Aangeboren hartafwijkingen & Seksualiteit

Philippine Kiès

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

Leiden University Medical Center

Amsterdam UMC
University Medical Centers

Introductie

CAHAL

Center for Congenital Heart Disease

Amsterdam - Leiden

Leiden University Medical Center

Amsterdam UMC University Medical Centers

Sexual Health and Well-Being in Adults With Congenital Heart Disease

A International Society of Adult Congenital Heart Disease Statement

Lorna Swan, MBChB, MD,[a] Jonathan Windram, MBChB,[b] Luke Burchill, MBBS, PhD,[c] Laila Akbar Ladak, PhD, MScN, BScN, RN,[d] Leigh C. Reardon, MD,[e] Beatriz Fernandez, MD,[f] Roni M. Jacobsen, MD,[g] Maggie Simpson, BSc, MRes,[h] David Harrison, MD,[i] Liza Morton, PhD[j]

ABSTRACT

As health care outcomes improve the priority for those living with adult congenital heart disease have changed to a more holistic focus on quality of life and well-being. Although health care has embraced this, there are still areas where there is a deficit in advice, allyship, and advocacy. One of these deficits is in the area of sexual health and well-being. A healthy sexual life has a myriad of physical and psychosocial benefits. However, individuals with adult congenital heart disease may have significant barriers to achieving well-being in this aspect of their lives. These barriers and their potential solutions are outlined in this paper. (JACC Adv 2023;2:100716) © 2023 The Authors. Published by Elsevier on behalf of the American College of Cardiology Foundation. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/).

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

HIGHLIGHTS

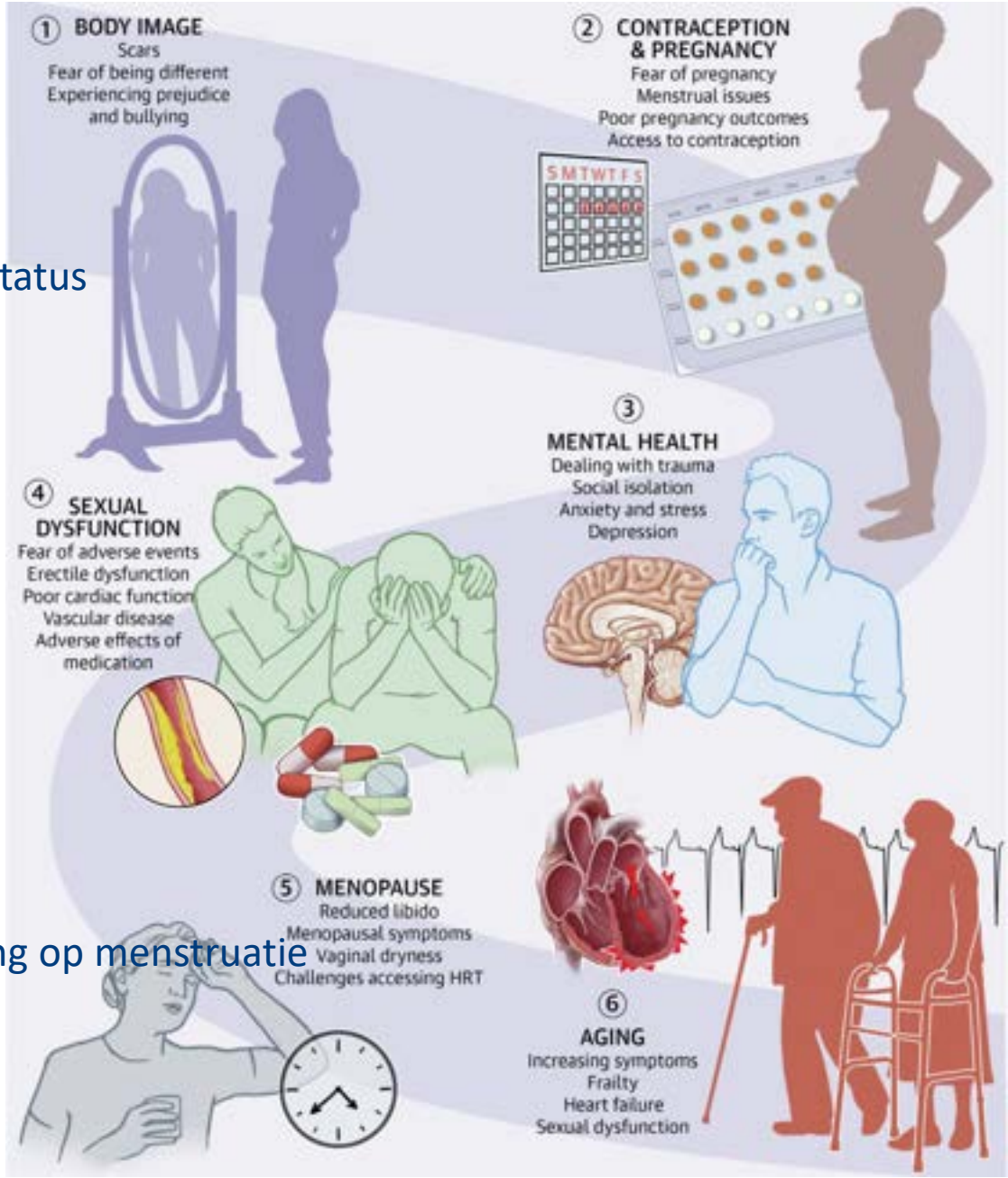
- Sexual dysfunction is common in individuals living with congenital heart disease.
- The adult congenital heart disease team should provide an open inclusive environment to discuss sexual health.
- Psychological and physical barriers to having a fulfilling sexual life are often treatable.
- Further education and research are needed to improve this aspect of holistic adult congenital heart disease care.

Seksuele disfunctie: 28%

RF:
Inspanningsintolerantie/functionele status
Hartritmestoornissen,
Medicatie.

Erectiestoornissen:
10–43% van de mannen
RF:
hogere leeftijd
Angst voor seksuele activiteit

Menstruatieproblemen:
83% van de jongvolwassen vrouwen
20% zoekt hiervoor medische hulp.
Informeer actief over effect antistolling op menstruatie



Waarom dit onderwerp in de spreekkamer ?

