PECSIG Programme

Preparing for Transition: what you (and your patient) need to know

Sheena Vernon

Lead nurse

University Hospitals Bristol and Weston

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Disclosures

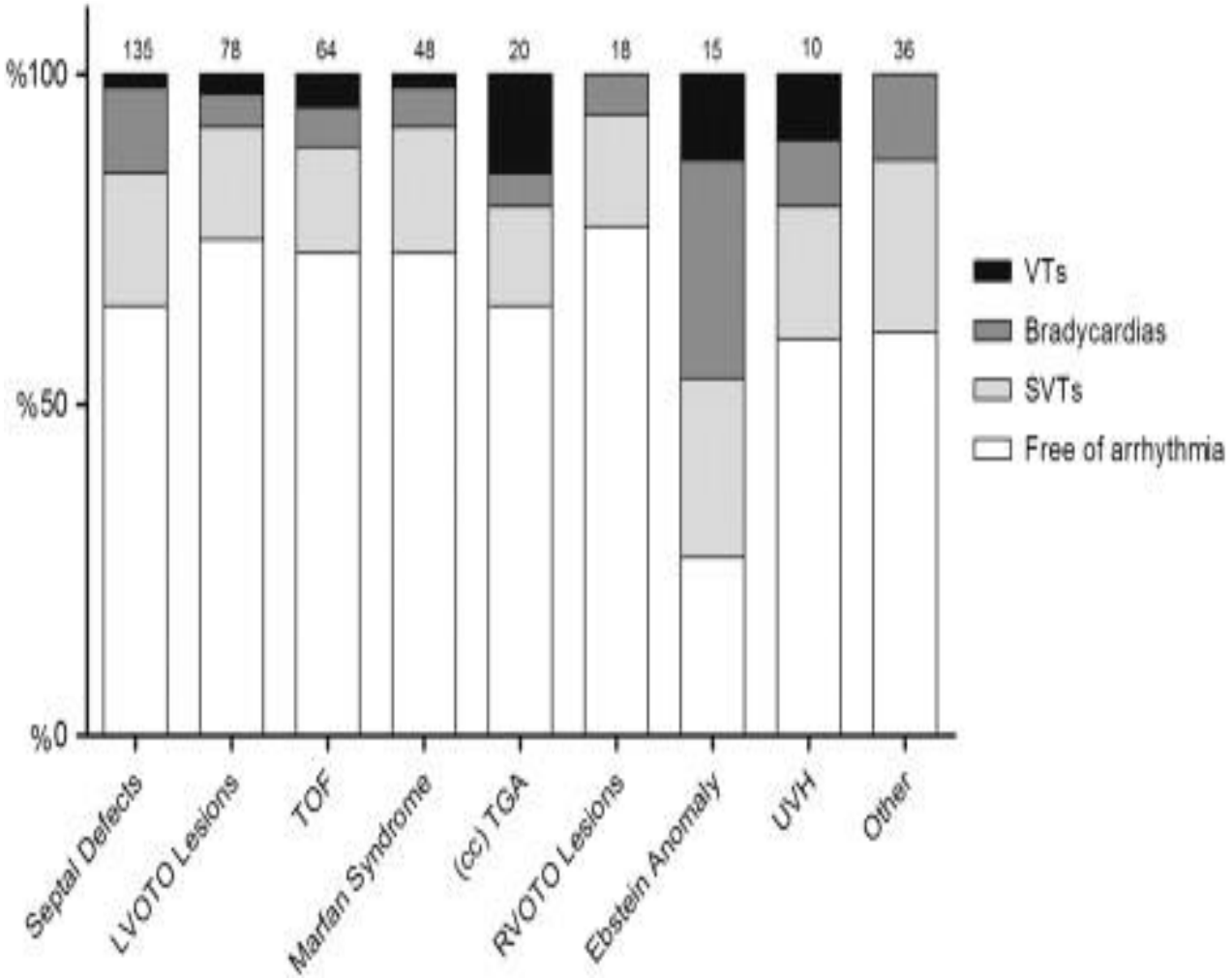
None

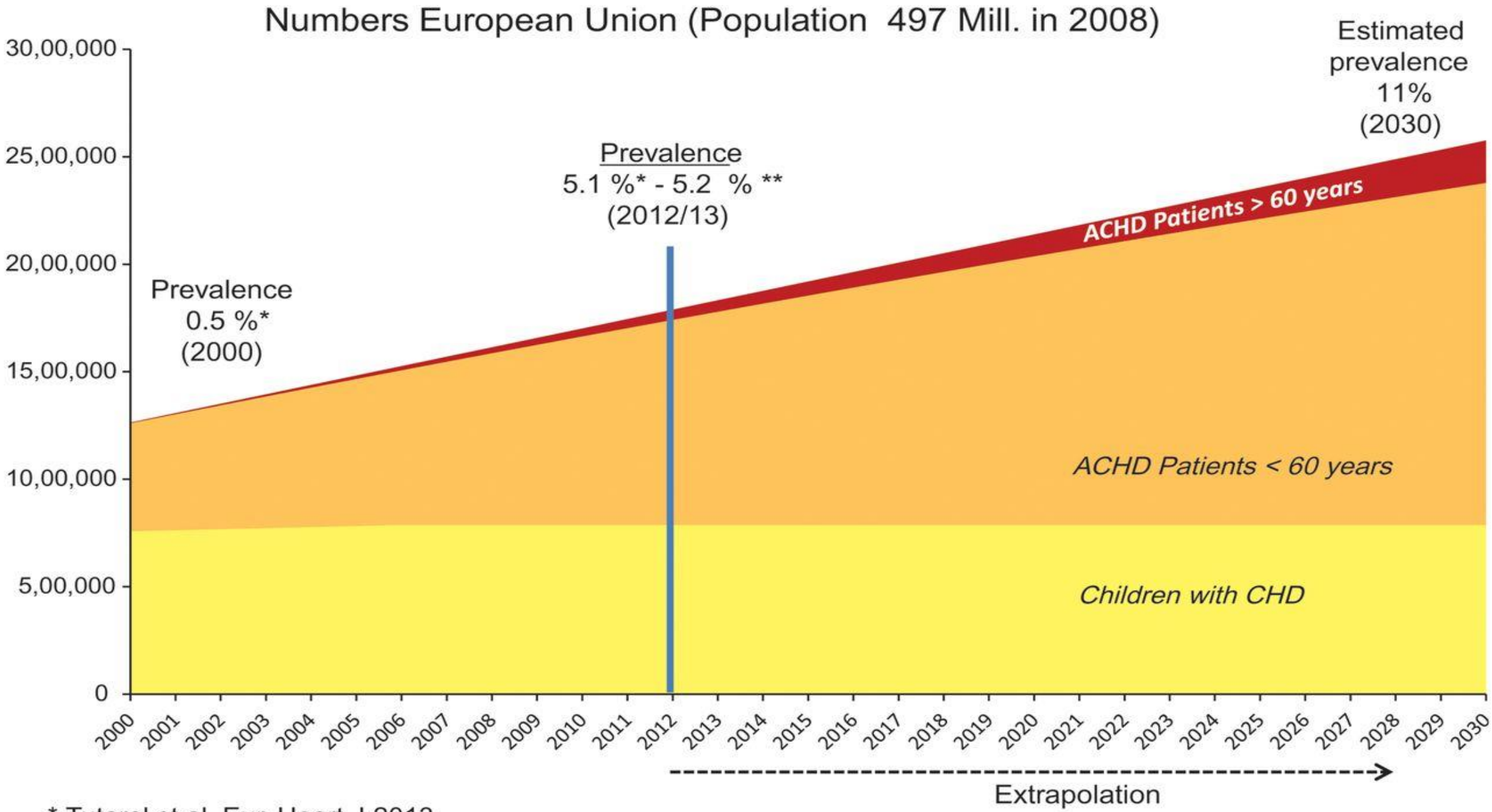
Standards

Section A: The network approach
Section B: Staffing and skills
Section C: Facilities
Section D: Interdependencies
Section E: Training and education
Section F: Organisation, governance and audit
Section G: Research
Section H: Communication with patients
Section I: **Transition**
Section J: Pregnancy and contraception
Section K: Foetal diagnosis
Section L: Palliative care and bereavement
Section M: Dental

