- Infective Endocarditis
- Arrhythmias/heart failure
- Surgery +/- re-operation – risks Intervention
- Stroke
- Cyanosis/Polycythaemia
- Pregnancy/Contraception
- Coronary Artery Disease

ARRHYTHMIAS

- Operative procedures from the early years resulting in arrhythmias due to scarring affecting the conducting pathway
- A/F, atrial flutter are signs of deterioration in patients with Fontans, Fallots, A.S, single ventricle hearts and right sided conduit
- Treatment return them to S/R and anti-coagulate.
- Risk of S.C.D.
- Ablation, pacemaker or I.C.D.

SURGERY

- Risk of re-operation in this group
- Adhesions, bleeding, longer by-pass time.
- Affects renal and liver function
- Risk of arrhythmias post –op
- Cyanosed patient will require a higher PCV
- Higher filling pressures may be needed in some conditions
- Pericardial and pleural effusions may occur

OUTPATIENTS



OUTPATIENTS



CYANOSIS

- Cyanosis results from an increase in circulating RBC as the body attempts to improve its oxygen carrying capacity
- Increased viscosity can lead to thrombosis, stroke, embolus, infection brain abscess, PH, gout, gall stones, iron deficiency, arrhythmias, and renal dysfunction
- Caution if NBM, IV fluids

CYANOSIS





Bristol Heart In

- Upstairs for
- ↻ Level 6 Day
- ↻ Level 7 Wa
- ↻ Level 8 Wa
- ↻ Lifts