

Ongoing support for rural heart patients

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People who are in need of heart procedures and who experience “heart events”, come from all walks of life. For a lot of people it can be very stressful. Some have good support networks within their family or among their friends. Often, even when there is good personal support, the patient has a feeling of being alone. They’re in hospital, surrounded by health professionals, but possibly they don’t know anybody else who’s suffered a similar event or had similar surgery. Contact with other heart patients can be very reassuring on a number of levels. They can be reassured by meeting people who have experienced similar events, but are fit and healthy several years later. Just talking with somebody who’s experienced the emotional impacts of being a heart patient can be very supportive. Even people who work in major medical facilities, but become heart patients, can feel a need for some knowledge of what to expect from a patient’s point of view.

Heart Support—Australia is an organisation for the mutual support of heart patients. It was formed in 1986 by a group of people who had experienced open-heart surgery, and felt a need to support each other. The organisation has 36 branches with 22 branches in the country. We have approximately 2000 members with about 60 % residing in country towns and districts. HS-A is a not for profit organisation with a Board of Directors drawn from the membership in each State and Territory. The Directors all serve on a voluntary basis. We are a separate organisation from the Heart Foundation, with a different focus, but we absolutely follow their guidelines on healthy living. There are Heart Support branches in all mainland states, and in the Australian Capital Territory. Quite a few regional centres have their own Heart Support branches, also a number of smaller country towns. This being our 25th year as a support organisation, our branches will celebrate this milestone throughout the year.

Some of the branches operate basically as social clubs; others are primarily focused on fund-raising, to purchase medical and other health-related equipment for their local hospital or their community. Many branches operate a Heart Health Support Service, which I’ll explain in a moment. Some branches run walking groups, as a way to encourage heart-healthy exercise; the walking group in some cases has a nurse or physiotherapist in attendance. A number of country branches are involved with the Cardiac Rehabilitation Clinics in the larger centres, and are rostered to give talks to patients in rehabilitation under the supervision of the Cardiac Coordinator nurse.

The thing all branches have in common is that they are groups of heart patients, providing support for other heart patients. For the people who are active members of a branch, the organisation provides an ongoing support network.

The Heart Health Support Service is an additional support service provided for heart patients. The key feature is that volunteers from Heart Support—Australia visit patients in hospital. Usually it’s done by a visiting roster, and the patients we visit are selected by hospital staff. Sometimes the hospital visitors from Heart Support are invited to participate in patient-education classes and cardiac-rehabilitation sessions; this has the advantage that patients are getting information not only from the point of view of health professionals, but also from the point of view of other heart patients. The Heart Health Support Service visitors have been trained through a nationally-accredited program. Many of the branches in regional centres run a visiting service in their local hospital.

Nationally, Heart Support has produced a DVD called *One Life, A Second Chance—A Healthy Lifestyle Program*. This promotes patients taking greater responsibility for managing their heart condition by taking seriously the lifestyle recommendations for reducing risk factors for heart disease. The DVD is available free of charge to anyone interested in obtaining a copy. Also it could assist in the rehabilitation of rural cardiac patients if the DVD could be placed in local libraries and health centres.

At our annual National Conference, members from some of the regional branches express frustration because of losing contact with heart patients. In most regional hospitals, if a patient needs either open-heart surgery or a catheter procedure (such as having stents), or needs to be fitted with a pacemaker or an implanted defibrillator, they're sent to a hospital in a capital city. Usually from the city hospital they're discharged to home, or after major surgery they're discharged into temporary accommodation in the city until the doctors are happy for them to literally go home. A Heart Health Support Service often loses contact with the patient when they leave the city hospital. This shows a need for mechanisms to be put into place so that patients can get local support after their discharge from hospital; obviously whatever procedures are put into place would need to respect patient confidentiality.

The situation in Western Australia is a bit different to other parts of Australia. The state consists of the western third of this continent, and at present the only Heart Support branch in the state is in Perth. Patients from all over the state come to Perth for their heart surgery, whether they're from Kununurra in the far north, further away from Perth than Adelaide is, or from Esperance, on the south-east coast, or from Useless Loop, close to the western tip of the continent. When we do the hospital visiting, we might be visiting patients who live just around the corner, or who come from distant mining communities and pastoral stations, or from remote Aboriginal communities. We're able to provide a limited hospital-visiting service while the patients are in Perth, but for rural patients we're very conscious that there is little support, other than clinical, when they're back wherever they live.

It is acknowledged that cardiologists, medical practitioners, community nurses and physiotherapists play a very important part in the recovery of post operation heart patients. In the Eastern States many of the country health service units have a Cardiac Rehabilitation Centre established with a dedicated Cardiac Nurse Coordinator. This is the case in some Regional Centres in WA but not all, particularly in the North West. We believe that more resources should be directed towards Cardiac Rehabilitation in WA. There would also be the opportunity of reviving the Heart Support Services that were established in the 90s in WA, but went into recess after a few years.

One thing the Perth branch has done to add to its support services is to set up a 1300 telephone number as part of the Heart Health Support Service. This gives one number people can phone for support, and people phoning from anywhere in WA are only charged the cost of a local call. Calls to the 1300 number are switched between the homes of some of our members, all of whom are fully trained. Leaflets we give to the patients we visit include the 1300 phone service. This is just a small measure of support which a Perth-based group can give to rural and remote patients. We also send a newsletter several times a year to our members, and at least on some occasions include health information in the newsletter. Although most of our members live in the metropolitan area, there are some who live a long way from Perth.

We have made some attempts to establish groups in two regional centres in WA, but the dynamics of an organisation like ours is that it needs a local person with a lot of enthusiasm, time, and ability, to get a branch formed. We weren't aware of people in those communities who would have been able to take the initiative. From Perth we would have been able to give support, but a large part of the input needed to be local.

In our contacts with people from outside Perth, we've become aware that even support from health professionals is limited for people in non-metropolitan parts of WA. Even in our larger regional centres, there are few opportunities to consult a cardiologist without travelling to Perth. In a visit to a major Regional centre a group of our members found that cardiac rehabilitation services were limited at the Health Service. We believe that cardiac patients participating in cardiac rehabilitation programs are less likely to be re-admitted.

Across Australia, Heart Support branches offer a range of support services to their communities, including many regional communities. The Perth branch is a small group of people trying to give support to people from a large city, and from throughout a state covering a vast area. In this state there's a great need for more

ongoing support for rural patients, both from the state's health service and from voluntary groups such as Heart Support—Australia.

How can Heart Support - Australia improve our services to country people? Appeal to younger heart patients to join our organisation and spread the healthy lifestyle message. Open more country branches so that more support can be provided locally. Find ways to provide support to indigenous heart patients. Lobby governments for increased funding to provide such improved services.