

# Advance Care Plan (ACP) for Young Persons and Adults Living with Heart Failure

Dr Nang Kyi

Consultant Adult Congenital Cardiologist, University Hospital Southampton, Email: nang.kyi@uhs.nhs.uk

Although many people living with heart failure are older, there are significant number of younger people with heart failure as a result of congenital heart disease, inherited cardiomyopathy, and chemotherapy.

With the advances in paediatric health care, cancer care, clinical genetic testing, treating heart attack, the prevalence of heart failure patients is predicted to continue to rise.

Currently, more than 97% of children who are born with congenital heart disease can be expected to reach adulthood<sup>1</sup>.

Approximately 80% of people with cardiovascular disease have at least one other health condition highlighting the need of multidisciplinary team input<sup>2</sup>.

Heart failure can have a significant effect on the quality of life of patients, their families, and carers.

The impact of heart failure includes physical limitations, emotional, social, and economic effect on those who live with it.

Therefore, alongside health services, psychological support and social support are much needed for heart failure patients.

With the right treatment and care, the outcomes and experience of people living with heart failure can be significantly improved, and the cost to the NHS associated with unplanned hospital admissions can also be reduced.



## OBJECTIVES

To **promote equity** of patient access to heart failure and palliative care

To **empower patients** and their carers to be actively involved in their care plan

To improve **inter-professional collaboration** amongst multidisciplinary teams.



## METHODS

**Forming working group:** Young adult cardiac ward sister and staff nurse, consultant in palliative care medicine, clinical nurse specialists (ACHD, Heart Failure, Hospital specialist palliative care), and hospital governance team

**Gathering materials:** ESC Recommendations for advance care planning in adults with congenital heart disease, ReSPECT – Child and Young Person's Advance Care Plan Collaborative, endorsed by NICE, The Caring Together Programme, One Chance To Get It Right

**Microsoft Teams meeting:** Delegating job, Contacting Royal Brompton Hospital, UHS cystic fibrosis team's experience in ACP

## RESULTS/ WORK IN PROGRESS

Drafting **Patient Information** factsheet on Advance care planning for Heart Failure Patients

Drafting **Patient Pathway** incorporating triggers for potential ACP discussions

To raise **Awareness** through charity (Somerville Heart Foundation, British Heart Foundation, social media)



## REFERENCES

Z Mandalenakis, K Gian, P Eriksson, H Liden, M Synnergren, H Wahlander, M Fedchenko, A Rosengren, M Dellborg. Survival in Children With Congenital Heart Disease: Have We Reached a Peak at 97%? Journal of the American Heart Association. 2020;9:e017704.

Tran J, Norton R, Conrad N, Rahimian F, Cancy D, Nazarzadeh M, et al. Patterns and temporal trends of comorbidity among adult patients with incident cardiovascular disease in the UK between 2000 and 2014: A population-based cohort study. PLoS Med. 2018; 15(3):e1002513.