Fontan Patient Education Day April 28, 2024



Living better with a Fontan circulation: become the CEO of your health

Dr. Isabelle Vonder Muhll Associate Professor of Medicine Director, Northern Alberta Adult Congenital Heart Program







"charged with maximizing the value of an entity" - in this case YOU!







Minimizing risk with a Fontan circulation

Don't:

smoke cigarettes or cannabis use any drugs (including all forms of cannabis) drink alcohol become obese

Mitigates

Risks





Don't smoke any substance

Fontan circulation depends on excellent lung function Prevalence of cigarette smoking in ACHD: 14% men 11% women

Cardiac transplantation is not offered to smokers

Moons et al Can J Cardio 2019; 35(12):1842-50



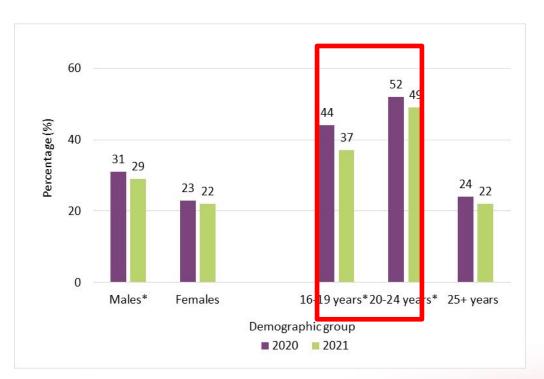
Image: Creator: Patrick Foto | Credit: krunja - stock.adobe.com





Cannabis Use in Canada

Poll Question 1



Data from Health Canada







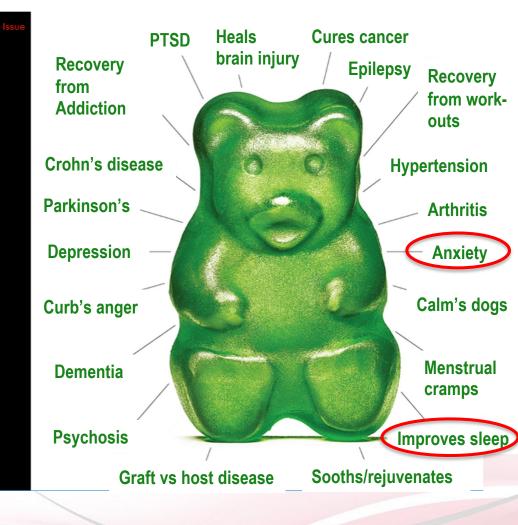
Cannabis is not a "cure-all"

The New York Times Magazine

Can CBD Really Do All That?

How one molecule from the cannabis plant came to be seen as a therapeutic cure-all.

By MOISES VELASQUEZ-MANOFF MAY 14, 2019







Limited Therapeutic Role for Cannabis





*after failure to respond to standard therapies







Cannabis probably harms the lungs

- Larger puff volumes + longer breath hold = ↑ delivery of inhaled elements compared to cigarettes
 - Similar combustion byproduct smoking tobacco
 - including carcinogens
- 个 tar burden because no filters
- Cannabis smokers have:
 - ↑ symptoms of cough, sputum and wheezing
 - 个 episodes of bronchitis
 - 个 airway inflammation on bronchoscopy and biopsy

