

The Role of the Fontan Nurse Specialist



DEBBIE MCPARLIN
FONTAN NURSE SPECIALIST
FREEMAN HOSPITAL

Patient



- Patient's advocate
 - Paediatric and adult services
 - Transition
- Lynchpin of the growing multi-disciplinary team
- Educate patients about their condition and their options
- Ensure increasingly complex clinical protocols are followed and regularly reviewed
- Work with staff acting as an expert for all disciplines, locally throughout the network and nationally.

Research



- Lead a qualitative study on patient experience
- Manage a clinical and research databases
- Clinical link for basic science researchers
- Increase awareness of research, encourage involvement in planning research and taking part in studies

Organisation



- Work with staff acting as an expert for all disciplines, locally, network and nationally.
- Lynch pin for all disciplines
- Provide education and training locally across the network and nationally
- Awareness of current developments in research and practice

Patient engagement



- Engagement is key- building relationships
- Routine clinic appointments
- Increased surveillance starts age 14 or 10 years post Fontan completion
- Transition/young adult
- Team -visible and accessible

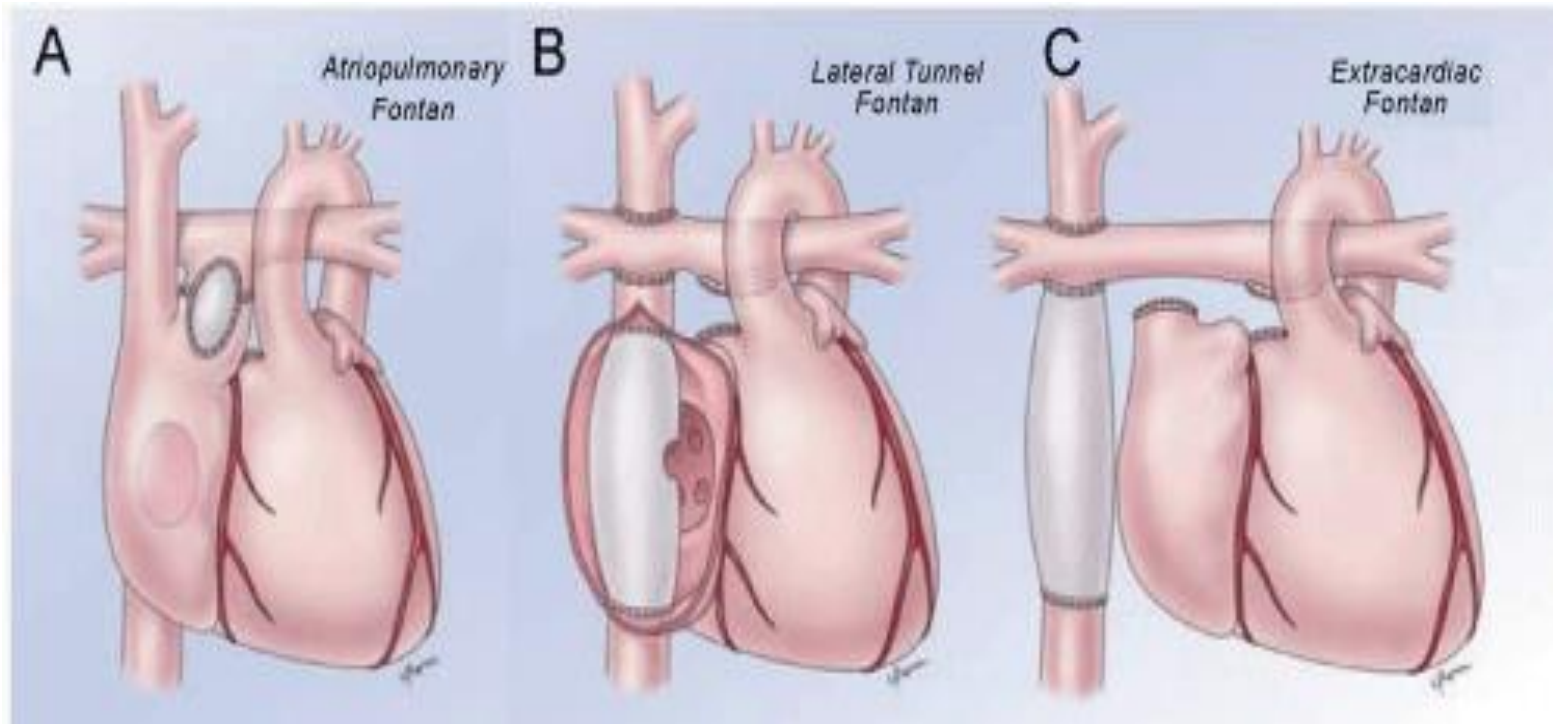
Education and guidance



- Anatomy
- Life style
- Social
- Psychological



Anatomy



Classic Fontan

Multistage Fontan

Life Style



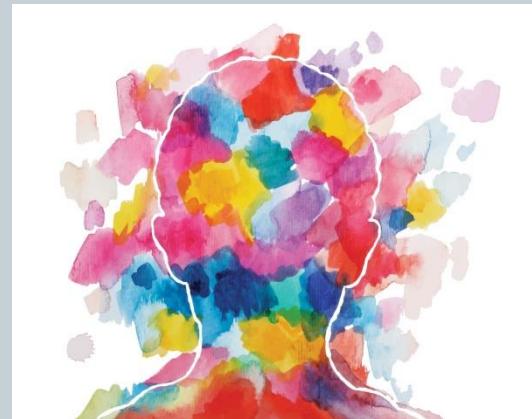
- Exercise
- Sex education
- Pregnancy
- Dental
- Diet
- Smoking/drugs/alcohol/tattoos/piercings



Psychological



- The psychological impact varies – but should not be overlooked.
- Anxiety and depression can be associated with disengagement, unemployment and lower quality of life.
 - Refer to psychology



Social



- Education
- Careers/Employment
- Benefits
- Insurance
- Driving
- Holidays
- Flying



Single Ventricle Surveillance Pathway

1st Stage

- Norwood/Shunts/Stents

2nd Stage

- Glenn

3rd Stage

- Fontan

Transition Age 11 years

Age 14 or 10 years post Fontan

- Paediatric surveillance commences
- Blood set
- Ado USS + ARFI
- Fibro scan if suspicious of cirrhosis

17-18 years transition into Adult clinic

- Adult outpatient surveillance continues yearly
- Blood set
- Abdominal Ultra sound
- Fibro scan

Surgical/medical management exhausted?

Transplant

- Transplant assessment

Palliation

- Involve Palliative care services

Surveillance



- Surveillance protocols
- Coordination of investigations
- FALD
- Heart failure
 - Intervention
 - Medical therapy
 - Surgical
 - Transplant

Research and Development



- Fontan and Transplant data base
- Research studies - Encourage patient and staff involvement in research projects
- What do the patients want- engagement
- Qualitative studies in patient experience
- Written information



The Goal



- Information/advice to stay independent and healthy
- Live the life the patient wants, supported to manage the risks
- Limited hospital visits/inpatient stays
- Empowered to make decisions
- To have choice, control, and to feel safe
- Support delivered by competent people
- Continuity
- Research

There are Many Questions we Need to Address as a Team



- How do we know when the Fontan Circulation is failing?
- Can we find better measures to assess this clinically?
- Who should we transplant?
- Are there alternatives to transplant?
- Does this affect our treatment in childhood?
- What do the families and patients want?

Thank you

