



# Karumah Community Centre

OVERVIEW OF OPERATIONS

## Introduction

Just as the needs of people living with HIV (PLWH) have changed over recent decades, Karumah has also changed the way it supports them. In addition to social events and workshops Karumah also offers a chronic care self-management outreach program. However, despite Karumah's services being much-needed and events being well-attended we are only operating on a part-time basis and a number of further outreach initiatives cannot be rolled out without extra funding. Financial support is urgently required to ensure that PLWH in the Hunter gain the skills and support they need to improve their quality of life.

## About Karumah

Since its foundation in 1989, Karumah has provided much-needed assistance, peer support, welfare and a safe place for PLWH in poor health. However, with the introduction and use of anti-retroviral therapy, health outcomes have improved and PLWH lead longer, more productive lives and no longer need the intensive support they received from Karumah in the past. To meet the changing needs of PLWH, Karumah has had to make changes to its service delivery and now supports PLWH by offering a case management service based on chronic care self-management (ccsm). Chronic care self-management works on the assumption that people are their own experts and encourages them to actively engage in processes that protect and promote their own health.

Karumah no longer offers a welfare model of service delivery which entailed giving handouts and making PLWH dependent, but rather focuses on assisting them in self-managing their condition. We do this by going out into the community and spending quality time with PLWH, to find out how they are, what they need and how Karumah can help them achieve their goals. We link them to other services, help them with referrals and work with them on any barriers they have self-managing their health and life needs.

Karumah's aims are to:

- improve the health and well-being of PLWH in the HNE Region
- reduce strain on other essential services and keep PLWH out of hospital
- reach and engage PLWH who would normally fall through the health and community service gaps
- self-empower PLWH with skills and strategies to better self-manage their condition
- provide a unique service which avoids duplication of other existing services

- address isolation and mental health issues in PLWH
- address stigma and discrimination in the community.

## Our operations

Karumah is overseen by a Board of Management; the board derives its authority through the company's constitution and the *Corporations Act 2009*. The Board is primarily responsible for strategic leadership, while the Coordinator and staff members are responsible for internal management and execution.

Karumah follows good governance practices that include being accountable, transparent, responsive, equitable and inclusive, and operates under policy and procedure guidelines. Karumah has ASES accreditation and meets all QIP standards.

## Our services

The concept of chronic care self-management has been around for some time; it is a model of service delivery that recognises that people are their own experts and encourages them to actively engage in activities that protect and promote their own health. Karumah's comprehensive case management model of chronic care self-management helps PLWH better manage their condition over the long term and potentially reduces strain on other essential services, as well as reducing hospital presentations.

## The move from centre activities to community activities

Our centre has traditionally provided a place where PLWH can come without being discriminated against and discuss medication, treatment or even just the weather. But changing times and funding body requirements have meant Karumah has moved its centre activities off site and into the community. This is in-line with our strategic direction; mission statement, values and vision.

Karumah now hosts a Thursday lunch twice a month at a local Hotel and this has been well received and well attended. PLWH like the normality of the lunches and they are very social occasions. Karumah also hosts a variety of 'Coffee Clubs' on a monthly basis for specific groups such as HIV carers, women, gay men and mixed events and this is in place of Tuesday centre days.

## Outreach program

Our case manager conducts comprehensive assessments, listens to stories, identifies barriers and issues, and works collaboratively with service users to address identified problems. Karumah advocates, liaises, makes referrals and follows up with service users to assist them better self-manage their lives. Our approach is long-term, person-centred and evidence-based.

## Building networks

Isolation is an issue, with 80.5% of service users identifying it as a major problem. Karumah addresses this by developing social events to build sustainable social networks and links within the community. Some examples are listed below:

- Karumah holds a Thursday lunch every fortnight at a local Hotel where PLWH can come and meet up for a delicious lunch and share good company. Karumah subsidises the lunches for members.
- Karumah also has regular coffee clubs for various HIV groups, e.g. Carers, women, heterosexual people with HIV, gay people with HIV. Karumah also subsidises these events for its members.
- Karumah also holds regular BBQ's
- Karumah holds regular lunches for our positive heterosexuals.
- Karumah works in partnership with Positive Life, Pozhet, JH Hospital (immunology unit), Pacific Clinic and ACON to provide current and relevant workshops for PLWH. These workshops are generally free and well attended.