Verstrekken van de juiste informatie is van groot belang

Veiligheid

Kwaliteit van leven







Na enige vorm van een hartafwijking:
2/3 vd mannen
1/2 vd vrouwen
probleem met seksualiteit



Wat is er bekend?

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

Leiden University Medical Center

Amsterdam UMC
University Medical Centers

Sexual function in patients with advanced heart failure

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

Tiny Jaarsma, DRS, Kathleen Dracup, DNSc, RN, Julie Walden, MN, RN, and Lynne Warner Stevenson, MD, Maastricht, The Netherlands; Los Angeles, Calif.; and Boston, Mass.

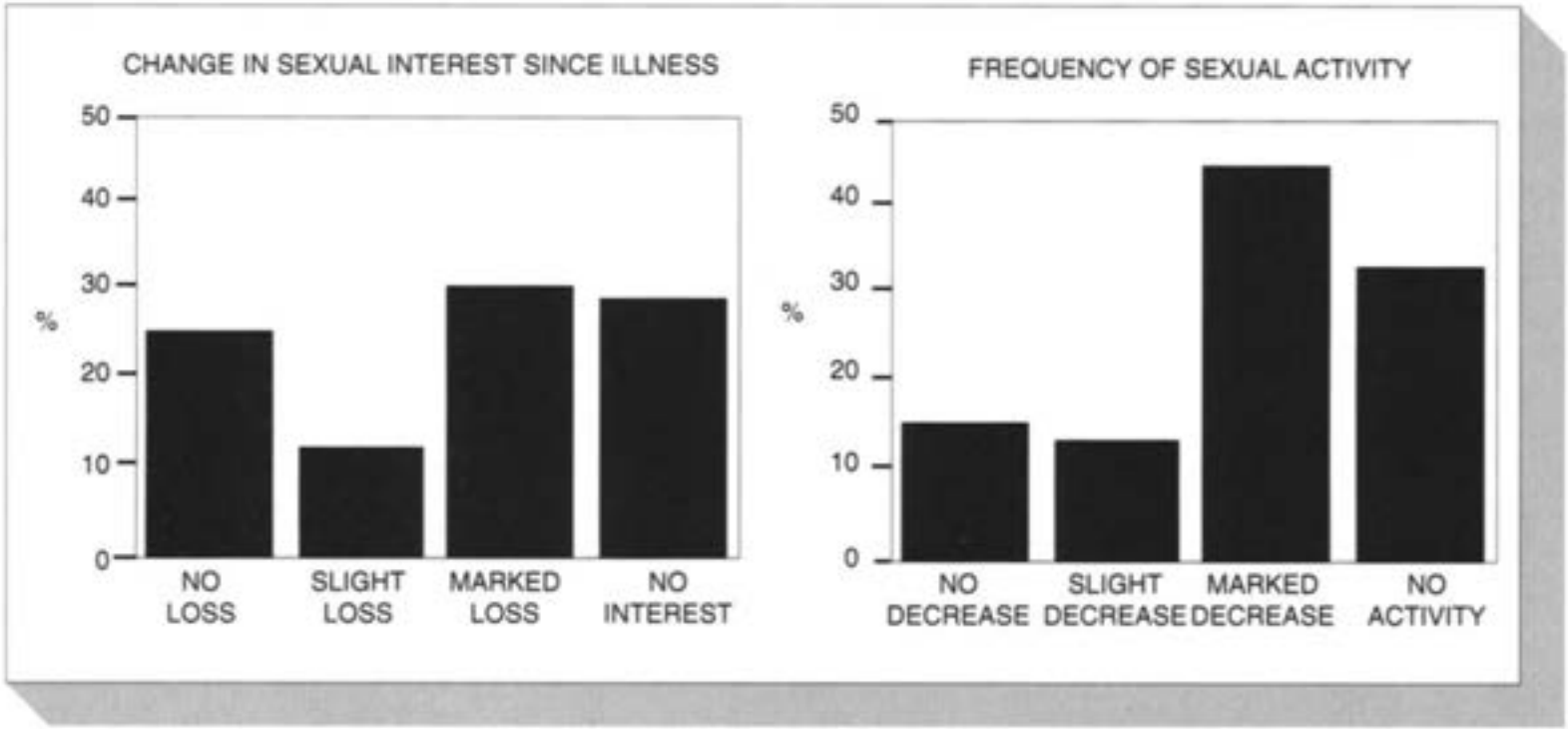


Fig. 1 Percentage of patients ($N = 62$) who reported change in sexual interest since illness and decrease in frequency of sexual activity since onset of heart failure symptoms.

Sexual function in patients with advanced heart failure

Tiny Jaarsma, DRS, Kathleen Dracup, DNSc, RN, Julie Walden, MN, RN, and Lynne Warner Stevenson, MD, Maastricht, The Netherlands; Los Angeles, Calif.; and Boston, Mass.

