Fontan Patient Education Day April 28, 2024



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

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"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



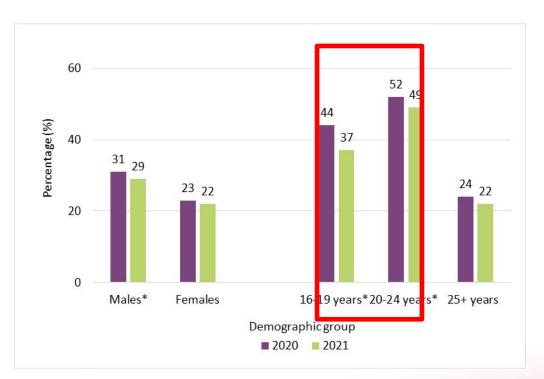
Image: Creator: Patrick Foto | Credit: krunja - stock.adobe.com





## Cannabis Use in Canada

#### **Poll Question 1**



Data from Health Canada







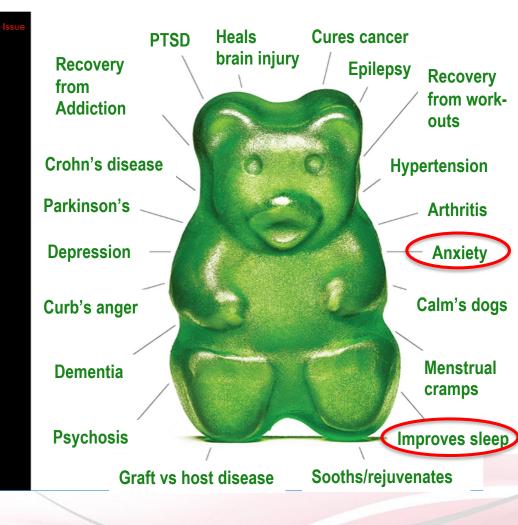
# Cannabis is not a "cure-all"

