

# Summary of Scottish National Advanced Heart Failure Service Strategy

## 1: Background

The Scottish National Advanced Heart Failure Service was established in 2006 to provide advanced treatment options including heart transplantation for patients whose lives are threatened or who may be disabled by heart failure despite all standard modern treatment. Specifically, as part of its remit, it is charged with considering the introduction of new technologies which have emerged since the inauguration of the Scottish Heart Transplant Unit in 1992.

The service is now based at the Golden Jubilee National Hospital, part of the NHS National Waiting Times Centre Special Health Board. The West of Scotland Heart and Lung Centre is also managed by the Board as well as three national services - the Scottish Pulmonary Vascular Unit (SPVU), Scottish Adult Congenital Cardiac Service (SACCS) and the Scottish National Advanced Heart Failure Service (SNAHFS).

The strategy, part of a wider reassessment of the Board's Clinical Strategy, describes the way forward for the **Scottish National Advanced Heart Failure Service**. It follows the direction set out in Better Health, Better Care and the 'Better Heart Disease and Stroke Action Plan' in responding to challenges such as evidence based developments, listening to patients about the kind of service they want, and reducing health inequalities across Scotland. Our approach strongly underpins the six dimensions of quality care – patient centred, safe, effective, efficient, equitable and timely.

It is critically important to recognise that heart transplantation procedures should not be considered in isolation but as one of several options now available for patients with severe heart failure.

# 2: Significant unmet need

There is a clear unmet need for advanced heart failure therapies in Scotland.

The low rate of heart transplantation in Scotland does not reflect the true need for life-saving and life-enhancing treatments such as cardiac transplantation and ventricular assist devices (VADs).

Between 1986 and 2003, around 3000 Scottish patients aged less than 65 were hospitalised each year with heart failure for the first time, 1000 of these young people were dead within a year.

The precise number of people who would benefit from transplantation or VAD support is unknown. No study has systematically examined the profile of individual patients in a large population in Scotland or any other country to investigate how many would meet the inclusion and exclusion criteria for listing for cardiac transplantation (or bridging to transplantation with a VAD).

Our aim is to transplant approximately 11 patients each year. This projection is based upon unmet need and the availability of donor organs following a review of transplantation rates in a number of European countries.

## 3: The way forward - our key actions

We have identified three key elements in addressing this need.

- 1. The development of a consistent, equitable, Scotland–wide referral pathway for advanced heart failure.
- 2. A need to increase the number of donor organs and the implantation rate of these.
- 3. There is a requirement to develop a comprehensive Scottish VAD programme within the SNAHFS at the Golden Jubilee National Hospital.

### 3.1 Work with Health Boards to improve the referral pathways for patients

We will do this by raising awareness and educating health professionals throughout Scotland of the benefits of heart transplantation and VADs. We will ensure that appropriate patients are referred from every region for these therapies by distributing clear referral guidelines.

Improving the care for patients locally is a key element of this strategy. Sharing models of care for heart failure that improve patient management is being supported by the National Advisory Committee for Heart Disease.

If all patients with heart failure were managed similarly to those with heart attacks, i.e. in specialist units by cardiologists and specialist nurses, those suitable for referral to SNAHFS would be easy to identify.

At present, however, the majority of patients with heart failure are managed by a diverse group of clinicians in non heart specialist wards. 70% of patients in the Scottish National Heart Failure Audit, carried out by the SNAHFS and funded by NHS Quality Improvement Scotland, were managed by non-cardiologists.

Patients that should be referred for consideration of cardiac transplantation or ventricular assist device support should be those with acute or chronic heart failure for whom conventional management such as drugs or complex pacemakers is not suitable.



# 3.2. Increase the number of heart transplants by increasing the availability of donor hearts.

While transplant activity is increasing overall, there are issues in relation to the number of donor hearts becoming available.

We intend to support the national campaign to increase the number of donated hearts and to increase our rates of implantation of these organs. To help us do so, we have set up a group to gather data prospectively on all organs offered, to ensure their optimal use. This data will then be presented to the Scottish Transplant Group for consideration.



Heart transplant recipient Georgina Burt prepares to go home following her surgery in 2008

All offers are reviewed weekly by a multi-disciplinary team who have also put in place a number of review and scrutiny mechanisms in relation to donation and implantation. These include arrangements for transporting hearts, and better communication links with Intensive Care Units across Scotland.

### 3.3 Develop a Scottish VAD programme

VADs (ventricular assist devices) are mechanical hearts that can assist the failing heart by pumping blood around the body, and as a result can markedly improve the clinical status of the patient.

VADS can either be short term or long term.

#### 3.3.1 Short term VADs

Short term VADs are devices in which the pump is external to the body providing circulatory support for days to weeks in a hospital setting, often in intensive care.

Patients who need short term VADs typically are those at the most acute and severe end of the spectrum of heart failure. They are too unwell to receive a transplant or a long term VAD.

Patients who stabilise sufficiently on short term VADs can either be transplanted or receive a long term VAD.

There are two indications for short term VADS.

Short term VADs can be used:

- as a bridge to recovery of the patient's own heart;
- as a bridge to a heart transplant;
- as a bridge to a long term VAD; or
- to support a transplanted heart in the first few days if it initially fails.

Short term VADs will enable about 50% of all patients with very severe acute heart failure who would otherwise have died to be transplanted or to receive a long term VAD.

### 3.3.2 Long term VADs

Long term VADs are devices in which the pump is implanted inside the body next to the heart with only a power line passing to the outside.

These are intended for more prolonged support and patients can usually be discharged home to await transplantation and experience a very good quality of life.

Long term VADs are suitable for patients who need transplantation but who are unlikely to survive in a good clinical state.

VADs and cardiac transplantation, therefore, are complementary therapies.

Long term VADs can be used:

- as a bridge to transplant; or
- as a bridge to recovery in some cases this allows full organ recovery.

When long term VADs are used as a bridge to transplantation, 79% of extremely sick patients are now alive at 18 months.

In the UK, long term VADs are implanted solely as a bridge to transplantation. Occasionally the heart function can recover sufficiently on VAD support for the patient to return to independent living without the device.

In other world leading countries, especially Germany and the United States, VAD implantation is used as a treatment in its own right as a destination therapy without planned future transplant. The number of patients alive two years following implantation has increased from 23% to 60% over the last decade.

It is being considered on a UK basis whether to use long term VADS as "destination therapy" in patients who are not eligible for transplant.



Short term VAD recipient Heather McIntyre with physiotherapists

(Pagani JACC 2009;54:312-321).

# 4: Summary

The Golden Jubilee National Hospital is home to one of the largest heart and lung centres in the UK, and as such, we strive to be a centre of excellent in these specialties.

We already have the expert skills, capacity and infrastructure in place to provide a comprehensive service for advanced heart failure patients across Scotland.

By approving this new strategy, the Cabinet Secretary for Health and Wellbeing has ensured that we can continue to meet the critical needs of these patients in the future.



Long term VAD recipient Silvio Garcia with some of the advanced heart failure team

For more information on the strategy or the Scottish National Advanced Failure Service, contact:

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