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

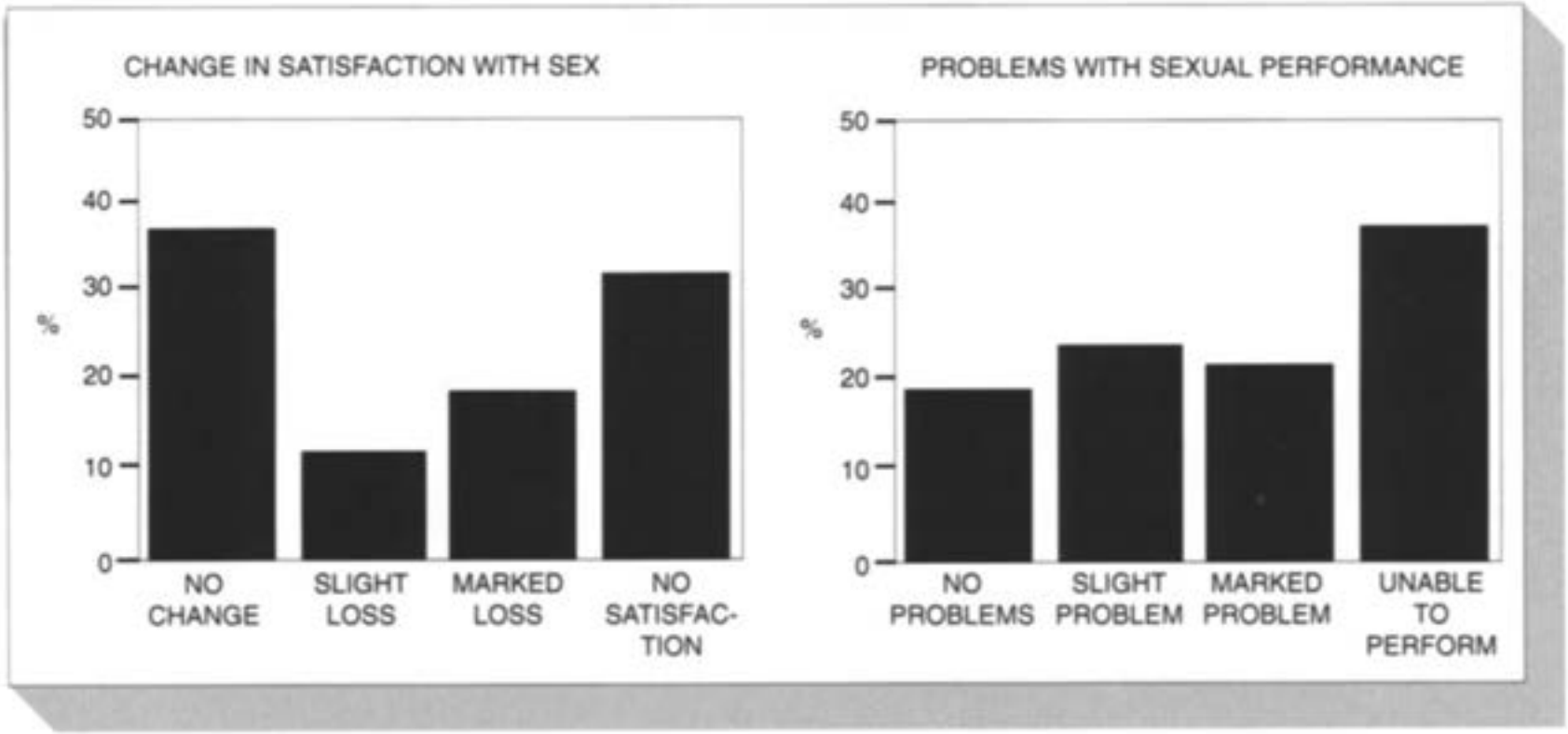


Fig 2 Percentage of patients ($N = 62$) who reported experiencing change in satisfaction with sex and problems with sexual performance since onset of heart failure symptoms.

AHA Scientific Statement

Sexual Activity and Cardiovascular Disease

A Scientific Statement From the American Heart Association

60-87 % HF patienten – seksuele problemen

↓

Interesse
Plezier/Voldoening
Prestatie/Uitvoering
Frequentie

25% helemaal niet meer seksueel actief

Circulation. 2012;125:1058-1072

Sexual function of patients with heart failure: facts and numbers

Tiny Jaarsma[1,2]*

ESC HEART FAILURE
ESC Heart Failure 2017; **4**: 3–7
Published online 14 September 2016 in Wiley Online Library (wileyonlinelibrary.com) **DOI:** 10.1002/ehf2.12108

EDITORIAL

*Although the majority of health care professionals feel a certain responsibility to discuss patients' sexual health, in practice, they seldom address sex with their patients, even during cardiac rehabilitation or in general prac*tice.

ACHD population:

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

105 ♀♂ – 32 yr } overall 28% sexual dysfunction

Neiman Int J Cardiol. 2017;228: 953–7

Erectile dysfunction 30-38% @ 32-34 yrs

Cook Heart Rhtyhm. 2013;10:805–10 / Am J Cardiol. 2008;102:1728–30

- Wide variety of study designs/instruments
- Small samples
- no clear idea on pathophysiology, RF, medical therapy

Seksuologie

CAHAL

Center for Congenital Heart Disease

Amsterdam - Leiden

Leiden University Medical Center

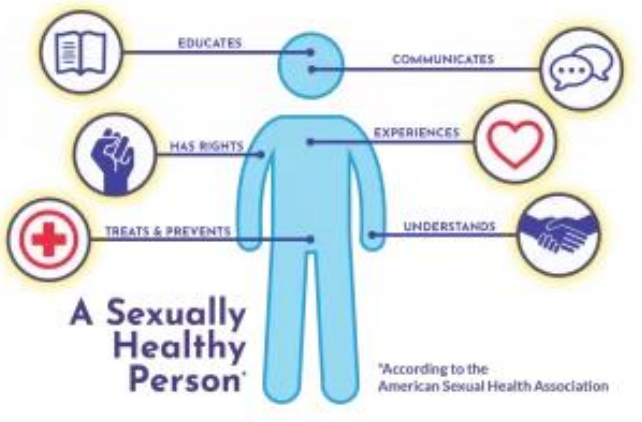
Amsterdam UMC University Medical Centers

Seksualiteit { Bio-Psycho-Sociaal

Biologisch: leeftijd
gezondheid
medicatiegebruik

Sociaal: cultuur
religie
relatie
opvoeding

Psychologisch: persoonlijkheid
psychische problemen
omgaan met seksualiteit
verwachtingen
normen en waarden



CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

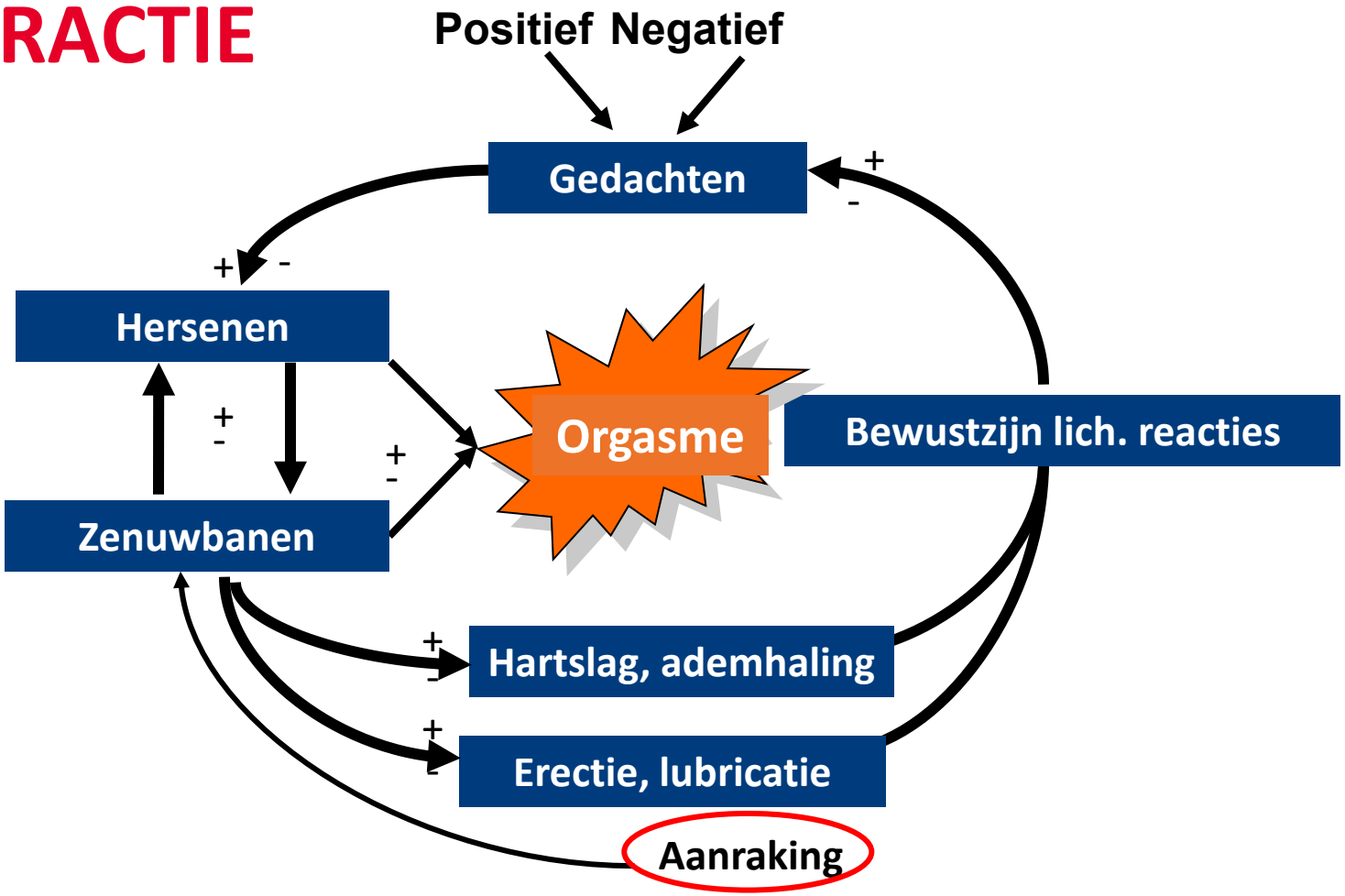
Fysiek nodig voor seks



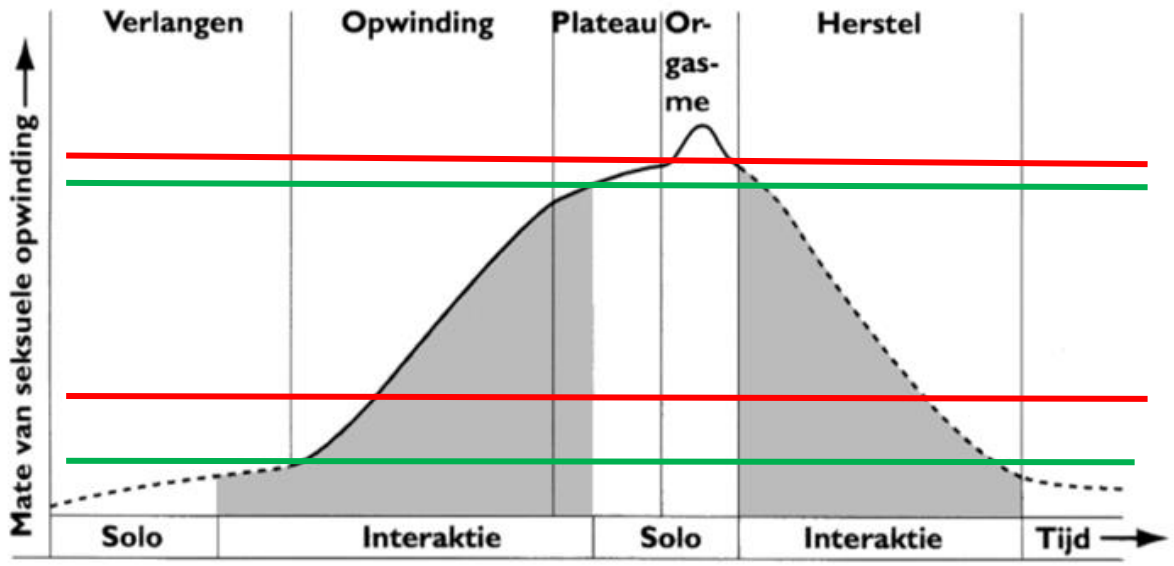
- Geslachtsorganen
- Bloedvaten
- Zenuwbanen
- BB spieren
- Hormonen

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

INTERACTIE



Seksule Respons Cyclus: fasen & drempels



- Context
- Communicatie
- Stimuli

- Stimulatie
- Lichaam
- Geest

- Concentratie
- Stimulatie
- Lichaam
- Geest

- Prettig
- Ontspannen
- Pijn
- Emoties

Seksuele problemen

Kunnen verschillende oorzaken hebben

De ziekte

- Direct: schade bloedvaten
- Indirect: angst infarct
- Behandeling: bijwerkingen medicatie

Mentale factoren

- Zelfbeeld
- Lichaamsbeeld
- Angst, depressie, rouw

Relatie factoren

- Verschil in wensen
- Verschil in omgaan
- Communicatie

Seksuele factoren

- Tijd
- Stimulatie
- Repertoire

Normen en waarden

Ervaringen

Fysiologie



Pre-orgasme: 2-3 METs

Orgamse: 3-4 METs

↓

Wandelen op vlakke ondergrond (~ 5 km/u)
1-2 trappen oplopen
Fietsen
Tuinieren

Matige, maar wel kortdurend ↑myocardiale O2 consumptie (10-15s)

Correlatie: + Functionele status (NYHA, 6MWT)
- LVEF

Fysiologie



Laboratoriumonderzoek:
Max HF 140-180/min
Bloeddruk ↑ 80/50 mmHg tijdens orgasme

Home-monitoring:
Max HF 117/min tijdens orgasme
Bloeddruk 162/89 mmHg.