Transition-what you need to know

- Most need <u>lifelong</u> care
- Problems arrhythmia / heart failure
- Surgery and intervention
- Endocarditis
- PH
- Pregnancy
- End of life care
- Big numbers





* Tutarel et al. Eur. Heart J 2013

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

Relative and actual age

	Patient's age (years)								
	20	**25**	**30**	**35**	**40**	**45**	**50**	**55**	**60**
ASD	25	26	32	38	42	47	52	57	61
Valvar disease	29	31	36	40	45	49	54	59	63
VSD	28	30	36	40	44	49	53	59	63
Aortic Coarctation	32	33	38	43	47	52	56	62	66
AVSD	33	34	39	44	48	52	57	62	66
Marfan syndrome	37	38	42	46	50	54	59	64	68
Tetralogy of Fallot	37	38	42	47	50	54	60	65	69
Ebstein anomaly	42	43	47	51	54	59	63	68	72
Systemic RV	46	48	51	55	59	63	67	72	76
Eisenmenger syndrome	57	58	62	65	69	73	77	81	84
Complex CHD	58	59	63	67	70	74	78	82	85
Fontan	64	65	68	72	75	78	82	86	91

Age difference:

- >40
- 30-40
- 20-30
- 10-20
- 5-10
- 2-5
- <2

Values present relative age adjusted for predicted 5-years mortality. Colors reflect the difference between relative and actual age. For example a 40 year old Fontan patient has a mortality rate that is comparable to that of a 75 year old individual without CHD.

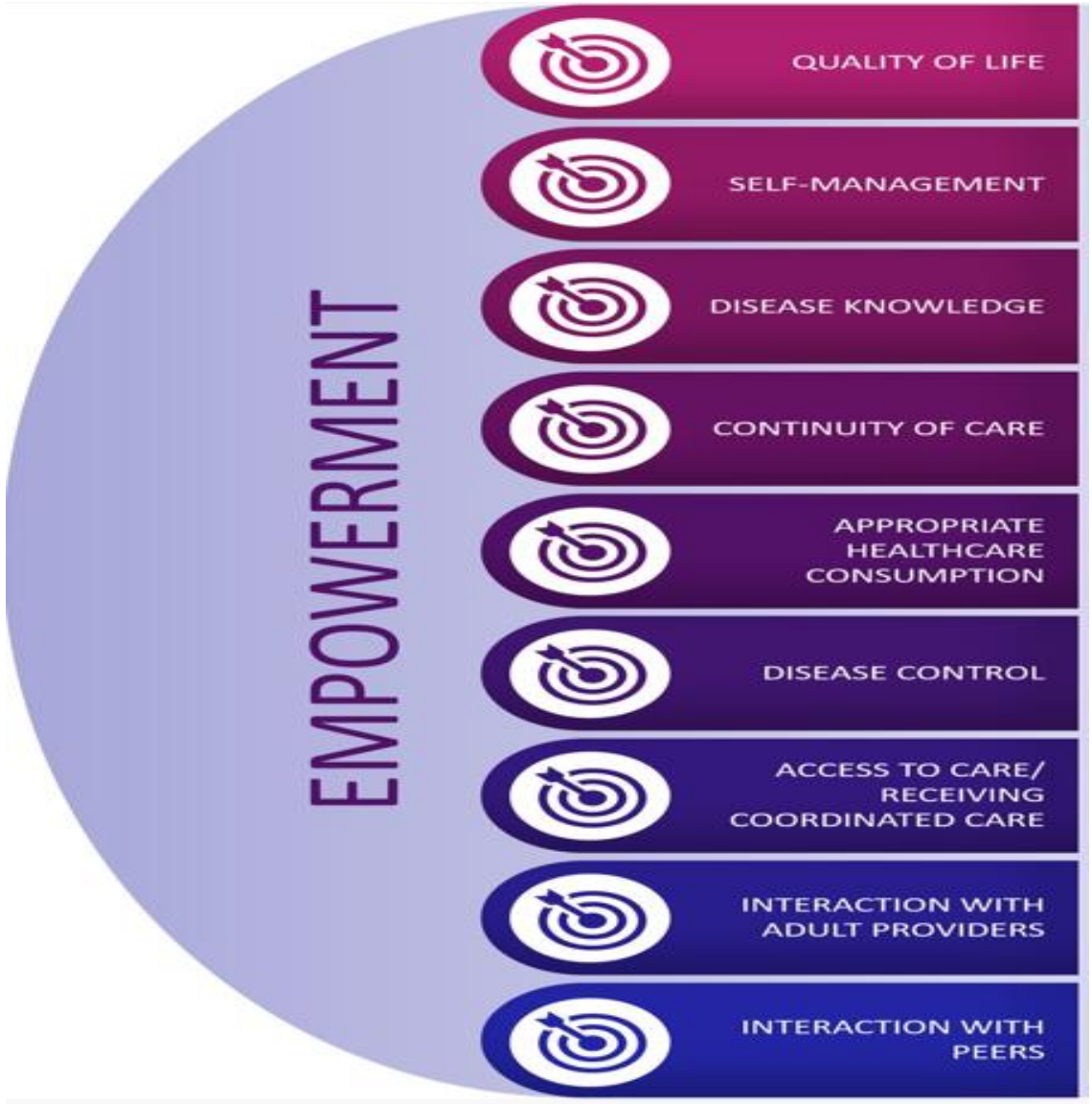
Purpose of Transition

- Should begin at age 13yrs
- Prepare young people for transfer to adult services
- To enable young people to manage their own health care, stay fit and well and out of hospital
- To understand their condition, medication and treatment plan
- Meet or introduce to the adult team

Goal

- Give an uninterrupted and co-ordinated transfer to adult services
- Develop skills in self-care
- **Empower patients** to manage their own health care
- Give in a developmentally appropriate way
- Educate around condition
- Support family in changing role
- May never happen!

ESC
European Society of Cardiology



Additional needs

- 25/10000 Downs Syndrome, 40% D.S. have CHD
- 17 % CHD occurs in association with a syndrome eg Turners/ Williams/ Noonan's Syndrome etc
- Need to mindful of levels of understanding
- Conversations with young person and family, education e.g. lifestyle
- Support to family, hospital stay, involve community teams and charities
- Capacity assessment
- Best interest meeting

Transition v Transfer

Transition is an **active process** that considers medical, psychosocial and educational needs of adolescents as they move from child centred to adult centred healthcare (13yrs)

Transfer is an **event** which happens on one occasion when information or people move from one place to another (16yrs)

If it does not happen

- Poorly planned transition is associated with risk of **non-adherence to treatment**
- **Loss to follow-up**
- **Psychological** distress

- Measurable adverse consequences in **morbidity and mortality**
- Poor social and educational outcomes

