

2018 – A Review

In 2018 the CanCare Navigation Program trained two cohorts of volunteers, received 35 referrals and conducted three volunteer professional development workshop. CanCare volunteers supported 50 people with cancer in the St George and Sutherland area. These people were referred from St George Public and St George Private Hospital, Sutherland Hospital and Waratah Private Hospital. Two people self-referred into the program.

A highlight for the year was recognition of the program's success by the Sydney Community Health Network. The program won a Wellness Award in the Wellbeing category. The category was highly contested with over 30 applications being received.

The 50 people who accessed the service were supported by 20 volunteers. Our volunteers supported 1- 3 people each depending on their availability and the needs of the people they were supporting. Time spent navigating each week ranged from 1 - 10 hours and the range of tasks our navigators performed were diverse.

The diverse range of tasks reflects the customised support our volunteers provide. Volunteers and the people they were supporting used a range of methods to communicate which included face to face, phone, email, Whats App and text messages.



CanCare Volunteers spent approximately 900 hours providing free support to the 50 people using the CanCare service. This is approximately \$20,000 (\$22 per hour) worth of free support our volunteers provided to people with cancer in the St George and Sutherland area.

All CanCare volunteers have attended the 2-day CanCare Navigator Training Program and most participated in the 3 professional development workshops held in 2018. Guest speakers presented at the workshops and were selected based on the needs identified by the CanCare volunteers. Guest speakers presented on My Aged Care, Centrelink, The role of the Cancer Council, NSW Public Trustee, Palliative Care and Cancer.

On average it has cost the Prostate and Breast Cancer Foundation \$310 to train each volunteer and approximately \$30 for each volunteer to attend the three professional development workshops held in 2018.

Our volunteers organised two volunteer peer support morning teas where they discussed



the challenges of being a CanCare Navigator. These provided an opportunity for volunteers to collate their feedback and advocate for changes to the program, resources they need to assist them in their role and identify

Training new volunteers

common challenges people with cancer are experiencing. An important outcome from this was the establishment of a peer support program where new volunteers are supported by a more experienced volunteer.

The Prostate and Breast Cancer Foundation donated 40 Christmas presents to St George hospital for people with cancer and their families. The presents were a gift for people who were in hospital on Christmas day.

CanCare Users

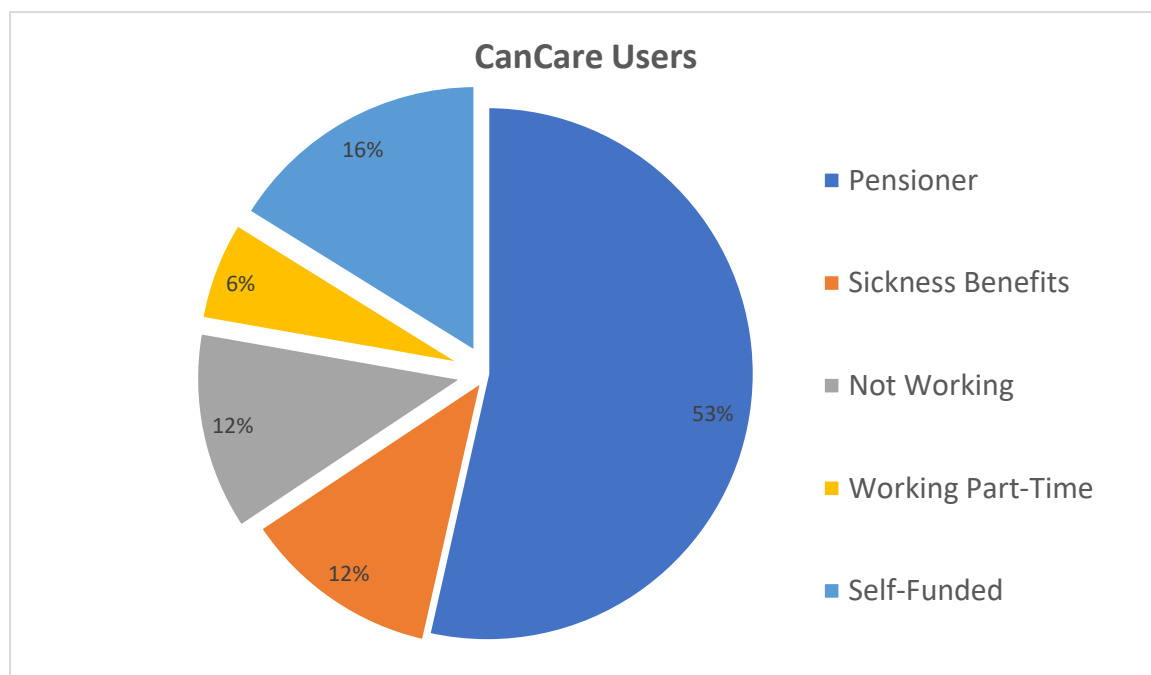
The target group for the CanCare program are people with any type of cancer who are vulnerable, socially isolated or economically disadvantaged. An analysis of the program users demonstrates that many of the program users fall into these categories.