Houding: (studie 8 mannen)
Bovenop- en onderliggend gelijk
Hartslag 114-117/min
Bloeddruk ~ 160/80 mmHg

Risico

Sudden cardiac deaths: <2% v inspanninggerelateerde SCD tijdens SA *(buitenechtelijke setting)*

Hartinfarct: 0.7-0.9% < 1 uur vooraf seksueel actief

(stress, boosheid, andere inspanning => groter risico)



- Vb 50 jr man, blanco, verhoogt zijn jaarlijkse kans op een infarct van 1% naar 1,01% door wekelijks seksueel actief te zijn

Chronische Angina Pectoris:

Helemaal gelijk aan klachten bij elke andere vorm van dagelijkse inspanning



Medicatie voor bloeddruk / hartslag

Nitros spray





https://www.uptodate.com/contents/sexual-activity-inpatients-with-cardiovascular-disease; Canadian Journal of Cardiology 32 (2016) 410-420

Subpopulaties - ICD

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

Angst voor ICD therapie of juist uitblijven van therapie pt /partner

Table. Frequently Asked Questions and Answers

Question	Answer
What will sexual activity do to my heart?	Sex is considered a moderate activity and represents only a moderate stress on the heart. The absolute cardiac risk during sexual activity is actually extremely low.
Is sex safe?	For most patients, sexual activity is a safe practice. Even if sexual intercourse is not possible for a particular patient, this should not discourage someone from engaging in intimate activities with his or her partner.
What if I get shocked during sex?	Receiving a shock during sex is no different from receiving a shock during any other activity. If you receive 1 shock and feel fine afterward, contact your doctor or clinic as soon as possible. If you receive more than 1 shock, call your doctor or 911 immediately. If you receive any number of shocks and do not feel fine afterward, call 911 (or the emergency number in your area) immediately.
Could I hurt my partner if I receive a shock during sex?	Your partner is not in any danger from your receiving a shock. This will not hurt your partner in any way or cause pain.
Are other patients concerned about sex too?	Many patients have fear regarding sexual activity. This is a significant concern for many ICD patients. In fact, many never return to sexual activity after implantation of their device because of this fear! Communicating with your doctor and feeling confident in the safety of your device is essential to getting back to living life to the fullest!

Sexual Health for Patients With an Implantable Cardioverter Defibrillator (Circulation. 2010;122:e465-e467)