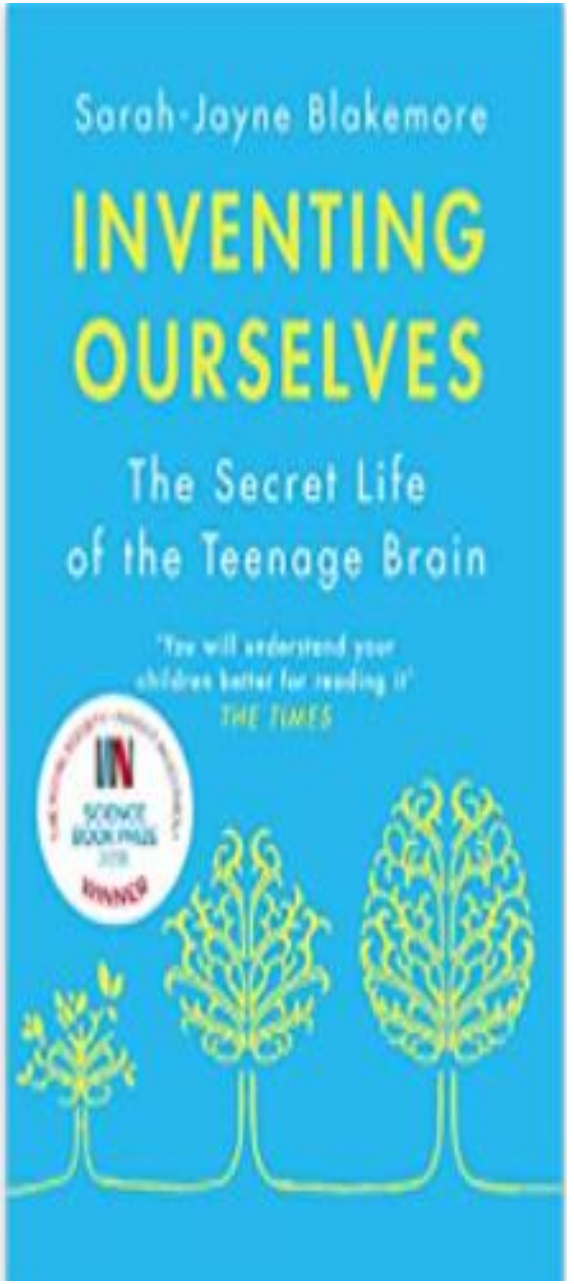
Lost to follow up

- 50%-75% patients lost to follow-up
- Reasons for lapse in care x 6
- Lost to follow-up and symptomatic 36%

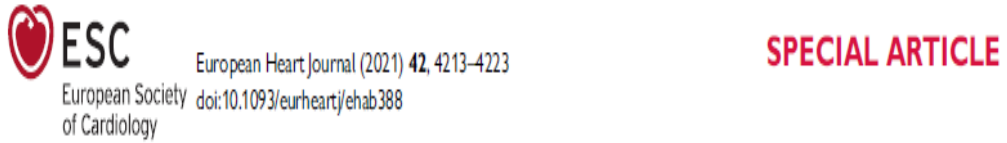
- Proportion of patients **admitted to A and E** nearly doubled around the time of transition
- Patients must acquire appropriate beliefs about adult care well before transfer

Brain development

- Adolescents can have a tendency to take risks, more so when they are with their friends
- The drive is to become independent and impress
- The limbic system which is involved in emotion processing and reward processing, it gives you a kick out of taking risks
- The pre-frontal cortex, which stops us taking risks is still in development in adolescents leading to risk taking
- **Age and development based approach needs to be considered in clinic discussions-this changes in the context of chronic illness**


Sarah-Jayne Blakemore
INVENTING OURSELVES
The Secret Life of the Teenage Brain
'You will understand your children better for reading it'
THE TIMES

Resources



European Heart Journal (2021) 42, 4213–4223
doi:10.1093/eurheartj/ehab388

SPECIAL ARTICLE

Transition to adulthood and transfer to adult care of adolescents with congenital heart disease: a global consensus statement of the ESC Association of Cardiovascular Nursing and Allied Professions (ACNAP), the ESC Working Group on Adult Congenital Heart Disease (WG ACHD), the Association for European Paediatric and Congenital Cardiology (AEPC),

Transition & Young People

Click here for clinical information on transition and the care of young people with CHD

Find out more ›

ACHD

ESC European Society of Cardiology

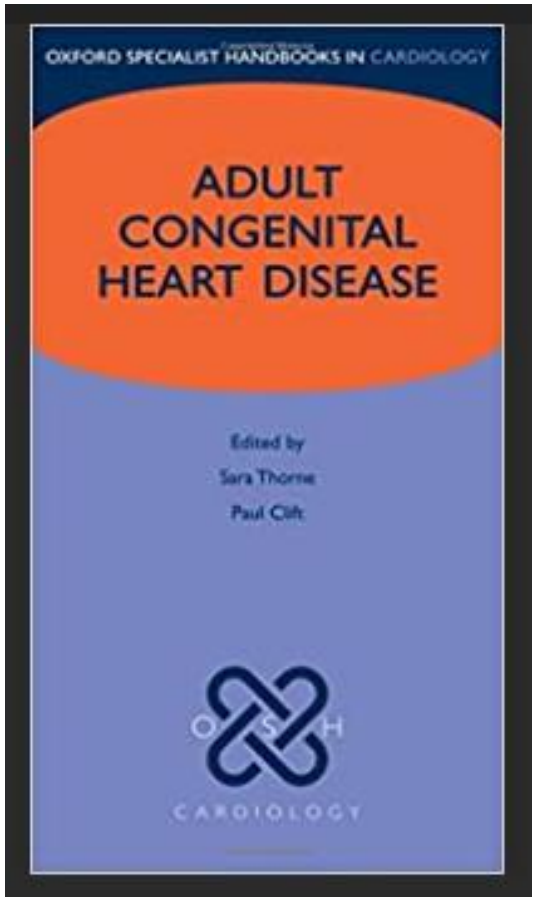
European Heart Journal (2020) **00**, 1–83
doi:10.1093/eurheartj/ehaa554

ESC GUIDELINES

2020 ESC Guidelines for the management of adult congenital heart disease

The Task Force for the management of adult congenital heart disease of the European Society of Cardiology (ESC)

and symptomatic patients. In addition, the patient should be questioned about his/her lifestyle to detect progressive changes in daily activity in order to limit the subjectivity of symptom analysis. In symptomatic patients, alternative causes such as anaemia, depression, weight gain, and physical deconditioning, besides the congenital defect and its sequelae or residuae, should be kept in mind and further excluded if necessary.



Jargon free conversation

- **Half** of what a person is told is forgotten and **half** of what they remember is misunderstood

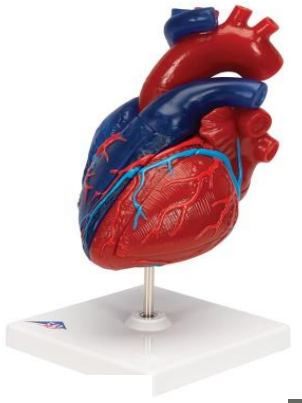
- Xander

Practical tips-what our patients need to know

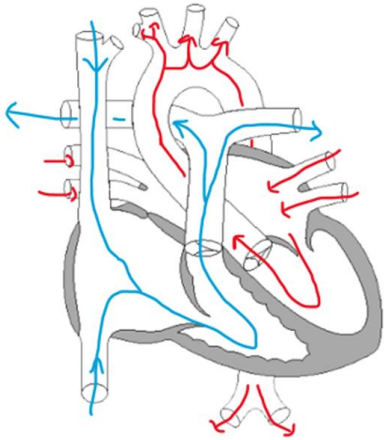
- Heart condition
- Medication
- Diet, alcohol, smoking and drugs
- Endocarditis risk
- Exercise guidelines
- Sex, pregnancy and contraception
- Extreme sport / Risk taking
- Travel
- Support
- Pts have poor understanding

Tell me what you understand about your heart condition?

- How do young people receive information?
- Empowers young person to understand and manage conditions
- Explain pathway
- Help to recognize when things change
- Computer, screen, websites, BHF
- Paper information- BHF Mullins
- Anatomical mould
- Heart model
- Hand drawing
- Parents
- Repeat back



Heartpedia



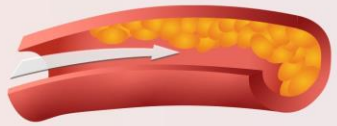
Can you tell me what tablets you are taking…?

- What are they for?
- Check adherence
- Side effects
- Warfarin / INR testing
- Amiodarone / TFTest
- Talk back method
- Build confidence
- Literacy is significant

Acquired risk factors in ACHD

Prevalence compared to background population

- Arterial hypertension ↑
- Diabetes ↑
- Psychological disorders ↑
- Dyslipidaemia —
- Obesity —
- Smoking ↓



- Increased ASCVD risk factors
- Increased ASCVD burden
- Increased ASCVD morbidity and mortality

Risk factor modification in ACHD

- Patient education
- Specific ACHD risk factor control
- Healthy life-style modification
- Medical therapy adherence
- Psychotherapeutic stress management
- Population and global level interventions

Awareness → Therapy

Brida et al (2023) Acquired cardiovascular disease in adults with congenital heart disease: A call to action for timely preventive measures—a clinical consensus statement of the European Society of Cardiology Working Group on Adult Congenital Heart Disease in collaboration with the European Association of Preventive Cardiology and the European Association of Percutaneous Cardiovascular Interventions. European Heart Journal. 00. Pp 1-16.