CanCare users during 2018:

- 53% (n=26) Pensioners
The most common being the Aged Pension, 3 people were on the Disability Pension and 3 were receiving pension support through the Department of Veteran Affairs.
- 12% Sickness Benefits
These people were receiving a sickness benefit and were hoping to return to work following their treatment.
- 12% Not Working
These people were unable to work as a result of their treatment and were not receiving any income support. Many were under financial pressure as a result of this.
- 16% Self-Funded Retirees.
- 6% Working Part-Time
These people were working part-time during their treatment.

The out of pocket expenses incurred as a result of a cancer diagnosis placed additional financial pressure on those who are financially vulnerable. The cost of transport was an additional expense many found difficult to manage.

The users of the service ranged in age from 25 – 93 years with 32% being 70 plus. Of these users 65% (n=32) were female and 35% (n=17) male.



Living Arrangements

The service also targets people who are socially isolated. Studies have demonstrated social isolation can have a devastating impact on the lives of people with cancer. A large American Cancer Study links social isolation with an increase in cancer mortality. Social isolation can: impact on people not eating, stop people from taking care of themselves, cause delays in reporting problems and can result in people missing medical appointments.

CanCare users were socially isolated as a direct result of their cancer, because they did not live near a family member or they did not have any immediate family. People who were socially isolated were the biggest beneficiaries of the CanCare program, with 64% (n=32) of the program users living alone. In this group 5 lived in social housing and another 3 lived in a vulnerable housing situation. This included living above a garage, in a small room in a friend's social housing accommodation and in a caravan park.

Of the remaining users 22% (n=11) lived with one other family member. Most often this was an elderly partner who was often overwhelmed with the additional support required as a result of a person's cancer treatment.

Only 14% (n=7) live with more than one person where any additional burden could be shared with other family members.

Support Provided

The role of the CanCare Navigator is to provide one-on-one customised support to people with cancer through peer support, education and advocacy. CanCare Navigators identified a range of issues a person needed support with. The diverse range of support our navigators provided demonstrates our volunteers are providing the right support at the right time.

Liaison with a health professional was one of the most common tasks performed. This included liaison with a Social Worker, a General Practitioner, Cancer Nurse Coordinator, Community Nurse, Specialist, Physiotherapists etc. This liaison often involved the navigator making a health professional aware of a change in a person's condition, attending a medical appointment, clarifying a treatment instruction, clarifying the status of a My Aged Care referral, following up on a Centrelink application and discussing a side effect the most common being pain.

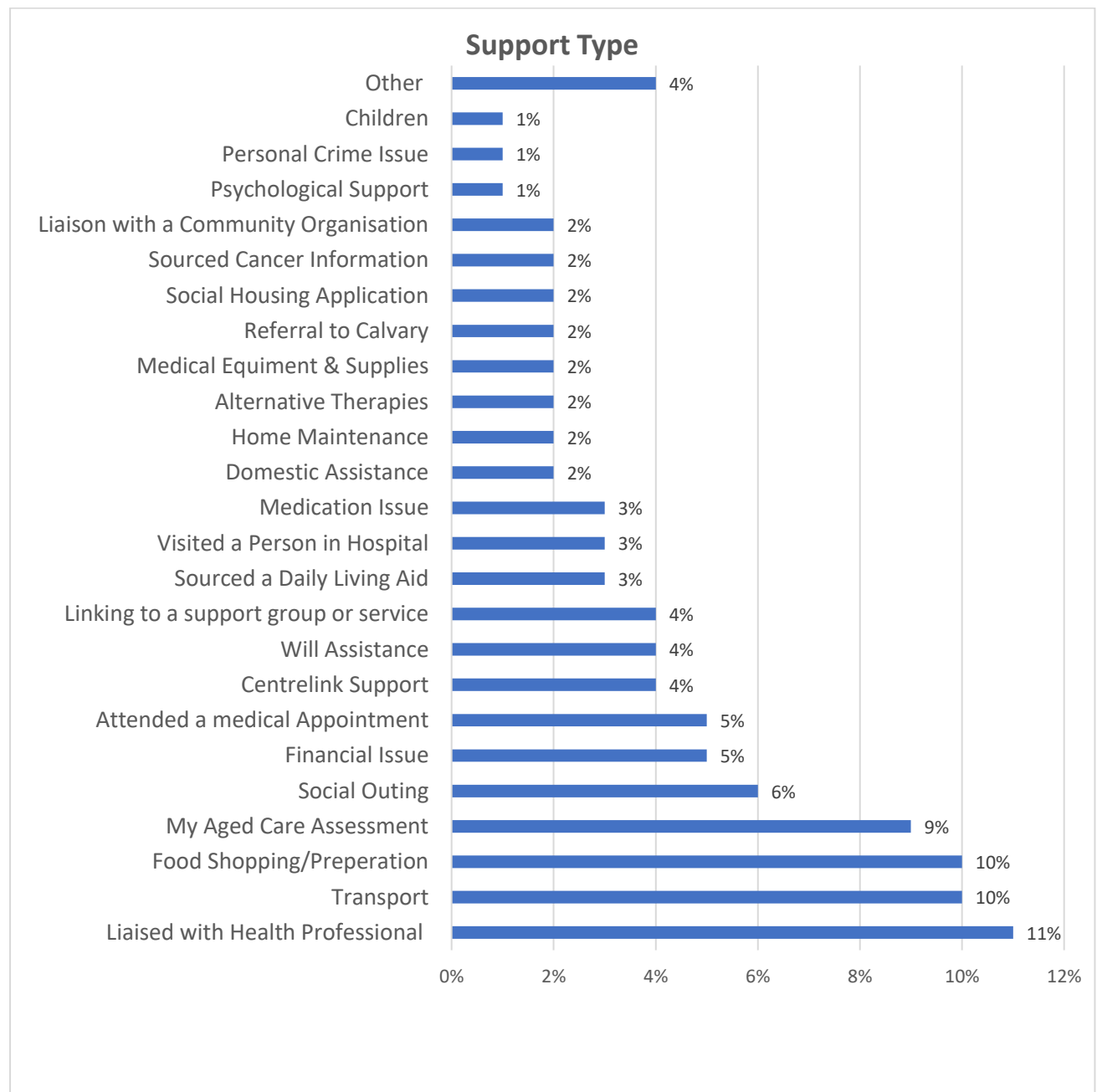
Transport was a common challenge a navigator managed. This included organising transport or taking a person to a medical appointment. Many socially isolated people have limited transport options. Navigators often organised community transport and PBCF often funded Uber and community transport. Referrals to specialists out of the area a person lives were a challenge for navigators and users and caused much stress.