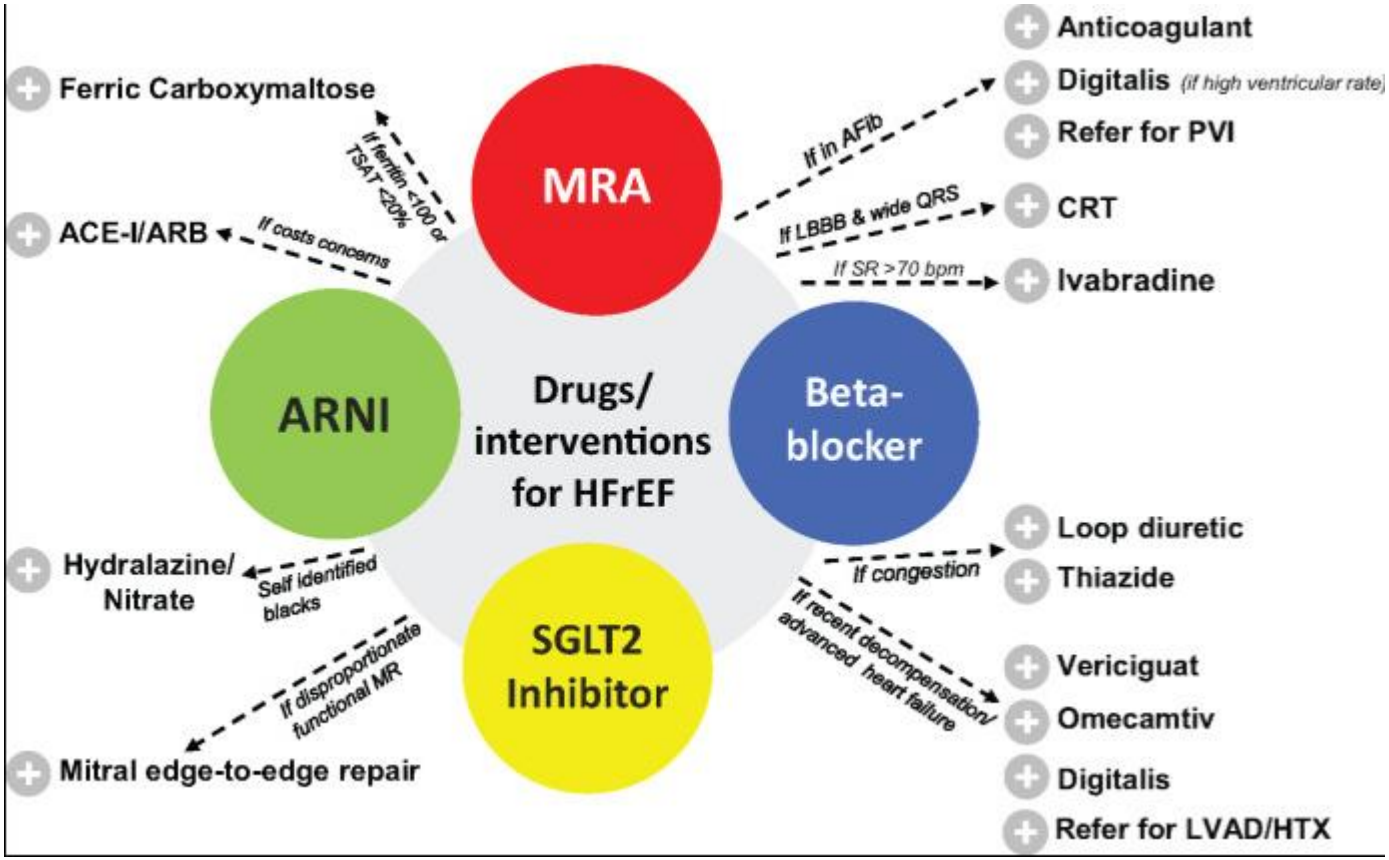
Post-event /interventie

- ≥ 1 week na hartinfarct als verder klachtenvrij
- ≥ 2 weken na dotter in 1 of meerdere vaten / klepinterventie (als lies of pols goed dicht zijn)
- ≥ 6-8 weken na open hart operatie (als het borstbeen goed is vastgegroeid)
- Bij mild-matige klepafwijkingen of als ernstig kleplijden onder controle is
- Bij implantatie pacemaker / ICD (nb 6 weken arm niet heffen boven de schouder)

TABLE 2 Cardiac Drugs That May Be Associated With Sexual Dysfunction

Type of Sexual Dysfunction	Drug
Erectile dysfunction	Angiotensin receptor blockers, beta-blockers, clonidine, calcium-channel blockers, diuretics, digoxin, methyldopa, spironolactone, statins, thiazides
Vaginal dryness	Anticholinergics, antihistamines, beta-blockers, calcium-channel blockers, diuretics, spironolactone
Reduced libido	Diuretics, metoprolol, spironolactone
Priapism	Doxazosin, warfarin
Impaired ejaculation	Doxazosin
Testicular dysfunction (elevated serum gonadotrophins) (chronic epididymitis)	Amiodarone

Cardiac drugs that improve ventricular function/symptoms may improve sexual function.



Dapagliflozin improves ED in patients with DMII and enhances the efficacy of tadalafil. Further studies are needed to confirm our results explain the mechanism(s) by which dapagliflozin exerts its effects on ED *Diabetic Medicine. 2024;41:e15217*.

Sacubitril/Valsartan Improves Sexual Function and Fibrosis of the Clitoral and Vaginal Tissues in Female Spontaneously Hypertensive Rats. *J Cardiovasc Pharmacol. 2022 Jun; 79(6): 858–872.*

MEDICATIE



Kalmerende-/ Slaapmedicatie	Verkrijgen en behouden van een erectie Verminderde doorbloeding ~ verminderd verlangen
Antidepressiva SSRI's	Remmen het orgasme Verminderde doorbloeding ~ verminderd verlangen

MEDICATIE - coronairlijden

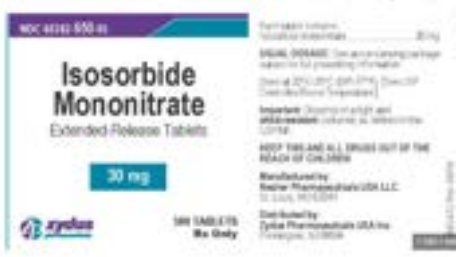
Sildenafil:

Verbetering erectie in 70%

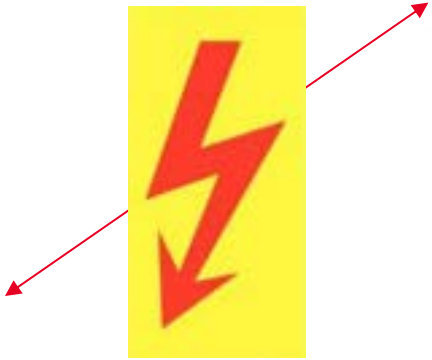
Bloeddruk ~ 8 mmHg omlaag



Maar veel meer bij nitraten !







Communicatie

CAHAL

Center for Congenital Heart Disease

Amsterdam - Leiden

Leiden University Medical Center

Amsterdam UMC University Medical Centers


If there's a problem, I hope he brings it up...
I hope he asks me!!

Literatuur-Communicatie:



86 ♂ :46% never discussed ED

Cook, Am J Cardiol. 2008;102:1728–30

58% ♂ : appreciates written information

Nicolai Am Heart J. 2014;167:178–85.

NVVC : 16% of cardiologists discusses sexual health

Nicolai Am Heart J. 2014;167:178–85.

Literatuur- Communicatie:

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

Table 3 Sources of information regarding sexuality, contraception, as well as pregnancy (multiple answers possible)

	Sexuality ($n = 362^a$)		Contraception ($n = 392^a$)		Pregnancy ($n = 371^a$)		p
	n	%	n	%	n	%	
Other affected persons	15	4.1	21	5.4	33	8.9	0.020
Friends	199	55.0	180	45.9	185	49.9	0.045
Parents	98	27.1	111	28.3	170	45.8	<0.001
Physician	176	48.6	335	85.5	311	83.8	<0.001
Internet	85	23.5	97	24.7	112	30.2	0.088
Newspapers, magazines, books	104	28.7	91	23.2	107	28.8	0.132

[a] Women without any answer to the six response options were regarded as missing

Kaemmerer Clin Res Cardiol (2012) 101:901–907

Verpleegkundigen

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

Knowledge – *repetitive training*

Attitudes and beliefs – *sick/old/time/privacy*

Nurses' comfort – *younger patients*

Perceived barriers – *no clear discussion of their role*

J Clin Nurs. 2019;28:3065–3076.



Huisarts

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

RESEARCH Open Access

Check for updates

Let's talk about sex: exploring factors influencing the discussion of sexual health among chronically Ill patients in general practice

P. C. Barnhoorn[1*], Inge C. Prins[1], Hannah R. Zuurveen[2], Brenda L. den Oudsten[3], Marjolein E. M. den Ouden[4], Mattijs E. Numans[1], Henk W. Elzevier[5] and Gaby F. van Ek[6]

Conclusions

Dutch GPs do not routinely discuss sexual dysfunction with chronically ill patients, mainly due to lack of time.