Can you tell me about your diet?

Risk of being overweight e.g. breathlessness, MI, hypertension, stroke, type 2 diabetes and poor mobility

Advice

- Discuss CVS risk factors, normal BMI, poor diet, junk food
- Wholemeal options
- Low fat, 5 portions fruit and veg and fish
- Low salt
- Cholesterol awareness
- Consider problems with relationship with food?
- Refer to GP for weight loss management or advice?

Many young people drink alcohol, have you tried it?

Poor understanding safe drinking and stimulant drinks. 14 units a week and alcohol-free days

Risks

HR and BP increase, stroke

Prolongs INR

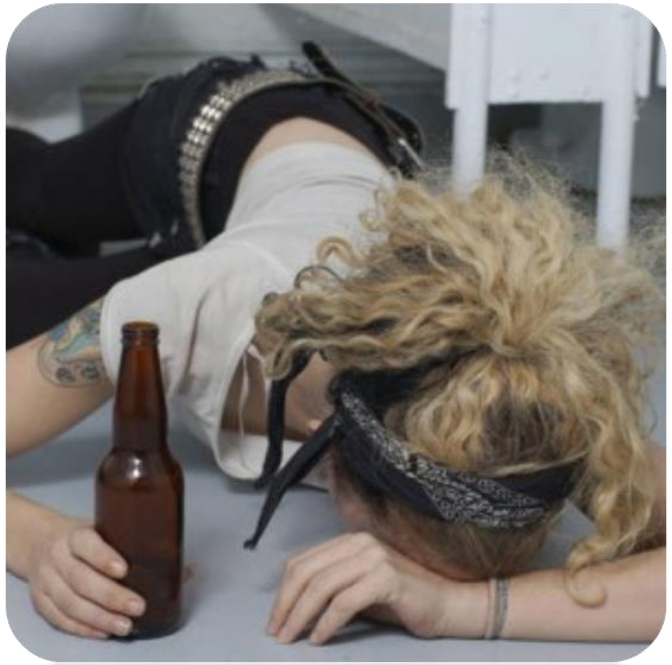
Vomiting reduces absorption of medication

Excessive volume HF

Liver problems

Some cancers

Accidents and mental health problems



www.drinkaware.co.uk

Do you know what a unit is?

- *www.drinkaware.co.uk*

Does anyone in your family smoke, have you tried it?

Risk of smoking

Leading cause of death

HR ↑

↓O2 RR ↑↑BP

↑Toxins 4000

↑risk of MI x 2, CVA +clotting

↑respiratory disease

↑ cancer

Coronary artery disease

COPD

Smoking cessation

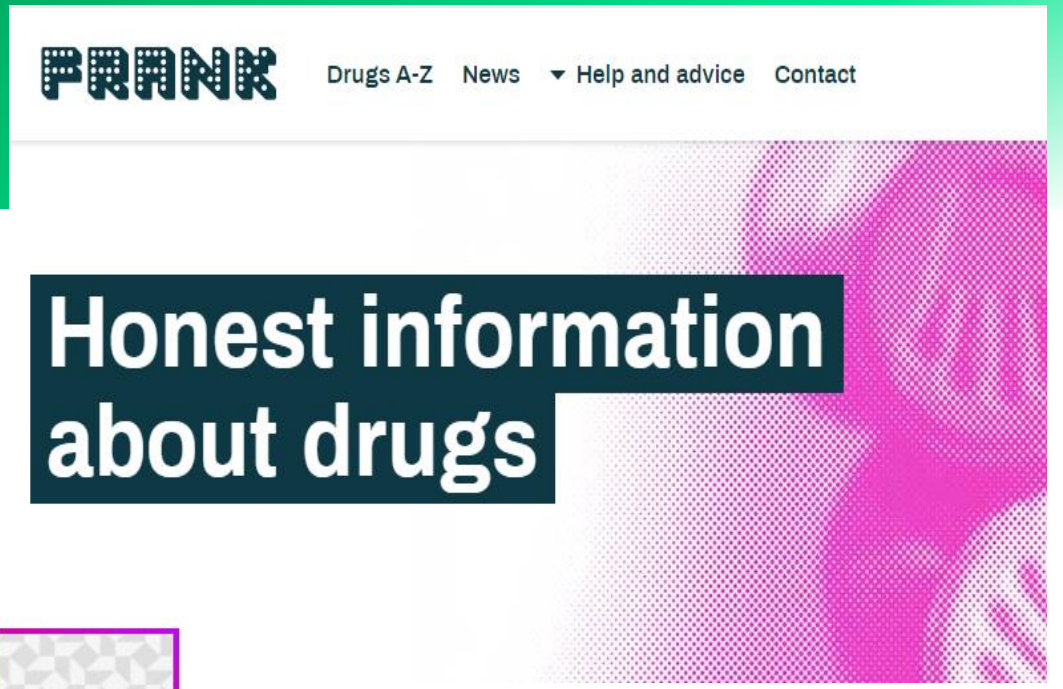
Nicotine replacement from GP

Risk of Vaping

- Coughing and headaches
- Sore throat and dizziness
- Effects on a never smoker powerful 2% nicotine
- Long term effects are unknown

www.ash.org

Recreational drugs?



Risks

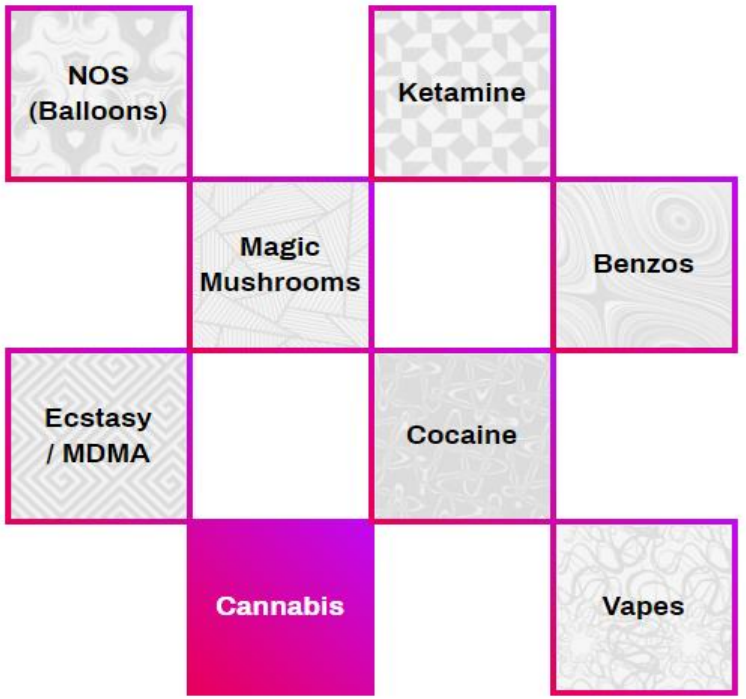
Ecstasy and speed arrhythmias

BZP arrhythmias

Ketamine slows down HR

IV - endocarditis

Advise against



ESC
European Society of Cardiology
European Heart Journal (2023) **44**, 3948–4042
https://doi.org/10.1093/eurheartj/ehad193

ESC GUIDELINES

2023 ESC Guidelines for the management of endocarditis

Developed by the task force on the management of endocarditis of the European Society of Cardiology (ESC)