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

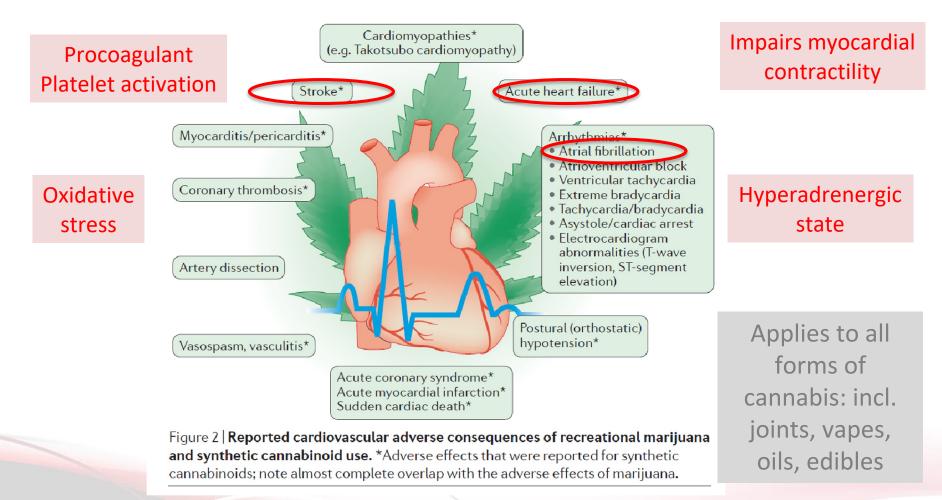


slide modified from Dr. Sheri Koshman





# Cannabis harms the heart

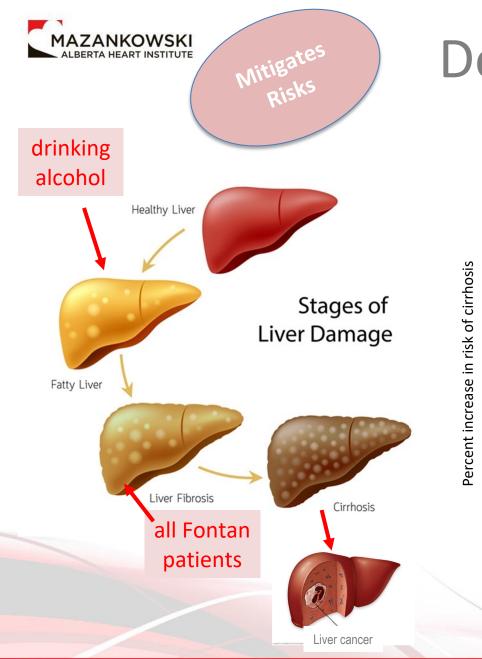


#### Cardiac transplantation is not offered to drug users

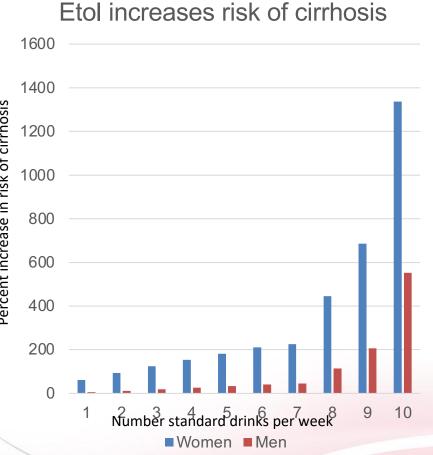


Nature Rev Cardiol 2018;15:151-166





# 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

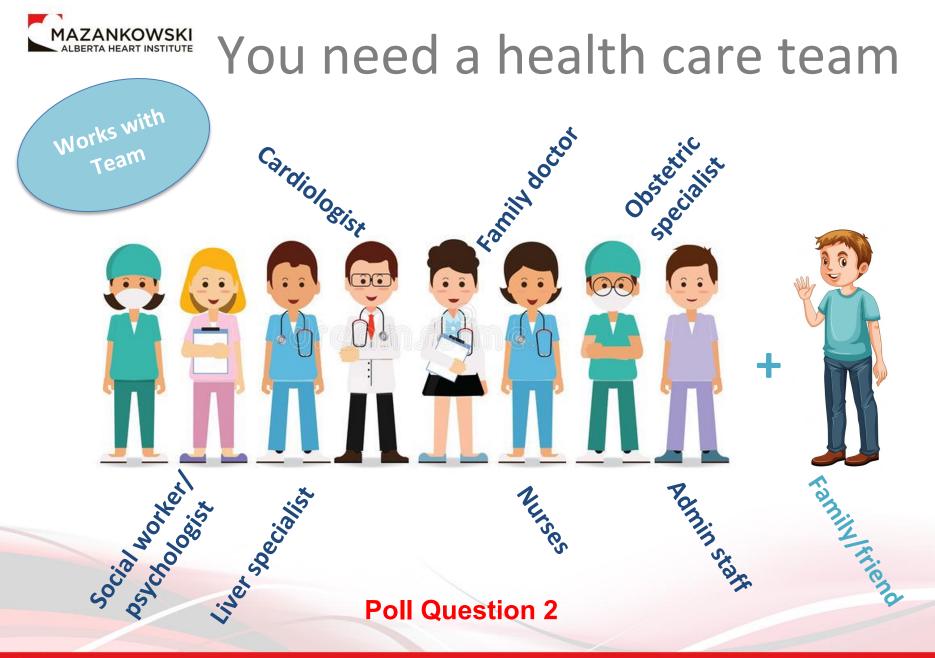


- Be organized
  - keep prescriptions current
  - have names, phone #s of your clinic handy
  - keep track of questions and answers
- The ACHD team is there to help you
  - ask questions: inform yourself
  - know the basic facts of your condition: passport/summary
  - anticipate future issues: pregnancy















## 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
<sup>1</sup> 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

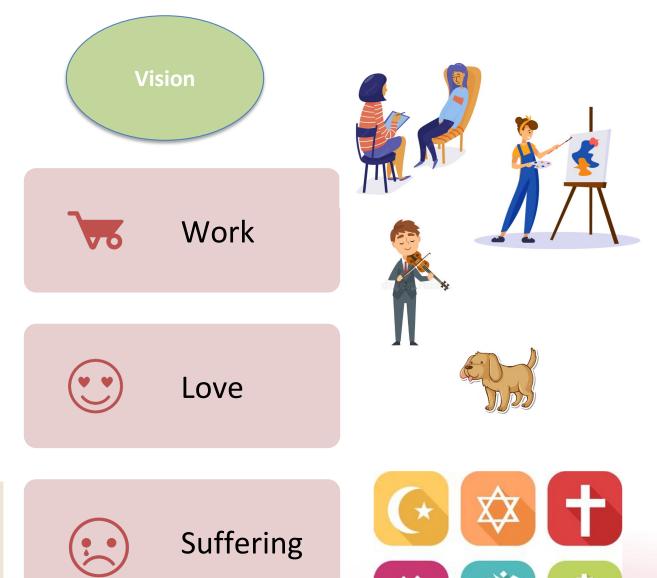






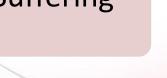








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### Become the CEO of your Fontan health



Maximizing the value of YOU!