Intimiteit & seksualiteit

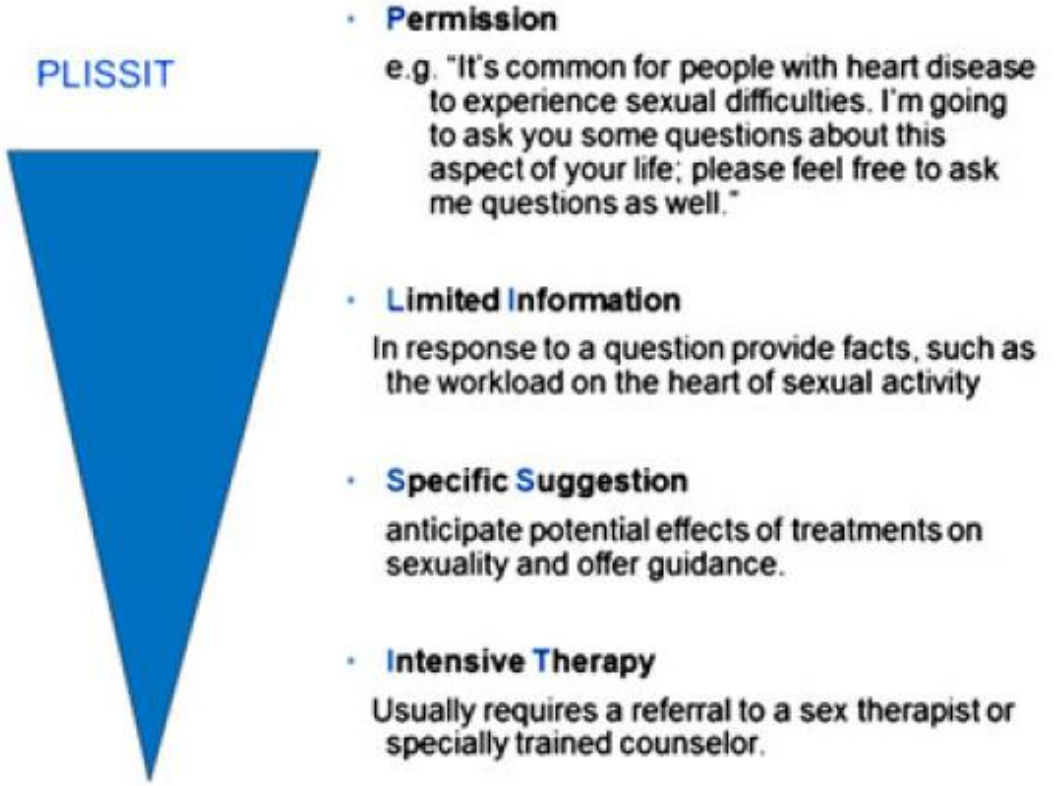
Gesprekken over seksualiteit
Wens van de patienten

- **Proactief initiëren**
- **Open houding**
- **Zn doorverwijzen naar psycholoog/seksuoloog**

n=90

Geen overval plegen, vraag toestemming

Figure 2 The PLISSIT model to guide education and counselling.[32]



ESC Heart Failure 2017; 4: 3–7

Pro-actief opnemen in je anamnese

CAHAL
Center for Congenital Heart Disease
Amsterdam - Leiden

TABLE 3 First Line Assessment for the Cardiac Health Care Team

Exploratory questions
Is your heart condition impacting on any other areas of your life?
How is your relationship doing?
How is your partner dealing with your health issues?
More specific questions
Any sexual or relationship problems?
Has your ability to enjoy sex changed?
Are you scared to have sex?
Baseline assessment
Assessment of physical fitness and symptoms
Plan for optimizing cardiac function
Review medication
Lifestyle issues
Explore psychological well-being
Consider further investigations and/or expert referral

Normaliseren- educatie

Table 1 Issues to consider when advising heart failure patients on sexual activity

General issues
- Choose appropriate setting
- Consider that sexual concerns are normal
- Discuss sexual activity for example within the context of exercise, during uptitration or initiation of medication
- Adapt terminology to the patients and partner

Assessment
- Use open-ended questions

Examples:

General
- Many people with heart failure (or with symptoms like you have) have concerns about resuming sex. What concerns do you have?
- Some people report sexual problems as a result of prescribing medication. How is this for you?

More specific
- Have you noticed any changes in your sexual performance such as problems with erections or orgasm, vaginal dryness, or decreased desire for sex? If so, how often has this occurred?

- Consider using questionnaires such as Multidimensional Sexual Self-concept Inventory (MSSI) or International Index of Erectile Function (IIEF) for men or International Index of Erectile Function (IIEF) for women
- Assess more than once if needed during the HF trajectory

Consider the right level of information and support needed
- Permission
- Limited information
- Specific suggestion
- Intensive therapy

Referral
- Refer to special trained counsellor, urologist, sexual therapist if needed
- Refer to cardiac rehab