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

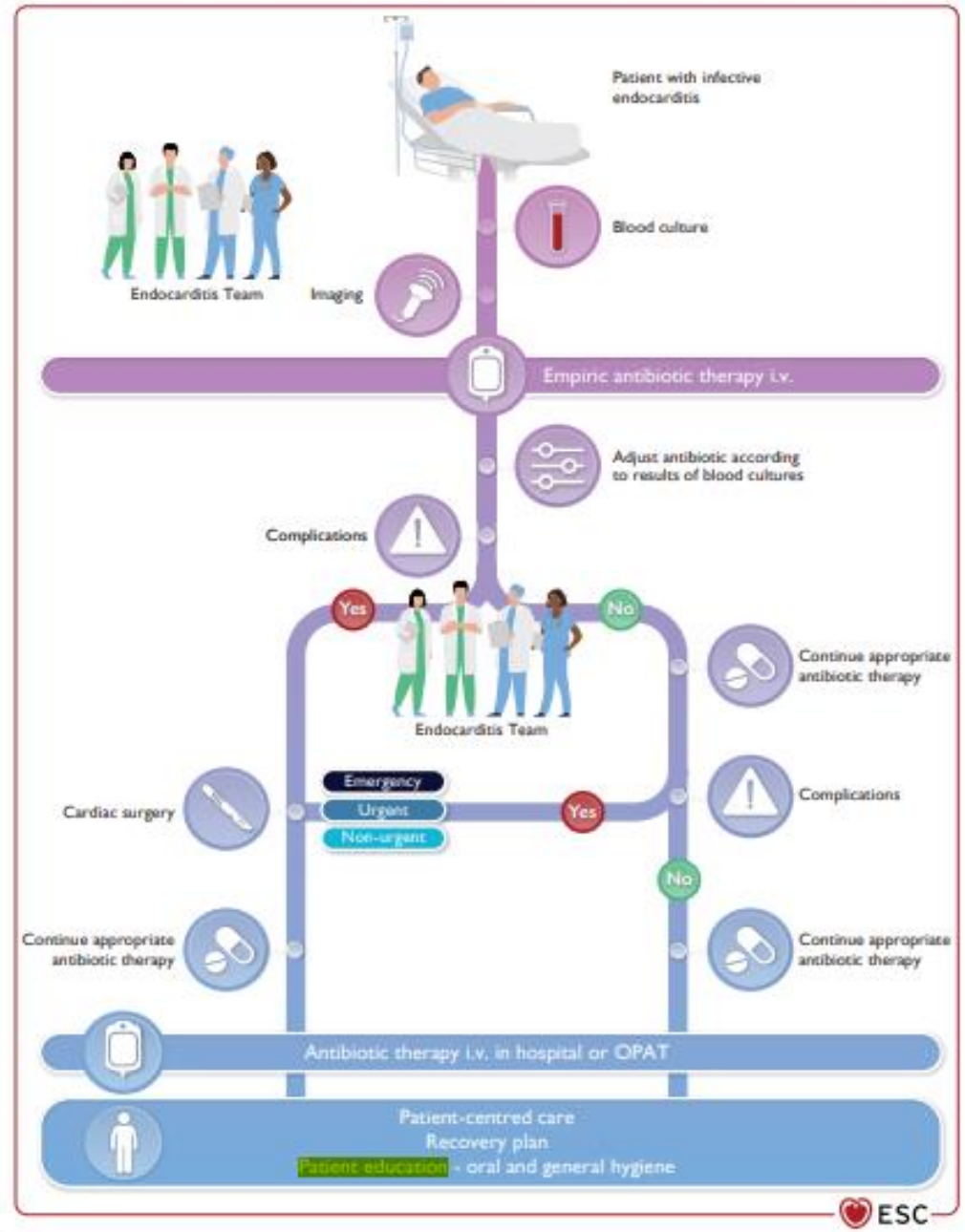


Figure 1 Management of patients with infective endocarditis. i.v., intravenous; OPAT, outpatient parenteral antibiotic therapy.

Endocarditis

Risk

- *Poor dental hygiene/abscesses*
- *Skin infections*
- *Poor nail and skin care*
- *Piercings*
- *Tattoos*
- *Contaminated needles*
- *Invasive procedures*
- *Intervention*
- *Prosthetic valves*
- *Previous endocarditis*
- *IV drug user*
- *Cosmetic procedures*

Advice

- Dentist
- Recognising symptoms
- Flu like symptoms lasting more than five days
- Night sweats
- No antibiotics before blood culture results
- Caution piercings
- Caution tattoos
- Contact specialist centre if unwell

Piercings and tattoos

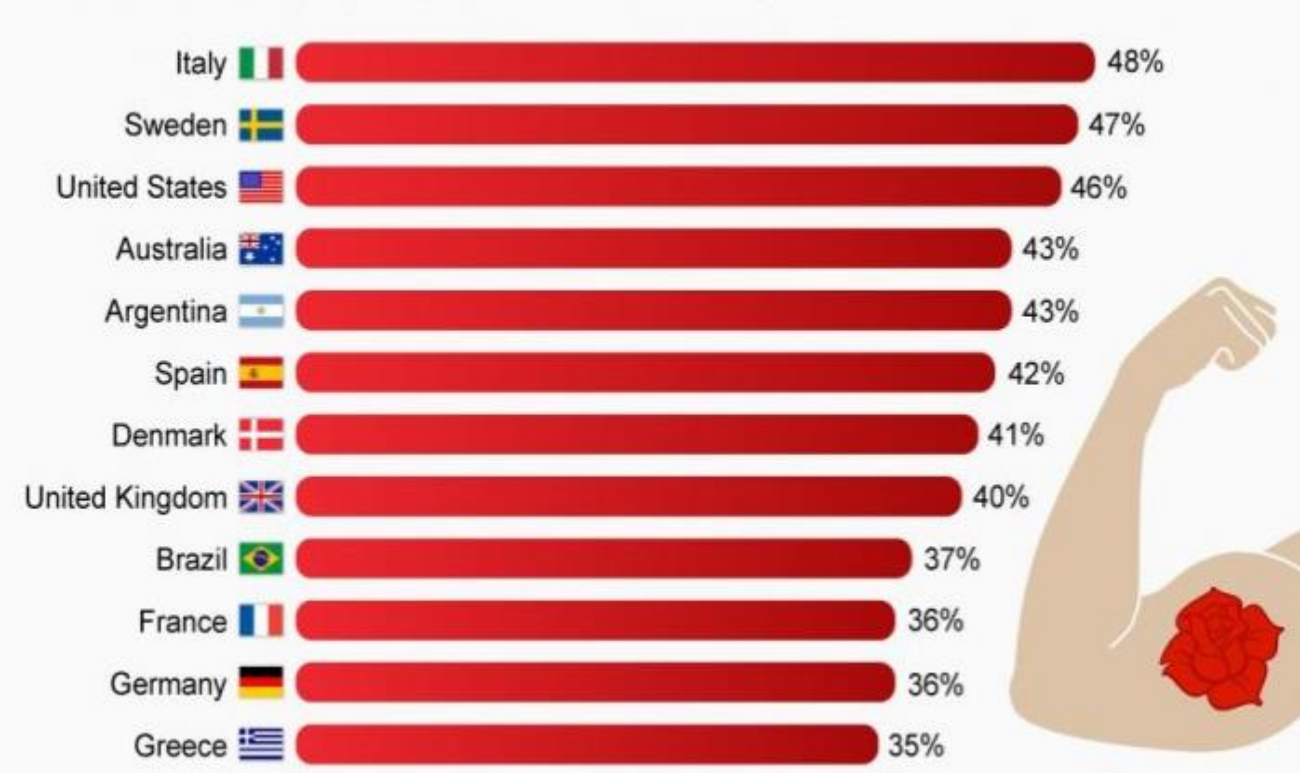
Risk

- 20% infected
- Infection if skin is broken
- Worse in nose, lip, tongue, belly button or genitalia

Advice

- Reputable, hygienic piercer
- Good skin care
- Ensure single use needles are used
- Remove infected ring/stud
- Do not replace until fully healed
- Tattoos……
- Reputable studio
- Clean ink
- New needle
- Gloves

Tattoos will happen



Education of high-risk patients to prevent infective endocarditis

Exercise is safe

- Exercise + active lifestyle in CHD lower than general population

- Isotonic (dynamic or CVS exercise) e.g. jogging or swimming
- Isometric (static) e.g. weight lifting and gym

- Depends on condition/ exercise on prescription helpful
- Based on haemodynamic, arrhythmia
- Avoid intense physical activity, competitiveor contact sport and weight lifting with mod to severe lesions
- Advise 150 mins mod intense exercise a week
- Sudden death is v rare

ESC European Society of Cardiology
European Heart Journal (2020) **0**, 1–10
doi:10.1093/eurheartj/ehaa501