## What makes Karumah unique?

Avoiding duplication of services is vital in ensuring NGOs provide value for money, fairness, integrity and transparency in service provision. NGOs also need to be cooperative, have diversity, be consistent and, particularly, have budget discipline. They also need to be able to reinvent themselves to meet current needs. It is helpful to understand the differences in the nature and scope of services, and Karumahs service model stands out amongst similarly funded organisations:

- Karumah is the only organisation that works specifically with PLWH in the Hunter region.
- It is the only centre in Australia that is owned and managed by PLWH.
- Karumah is the only service in the Hunter region which provides long-term chronic care self-management case management and support to PLWH.
- Karumah participates in research projects works alongside researchers and partners to build a strong evidence base around HIV funding

- Karumah uses service users input to creating social activities and develop educational workshops

There is strong evidence that Karumah is not duplicating other services in the HNE region, but rather complementing existing services and working with PLWH who, for a variety of reasons, have fallen through the gaps in available health care. Our approach is long-term self-managing support with the potential of reducing strain on mainstream services; Karumah has plans to take this service into the wider HNE regional areas where services are thin.

## Future programs

Traditional funding formats (grant applications) which have been in place for the last 25 years are being replaced with a new competitive tendering process. NGO's will have to bid for funding contracts set by the Ministry of Health who will consider the most suitable tender for the funding. The new funding criteria will be in place in the near future and those that wish to be competitive and sustain funding are preparing to meet the new requirements.

Karumahs chronic care self-management outreach program has had an overwhelming response from PLWH in the Hunter region and Karumah has exceeded all program targets and continues to grow and expand beyond expectation. Karumah would like to expand its services even further and has a number of programs ready to go when additional funding is available.

Improved health outcomes means there is an aging HIV population, and Karumah has been able to provide them with skills to manage their condition while living a fulfilling life. Karumah has proven that it can provide all these services for PLWH in the Hunter. Without Karumah, there becomes an increased burden on other health service providers in the area. But, more importantly, PLWH would lose their dignity as well as a unique support that is their own.

## Making a difference: a case study

Service user Karl, a 49-year-old gay man originally from Western Sydney but now from Newcastle, has been a member of Karumah for the past 12 years. Karl contracted HIV in 1989 and in the early days was very sick; in 2001 Karl became so sick he was not expected to live. It was at that time he was introduced to antiretroviral therapy. Now, 13 years on, Karl lives by himself and suffers from an anxiety disorder which is bordering on agoraphobia. He also has depression which he reported as debilitating and at times has had suicidal ideation. Karl has also had various lymphomas which have been successfully treated. He often comes down with pneumonia and the flu and has problems with recurring shingles. Karl is on a disability support pension having been unable to work for the past 23 years.

Karl has not been involved with Karumah for some time, having not had an interest or desire to attend organised social events. Karl was contacted by Karumah's case manager who made an appointment to visit him at his home. The first visit went for two hours during which Karl told his story. This was very therapeutic for Karl who has been unable to talk about his condition with anyone for some time, because of his fear of stigma and discrimination. Karl reported having a difficult childhood with rigid religious parents and being molested by a priest in a catholic institution. He struggled with his homosexuality as a teenager and was rejected by his parents when they found out he was gay. This led Karl into a life with the gay community of Kings Cross and eventually contracting HIV in 1989.

Karl said he was very lonely because he had not had a relationship for many years, he was not using dating sites and had little or no contact with his family who were still unable to come to terms with his homosexuality; he has still not told them he has HIV. Karl reported there were times when he struggled to find a reason to get out of bed. He took little pride in his appearance and surroundings and was also struggling to live on his pension. Karl lives in a Department of Housing complex which often has unpleasant neighbours who would crucify him if they knew he was gay or had HIV. This causes further isolation and compounds his depression. Karl was concerned about aging with HIV and what that meant for him. He sometimes stopped taking his medication because of lack of money and motivation.

On subsequent visits, Karl and his case manager were able to identify barriers that were holding Karl back from self-managing his conditions. Collaboratively, Karl and his case manager worked on strategies to meet goals Karl wanted to achieve and measured his progress with a numerical scoring system. As Karl achieved some of his goals, he was able to see his own input into self-managing his life appropriately. Safety plans were developed for those times when things got on top of him, and his case manager connected him socially with other PLWH with similar interests, so he could begin to build up networks for himself.

These days, Karl is feeling a bit better about himself. He has decided to go to TAFE to study community welfare, an area he has always had an interest in. He has adhered to his medication regime and has not yet been sick this winter with the flu or pneumonia. Karl is taking pride in his own appearance and was referred to the HIV dental clinic to have his teeth fixed. Karl is developing a small but good network of people in his life, occasionally attending social events

organised through Karumah and also meeting people at TAFE. From evaluation forms, Karl shows a significant change in his sense of isolation and also measurable health improvements from meeting his goals and targets. Karl continues to receive support from the Karumah case manager to this day, although in a much lesser capacity.