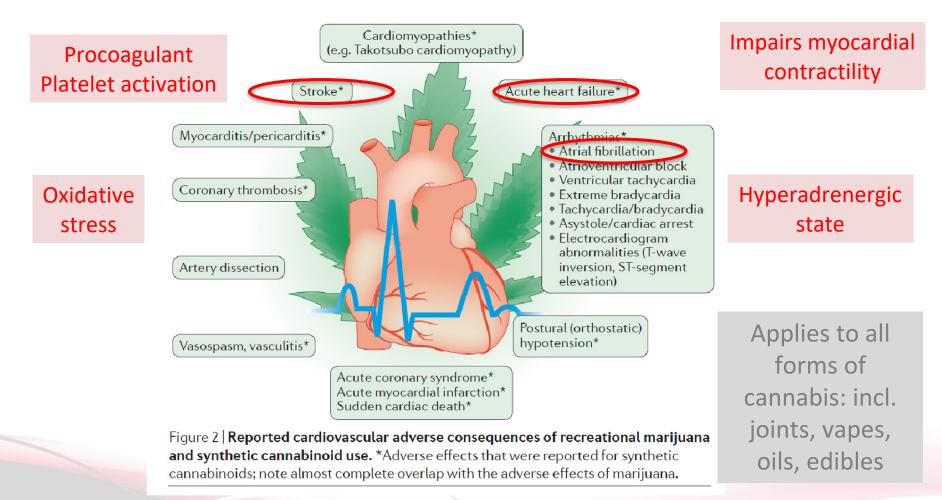


slide modified from Dr. Sheri Koshman





Cannabis harms the heart

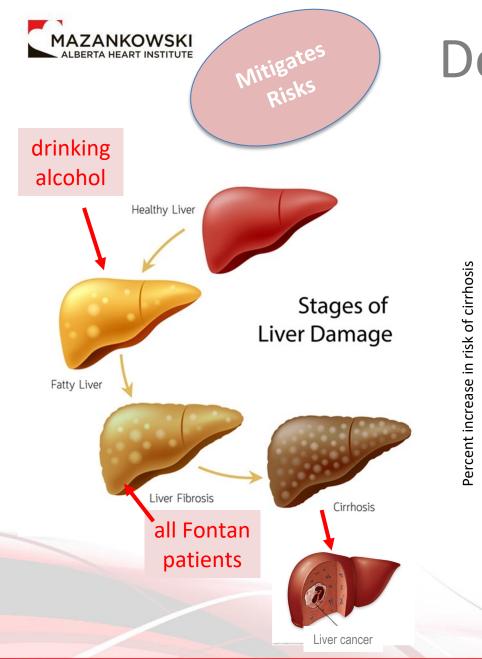


Cardiac transplantation is not offered to drug users

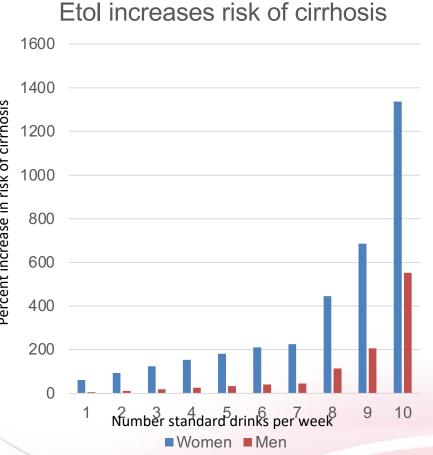


Nature Rev Cardiol 2018;15:151-166





Don't drink alcohol



Canada's Guidance on Alcohol and Health, 2023







Cardiac transplantation is not offered if BMI>35



https://www.lybrate.com/topic/what-are-the-health-risks-of-overweight-and-obesity





Attend clinic appointments and engage with your HCPs

- Everyone's busy: come at least annually
 - if you don't get an appointment, don't assume you don't need to be seen



- Be organized
 - keep prescriptions current
 - have names, phone #s of your clinic handy
 - keep track of questions and answers
- The ACHD team is there to help you
 - ask questions: inform yourself
 - know the basic facts of your condition: passport/summary
 - anticipate future issues: pregnancy















Exercise regularly

- Recommendation for physical activity for Canadians is 150 min weekly of moderately vigorous exercise
- Fontan circulation very dependent on skeletal muscle (act like an extra-ventricle for the heart)



Poll Question 3







Exercise: the Ultimate Pill for the Fontan circulation

Improve muscle mass

Improve lung function





Improve diastolic function

Improve cardiac output

Reduce inflammation

Improve Quality of Life

Adapted from a slide of Dr. Rachel Cordina





Cardiopulmonary exercise test



Poll Question 4







Exercise Ability is reduced in Fontans

- Average Fontan peak VO2: 20-27 mL/kg/min, 50-65% predicted
- Exercise training/cardiac rehabilitation can increase by 10-15%
- Australia/New Zealand study
 - n=133 Fontan underwent a cardiopulmonary test
 - 14 had score of 31 mL/kg/min = normal (>80% predicted)
 - = "Super-Fontan"
 - All Super-Fontans participated in moderate to vigorous sports





My advice to children and parents of Fontan:







My advice to adult Fontan patients:

| Address | Date |
|--------------------------|------------|
| ¹ X/Invest in | equipment |
| √Exercis | se at home |
| √Oı | n-line |
| apps/ | trainer |
| REFILL TIMES | , M.D. |

Proactive

Alberta Health Services





Do Not Underestimate the Benefits of Walking





Creator: Jordan Siemens | Credit: Getty Images









Poll Question 5

- Research has an up-front cost: money, time, risk
 - research and development is key to improving outcomes
- There is many things we don't know about the Fontan state
- The fruits of research may take time to be realized
 - it may not benefit you; but patients in the future may benefit







Have a Vision





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Have a Vision for your Life

- You are a person with congenital heart disease
 - living with health concerns
 - living with uncertainty
- Still: Squeeze the juice out of life!













"We all need purpose"

for our bodies, minds and souls

A shared purpose can be more fulfilling

Purpose can change at each stage of our life







Viktor Frankl Viennese psychiatrist

Finding a Purpose/Vision

The International Bestseller Adapted for Young Readers

MAN'S SEARCH FOR MEANING

VIKTOR E. FRANKL

Foreword by JOHN BOYNE author of The Boy In the Striped Pajamas 3 ways to find purpose/meaning

- Work
- Love
- Suffering







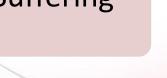








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Become the CEO of your Fontan health



Maximizing the value of YOU!