CURRENT OPINION

Recommendations for participation in competitive sport in adolescent and adult athletes with Congenital Heart Disease (CHD): position statement of the Sports Cardiology & Exercise Section of the European Association of Preventive Cardiology (EAPC), the European Society of Cardiology (ESC) Working Group on Adult Congenital Heart Disease and the Sports Cardiology, Physical Activity and Prevention Working Group of the Association for European Paediatric and Congenital Cardiology (AEPC)

Werner Budts [1,2†], Guido E. Pieles [3*†], Jolien W. Roos-Hesselink [4], Maria Sanz de la Garza[5], Flavio D'Ascenzi[6], George Giannakoulas [7], Jan Müller[8], Renate Oberhoffer[8], Doris Ehringer-Schetitska[9], Vesna Herceg-Cavrak[10], Harald Gabriel[11], Domenico Corrado [12], Frank van Buuren[13], Josef Niebauer[14], Mats Börjesson [15], Stefano Caselli [16], Peter Fritsch[17], Antonio Pelliccia[18], Hein Heidbuchel[19], Sanjay Sharma [20], A. Graham Stuart [3], and Michael Papadakis [20]

Physical Activity Recommendations Form

Heart Research UK

Name: ..... Date: (DD/MM/YY) ...../...../.....

Name of condition: .....

Intensity of exercise recommended:	(tick appropriate box)
Low (active, moving about, but no obvious change in breathing or heart rate)	
Moderate (get warmer, breathe harder, heart beats faster – but can still carry on a conversation)	
Vigorous (breathe much harder, heart beats much faster - difficult to carry on a conversation)	

Amount of physical activity recommended:	(tick appropriate box)
At least 60mins physical activity every day (National guidelines for 5-18 year olds)	
30 - 60mins physical activity every day	
Up to 30mins physical activity every day	

Types of exercise:	(circle as appropriate)
Dynamic (muscles work to produce movement e.g. running, swimming)	safe / best avoided
Static (muscles work hard but with little movement e.g. weightlifting, rugby scrum)	safe / best avoided
Up to 30mins physical activity every day	safe / best avoided

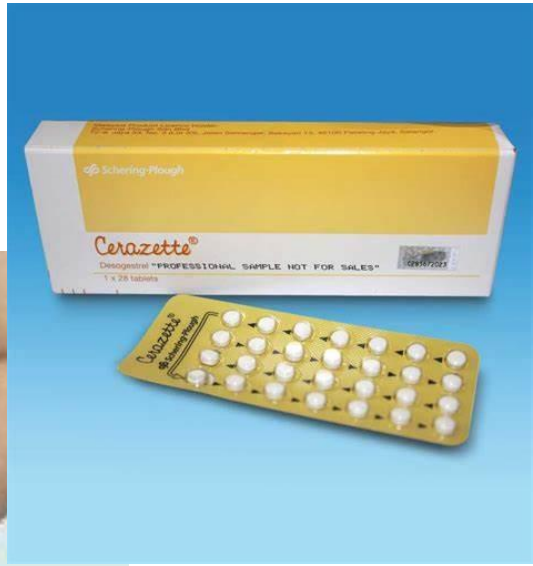
Activities to avoid:	(circle as appropriate)
Activities with a high risk of impact (e.g. martial arts, hockey)	safe / best avoided
Activities with a high risk of injuries, such as cuts and grazes	safe / best avoided
Other:	safe / best avoided

Competitive sport:	(tick appropriate box)
Avoid all competitive sports	
Participate in some competitive sports but rest when necessary	
Participate fully in all competitive sports	

Contraception

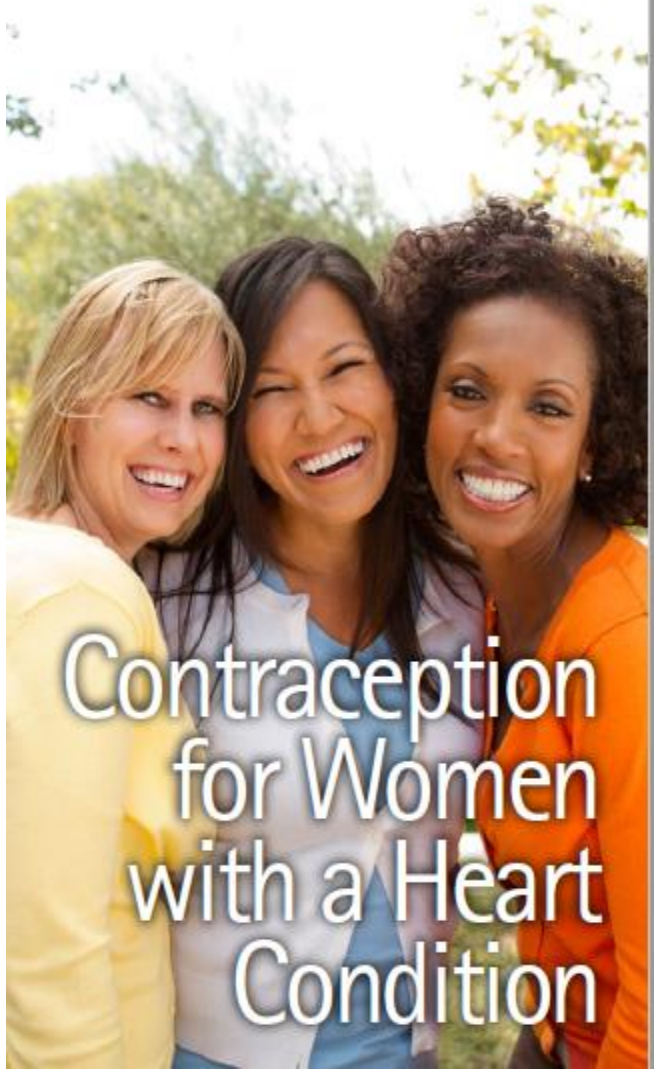
Contraception and a heart condition

- Most women regular methods
- **Cyanosis risk of thrombosis**, the combined pill may predispose to thrombosis
- Depo injection may cause bruising for the patients on Warfarin
- Progesterone only pill e.g. Cerazette
- Low progesterone implant e.g. Implanon 3yrs
- IUD theoretical risk of infection-vasovagal
- Morning after pill-ok
- Sterilization can be high risk



The Somerville Foundation

Supporting young people and adults born with a heart condition



Contraception for Women with a Heart Condition

The Somerville Foundation

Supporting young people and adults born with a heart condition

GUCH and Pregnancy

Pregnancy

- Symptom free before pregnancy will have normal pregnancy
- Circulating vol. doubles during pregnancy

Risks

- Increased risk due to heart failure, arrhythmias, thromboembolism and reduced oxygen to the foetus
- Saturations low advised not to become pregnant.
- Eisenmenger Syndrome -high risk
- Maternal mortality
- Foetal mortality
- Medication changes need to be considered
- Incidence of inheritance discussed

ESC
European Society of Cardiology
European Heart Journal (2018) **39**, 3165–3241
doi:10.1093/eurheartj/ehy340

ESC GUIDELINES

2018 ESC Guidelines for the management of cardiovascular diseases during pregnancy

The Task Force for the Management of Cardiovascular Diseases during Pregnancy of the European Society of Cardiology (ESC)

Endorsed by: the International Society of Gender Medicine (IGM), the German Institute of Gender in Medicine (DGesGM), the European Society of Anaesthesiology (ESA), and the European Society of Gynecology (ESG)

ESC European Society of Cardiology
European Heart Journal (2018) **39**, 3165–3241
doi:10.1093/eurheartj/ehy340