ESC Heart Failure 2017; 4: 3–7

Standaardiseren

Table 1 Tools for sexual function assessment

Sexual Health Inventory for Men (SHIM) [42••]	• For screening and diagnosing ED • Five-item validated survey • Likert rating scale (1–25) • Higher scores indicate better sexual health	Scale • No ED (22–25) • Mild (17–21) • Moderate (8–16) • Severe (1–7)
Index of Erectile Function-5 (ILEF-5) [43]	• Measurement of ED in men • Five-item tool • Ordinal measurements of items • Score ranges 5–25 • Reported sensitivity 0.98 and specificity 0.88 • Reported weighted $k = 0.85$ for agreement between the predicted and true ED classes	Scale • No ED (22–25) • Scores < 21 indicate ED • Mild–moderate (12–16) • Severe (5–7)
Female Sexual Function Index (FSFI) [44]	• Assessing women's sexual functioning • Six domains: desire, arousal, lubrication, orgasm, satisfaction, and pain • 19 items • Validated self-report questionnaire	Scoring • Each domain 0–5 or 1–5 • Full scale 2–36 • Higher scores indicate better sexual health
Brief Index of Sexual Functioning for Women (BISF-W) [45]:	• Assessment of women sexual functioning • 22-item self-report questionnaire • Seven domains: thoughts/desires, arousal, frequency of sexual activity, receptivity/initiation, pleasure/orgasm, relationship satisfaction, and problems affecting sexual function • Most are on Likert scale	Scoring • Each domain 0–12, 0–15, or 0–16 • Full scale − 16 to 75 • Higher scores indicate better sexual health
Arizona Sexual Experience Scale (ASEX) [46]	• Assessment of male and female sexual function • Five-item, male and female versions • Five domains: sexual drive, arousal, vaginal lubrication/penile erection, ability to reach orgasm, and satisfaction	Scoring • Range 5–30 • Ordinal scale • Higher scores indicate sexual dysfunction: • ASEX score > 19 or • Any one item > 5 or • Any three items ≥ 4

Sick and Sex heeft als doel aan ieder die geconfronteerd wordt met ziekte op toegankelijke wijze informatie te bieden op het gebied van seksualiteit, intimiteit en relatie.



Spotify

HARTENLUST



Stichting
Hartekind

sick and sex
WHERE CARE MEETS PEOPLE

TABLE 1 Resources for Individuals With ACHD and Health Care Providers

Name	Summary	Link
Heart disease (general)		
Sexual activity and heart patients: a contemporary perspective	Risk stratification and recommendations for sexual activity in those with heart conditions	https://pubmed.ncbi.nlm.nih.gov/26690295/
CDC: taking a sexual history	A guide for health professionals for taking sexual history, factsheet	https://www.cdc.gov/std/treatment/sexualhistory.pdf
AHA scientific statement Sexual activity and cardiovascular disease	Evidence based recommendations regarding sexual activity in patients with cardiovascular conditions	https://www.ahajournals.org/doi/10.1161/cir.0b013e3182447787
Sexual counseling for individuals with cardiovascular disease and their partners	Evidence based recommendation for sexual counseling in patients with cardiovascular disease and their partners	https://www.ahajournals.org/doi/full/10.1161/cir.0b013e3182447787#:~:text=In%20patients%20with%20unstable%20or,is%20stabilized%20and%20optimally%20managed
Domestic abuse	Responding to domestic abuse; a resource for health professionals	https://www.ahajournals.org/doi/full/10.1161/CIR.0b013e31829c2e53
Sexual advice association	Factsheet and self-assessment for those with heart conditions and erectile dysfunction	https://sexualadviceassociation.co.uk/wp-content/uploads/2016/02/Sex-and-the-Heart.pdf
BHF resource on erectile dysfunction and heart disease	Magazine from the British Heart Foundation. Advice and stories from individuals with heart conditions	https://www.bhf.org.uk/informationsupport/heart-matters-magazine/wellbeing/erectile-dysfunction
Up-to-date: Sexual activity in patients with cardiovascular disease	Evidenced based recommendations regarding sexual health and on sexual activity in patients with cardiovascular conditions Limited access required institutional login or paid access	https://www.uptodate.com/contents/sexual-activity-in-patients-with-cardiovascular-disease https://www.uptodate.com/contents/sexual-problems-in-females-beyond-the-basics https://www.uptodate.com/contents/sexual-problems-in-men-beyond-the-basics
United Nations Population Fund sexual and reproductive health	Overview and resources around advocacy for sexual and reproductive health from a global perspective	https://www.unfpa.org/sexual-reproductive-health
World Health Organization Sexual and Reproductive Health Research Team	Overview and resources around advocacy for sexual and reproductive health from a global perspective	https://www.who.int/teams/sexual-and-reproductive-health-and-research-(srh)/overview
Sexual health concerns in patients with cardiovascular disease	AHA paper focusing on common sexual activity concerns in patients with heart disease	https://www.ahajournals.org/doi/10.1161/CIRCULATIONAHA.113.004846
Heart-failure.net	Online portal for those with heart failure. Education resources and patient stories	https://heart-failure.net/
The sensuous heart S Cambre	Free online book focusing on the most common questions asked regarding sexual life after having a heart surgery or a MI	https://issuu.com/pandh/docs/thesensuousheartbook?e=1549653/9678051
American Health Association Statement of cardiovascular health for LGBTQ individuals	Overview of cardiovascular health issues for LGBTQ individuals	https://professional.heart.org/en/guidelines-and-statements/guidelines-and-statements-search
Identifying nonrecent childhood abuse	Patient and carer information on the signs of nonrecent abuse	https://www.ahajournals.org/doi/10.1161/CIR.0000000000000914
Resources for those with learning difficulties	Series of easy read downloadable leaflets on relationships and sex	https://www.mencap.org.uk/advice-and-support/relationships-and-sex
Adult congenital heart disease specific		
Relationships & sexuality for people with heart disease	Information for parents of children with congenital heart disease	https://www.aboutkidshealth.ca/article?contentid=1710&language=english
Healing hearts and minds, T Livecchi, L Morton, Oxford Press	Recently published book focusing on a psychological toolkit for those with CHD and their families	https://www.aboutkidshealth.ca/Article?contentid=1710&language=English
Intimacy & pulmonary hypertension	Booklet from the Pulmonary Hypertension Association UK focusing on how PH might affect sexual well-being and relationships	https://www.phauk.org/product/intimacy-and-ph/
AHA scientific statement. Psychological outcomes and interventions for individuals with congenital heart disease	Summary of the psychological outcomes and interventions in adults with CHD	https://www.ahajournals.org/doi/10.1161/HCQ.0000000000000110

ACHD = adult with congenital heart disease; AHA = American Heart Association; CHD = congenital heart disease; MI = myocardial infarction.

Kortom

- Noodzakelijke zorg
- Maak iemand verantwoordelijk
- Pro-actief en open houding
- Plissit Model – Gerichte informatie geven
- Analyseer het onderliggend mechanism van seksuele dysfunctie
- Weet op wie je kan terugvallen bij vragen

  (Cardioloog/ Verpleegkundig specialist, Seksuoloog, Psycholoog)