2018 ESC Guidelines for the management of

Table 3 Modified World Health Organization classification of maternal cardiovascular risk

	mWHO I	mWHO II	mWHO II–III	mWHO III	mWHO IV
Diagnosis (if otherwise well and uncomplicated)	Small or mild – pulmonary stenosis – patent ductus arteriosus – mitral valve prolapse Successfully repaired simple lesions (atrial or ventricular septal defect, patent ductus arteriosus, anomalous pulmonary venous drainage) Atrial or ventricular ectopic beats, isolated	Unoperated atrial or ventricular septal defect Repaired tetralogy of Fallot Most arrhythmias (supraventricular arrhythmias) Turner syndrome without aortic dilatation	Mild left ventricular impairment (EF >45%) Hypertrophic cardiomyopathy Native or tissue valve disease not considered WHO I or IV (mild mitral stenosis, moderate aortic stenosis) Marfan or other HTAD syndrome without aortic dilatation Aorta <45 mm in bicuspid	Moderate left ventricular impairment (EF 30–45%) Previous peripartum cardiomyopathy without any residual left ventricular impairment Mechanical valve Systemic right ventricle with good or mildly decreased ventricular function Fontan circulation. If otherwise the patient is well and the cardiac condition	Pulmonary arterial hypertension Severe systemic ventricular dysfunction (EF <30% or NYHA class III–IV) Previous peripartum cardiomyopathy with any residual left ventricular impairment Severe mitral stenosis Severe symptomatic aortic stenosis

High risk pregnancy

WHO I

- Pulmonary stenosis (small/mild)
- Patent ductus arteriosus (small/mild)
- Mitral valve prolapse (small/mild)
- Successfully repaired simple shunt defects (ASD, VSD, PDA, APVR)

Follow- up during pregnancy: once or twice in local hospital

Delivery: local hospital

WHO II

- Unrepaired ASD or VSD
- Repaired tetralogy of Fallot
- Turner syndrome without aortic dilatation

Follow- up during pregnancy: every trimester in local hospital

Delivery: local hospital

WHO II-III

- Mild left ventricular impairment (EF>54%)
- Native or tissue valve disease not considered WHO I or IV
- Marfan or other HTAD syndrome without aortic dilatation
- Aorta <45mm in bicuspid aortic valve
- Repaired coarctation
- AVSD

Follow- up during pregnancy: Bimonthly in expert centre

Delivery: Expert centre

WHO III

- Left ventricular impairment (30-45%)
- Mechanical valve
- Systemic right ventricle with good or mildly impaired function
- Fontan (if otherwise well)
- Unrepaired cyanotic disease
- Moderate mitral stenosis
- Severe asymptomatic aortic stenosis
- Moderate aortic dilatation

Follow- up during pregnancy: (bi)monthly in expert centre

Delivery: Expert centre

WHO IV: pregnancy not recommended

- Pulmonary arterial hypertension
- Severe systemic ventricular dysfunction (EF<30%)
- Moderate systemic right ventricular dysfunction
- Severe mitral stenosis
- Severe symptomatic aortic stenosis
- Severe aortic dilatation
- Vascular Ehlers-Danlos
- Severe (re)coarctation
- Fontan with any complication

Follow- up during pregnancy: Monthly in expert centre

Delivery: Expert centre

APVR = anomalous pulmonary venous return, ASD = atrial septal defect, AVSD = atrioventricular septal defect, EF = ejection fraction, ESC = European Society of Cardiology, HTAD = hereditary thoracic aorta disease, PDA = persistent ductus arteriosus, VSD = ventricular septal defect, WHO = World health organization

Adapted and modified for congenital heart disease , from the ESC 2018 "Cardiovascular diseases during Pregnancy (management of) Guidelines" Table 3

Education in Heart

Table 1 Lesion-specific risks

	Maternal cardiovascular risk	Obstetric risk (other than caesarean section)	Fetal/Neonatal risk*	References
ASD, repaired	3.6% arrhythmia, 3.6% persistent NYHA deterioration	11% hypertension/pre-eclampsia, 16% PPH	1.8% offspring mortality†	Yap *BJOG* 2009
ASD, unrepaired	4.5% arrhythmia, 3% persistent NYHA deterioration, 0.8% TIA	11% hypertension/pre-eclampsia, 8.3% PPH	3.0% offspring mortality	Yap *BJOG* 2009
VSD, repaired	2.3% arrhythmia	7% hypertension/pre-eclampsia, 12% PPH	21% SGA	Yap *BJOG* 2010
VSD, unrepaired	1% arrhythmia, 1% endocarditis	15% hypertension/pre-eclampsia, 9.6% PPH	6.7% SGA, 1% offspring mortality	Yap *BJOG* 2010
PDA	‡	‡	‡	
AVSD	23% persistent NYHA deterioration, 19% arrhythmias	17% hypertension/pre-eclampsia, 6.3% gestational diabetes, 21% PPH	10% SGA, 6.3% neonatal mortality	Drenthen *EHJ* 2005
TOF	8%–12% arrhythmia or heart failure, 2% persistent NYHA deterioration	8% hypertension/pre-eclampsia, 10% PPH	17%–21% SGA, 18% prematurity, 6.5% offspring mortality	Meijer *Heart* 2005, Balci *AHJ* 2011, Kampman *Us Obst Gyn* 2017
Ebstein	7.3% arrhythmia or heart failure	8.5% PPH	19%–27% prematurity, 18% offspring mortality	Connoly *JACC* 1994, Katsuragi *AJObstGyn* 2013, Lima *Arch Cardiovasc Dis* 2016
LVOT obstruction	3.8%–12% heart failure, 2%–5.7% arrhythmia, 1% endocarditis	6.4%–11% hypertension/pre-eclampsia, 4.2% PPH	8%–21% prematurity, 13% SGA, 0%–1.1% fetal mortality	Silversides *AJC* 2003, Yap *IJC* 2008, Tzemos *AHJ* 2009, Orwat *JACC* 2016
RVOT obstruction	9% heart failure	15% hypertension-related complication	17% prematurity, 4.8% offspring mortality	Drenthen *Heart* 2006, Greutmann *EHJ* 2010
TGA—after arterial switch	0%–12% arrhythmia or heart failure	‡	9%–21% prematurity	Stoll *JAMA* card 2018, Tobler *Am J Car* 2010, Fricke *Heart Lung Circ* 2019, Horiuchi *J Card* 2019
TGA—after atrial repair	6.6%–22% arrhythmia, 11%–14% persistent NYHA deterioration	18% hypertension/pre-eclampsia, 14% PPH	24%–38% prematurity, 22%–38% SGA, 12% offspring mortality	Drenthen *EHJ* 2005, Cataldo *BJOG* 2016, Trigas *Circ J* 2014
ccTGA	26%–32% heart failure, CVA or worsening of cyanosis	2% hypertension/pre-eclampsia, 14% PPH	9% prematurity, 1.3% offspring mortality	Therrien *Am J Card* 1999, Gelson *EJOG* 2011, Drenthen *JACC* 2007
Fontan	3%–37% arrhythmia, 4% thrombotic event, 3%–11% heart failure	14% PPH	59% prematurity, 20% SGA, 7.6%–17% offspring mortality	Garcia Ropero *Circ CV Qual Outcomes* 2018
Cyanotic disease	32% heart failure, arrhythmia or progression of hypoxaemia	10% PPH	37% prematurity, up to 24% fetal mortality	Ladouceur *Circ* 2017, Presbitero *Circ* 1994, Drenthen *JACC* 2007
PAH in CHD (note: very broad spectrum of results)	0%–28% mortality, 31%–35% RV failure, 7% pulmonary hypertensive crisis, 7%–14% thromboembolism, 9% arrhythmia	0%–6% pre-eclampsia, 0%–38% PPH	17%–86% prematurity, 0%–7% offspring mortality	Thomas *JAHA* 2017, Sliwa *EJHF* 2016, Bedard *EHJ* 2009
Eisenmenger	36% mortality, 21%–45% heart failure, 19% thromboembolism	29% PPH	65%–88%% prematurity, 38%–83% SGA, 10%–27% fetal mortality, 18%–25% perinatal mortality	Drenthen *JACC* 2007, Duan *BMC Pregnancy and Childbith* 2016
Coarctation	None reported	22% hypertension/pre-eclampsia	2% offspring mortality	Vriend *EHJ* 2005

WHO IV: pregnancy not recommended

Pulmonary arterial hypertension

Severe systemic ventricular dysfunction (EF<30%)

Moderate systemic right ventricular dysfunction

Severe mitral stenosis

Severe symptomatic aortic stenosis

Severe aortic dilatation

Vascular Ehlers-Danlos

Severe (re)coarctation

Fontan with any complication

Follow- up during pregnancy: Monthly in expert centre

Delivery: Expert centre

APVR = anomalous pulmonary venous return, ASD = atrial septal defect, AVSD = atrioventricular septal defect, EF = ejection fraction, ESC = European Society of Cardiology, HTAD = hereditary thoracic aorta disease, PDA = persistent ductus arteriosus, VSD = ventricular septal defect, WHO = World health organization

Adapted and modified for congenital heart disease , from the ESC 2018 "Cardiovascular diseases during Pregnancy (management of) Guidelines" Table 3

Extreme sports

Bungee jumping
Skiing
Parachute jump

Risks

High altitude/hypoxia
Warfarin
Diving HR↓
↑ pul oedema
↑air embolism
↑decompression R-L
One off may be ok

Theme park rides

Risks

HR

BP↑

BP↓

ICD pts avoid dodgems

Warfarin- risk of bleeding

Risk taking

Non-adherence,
DNA, medication,
INR testing unreliable

Engaging in
Extreme sport, unprotected sex
drugs, alcohol use

Leading to
Social problems
depression and mental health problems

How is your mood?

Untreated depression and
anxiety common

Smoking, alcohol, drugs dependency

Rarely diagnosed, undertreated
Led to reduced QOL

- Psychology Psychiatry
- CAMS

‘We have a psychology service for our patients’

Circulation: Cardiovascular Quality and Outcomes
Volume 15, Issue 8, August 2022; Page e000110
https://doi.org/10.1161/HCQ.0000000000000110

AHA SCIENTIFIC STATEMENT

Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association

Adrienne H. Kovacs, PhD, Chair, Judith Brouillette, MD, PhD, Patricia Ibeziako, MD, Jamie L. Jackson, PhD, Nadine A. Kasparian, PhD, Yuli Y. Kim, MD, Tracy Livecchi, LCSW, Christina Sillman, MSN, Lazaros K. Kochilas, MD, MS, FAHA, Vice Chair, and on behalf of the American Heart Association Council on Lifelong Congenital Heart Disease and Heart Health in the Young; and Stroke Council

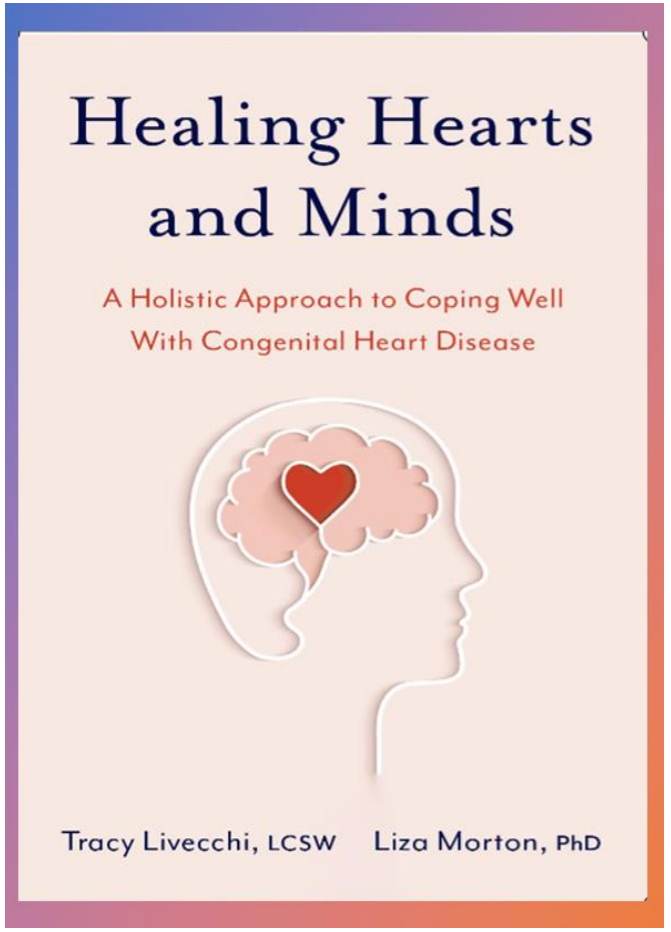
ABSTRACT: Although resilience and high quality of life are demonstrated by many individuals with congenital heart disease, a range of significant psychological challenges exists across the life span for this growing patient population. Psychiatric disorders represent the most common comorbidity among people with congenital heart disease. Clinicians are becoming increasingly

Psychology

Anxiety and Depression in 35% of ACHD patients – high health care utilization and mortality

Referral

- Anxiety and low mood relating to ACHD
- Surgery, procedure, new diagnosis, poor prognosis
- Trauma, PTSD fears and phobia
- Fear of bad news
- High risk pregnancy relating to ACHD
- Risk taking behaviour, compliance
- Body image
- Learning disability pts need additional support
- In patient support
- Patient Book club



Do your scars worry you?

- Scars
- Body image
- Changing faces camouflage make-up

CHANGING FACES

Providing support and promoting respect for everyone with a visible difference

Flying

Risks

Thrombosis, arrhythmia, infection

Oxygen, wheelchair

Advice

Hydrated, DVT prophylaxis

Aspirin

Fit to fly test by respiratory

Clinic letter

Travel insurance

Driving

Risks

Advice

After an event 6 months

Pacemaker 1 week

ICD secondary prevention 1 mth

ICD 6 mths

Inform DVLA

After surgery 4-6 weeks

HGLV reapply Insurance need to know

- Gov.uk

Social issues

Interrupted Education

- Peer pressure / bullying
- Employment Difficulties
- Benefits complicated
- High rates of rejection
- Insurance Problems

citizens advice

Benefits - introduction

Careers and Employment

Employment advice and support

Only 10% are totally disabled

Intellectual limitations

Isolation and low self esteem

Life Insurance

Mortgage and buying a house

Variable loading

Travel insurance shop around

National Careers Service

Helping you take the next step

www.direct.gov.uk/youngpeople

Next steps-transfer

- Conversations
- Written to adult colleagues detailed clinical hand over
- Medway proforma to handover coming soon
- Copied in a CNS/Link nurse to clinic letter
- Nurse will write to patient and provide contact details in the event of patient needing to contact the service before first ACHD appt
- Explain the plan to the young person and family reiterated in clinic letter
- Be clear about where and when ACHD appt will be

Give the info!

- YP pack, charity info
- Date for virtual YP evening
- Link to Tour of adult hospital

Bye!

Use CNS teams

South Wales and South West Congenital Heart Disease Network

Adult Congenital Heart Disease Nurse Specialists

Bristol Heart Institute

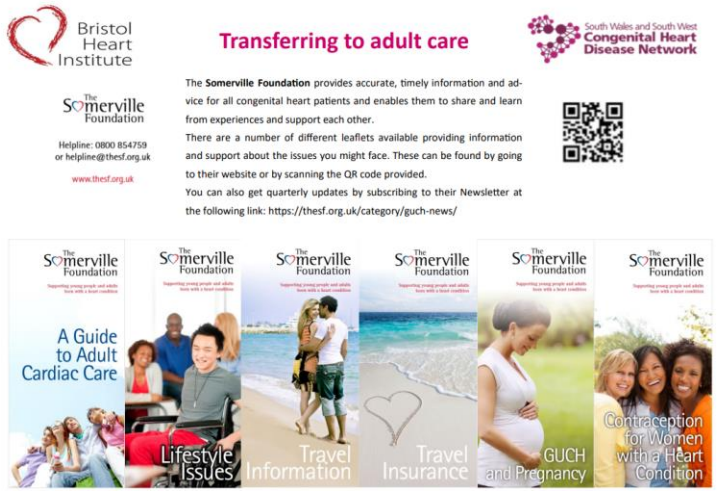
Are available to give advice and support on cardiac and lifestyle issues for you and emotional support for you and your family.

Monday to Friday, 8am – 4pm
Cardiac nurse specialist call 0117 342 6599 or email BHIACHDnurses@uhbw.nhs.uk
Hospital switchboard: 0117 923 0000 Bleep 3393

Support for patients

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

Youth at Heart



British Heart Foundation

On this page

Thankyou