Managing My Aged Care (MAC) was another common challenge people experience. This included organising a My Aged Care Assessment as a person's cancer diagnosis often resulted in a change in their health status, requesting a review of a current package to reflect the changing needs of a person or to discuss a service the person was receiving through their MAC provider. The wait for simple MAC support like a cleaner was a cause of

much distress for people urgently needing this type of assistance. The PBCF often funded cleaners until they were able to receive support through MAC.

Many elderly people who were socially isolated were not sure who was involved in their aged care and the role they played.

CanCare Navigator Support Type



Food preparation and food shopping were tasks our volunteers often engaged in. Social isolation often resulted in people missing meals. The support provided by our volunteers ensured these people had food and products such as Ensure and Sustagen.

The number of times a task was performed did not correlate with the length of time spent on the task. Whilst the number of tasks that involved Centrelink was small anecdotal feedback demonstrated that liaising with Centrelink is very time consuming. Navigators reported spending hours in Centrelink with a person trying to resolve an issue. Encounters with Centrelink often caused people much stress and the paperwork required was cumbersome and difficult for a person with cancer to manage.

Evaluation

Supportive care is used to describe the non-medical services a person with cancer may need. Supportive care in cancer focuses on the needs of the 'whole person' and involves finding out what people need and assisting them to address their needs.

Studies have shown people with cancer have high levels of unmet needs and these needs were highest in the psychological, health systems and information and physical and daily living domains. The majority of support our navigators provided fell into the domains where people have unmet needs.

Research shows that people with cancer who receive supportive care have lower rates of anxiety, mood disorders, nausea, vomiting and pain and people who perceive they have poor support have greater levels of psychosocial distress that can impact on their cancer outcomes

During 2018 program evaluations were conducted in February and July. We received a completed evaluation from 20% of people using the service at these times. An analyses of the results of the evaluation demonstrated that users found their navigator to be supportive or very supportive, and the level of support they provided was adequate for their needs. This indicates our volunteers are providing the right type of support to people with cancer when they need it.

All users thought the best thing about having a navigator was knowing there is always someone to contact if they had any problems. This has also been supported in the anecdotal feedback received through users and volunteers.

CanCare Navigators can play a major role in helping people manage their cancer needs. CanCare Navigators also provide a cost-effective opportunity to manage these unmet needs. Navigators become part of a person's support network which reduced their social isolation and helped them manage their many challenges..

Major Outcomes

Case Study A

A 70-year old male, living on his own, was discharged with no support, without an Aged Care Assessment and poor language and literacy skills. He was discharged from hospital with a Urostomy and Colostomy and staff were concerned he would be a failed discharge.

With the support of a CanCare Navigator he accessed all the support he needed and medical equipment required to manage his stomas. He has not required any in hospital care following his discharge 18 months ago and he is currently in remission.

Case Study B

A young single male (35 years) had a treatment plan that included radiotherapy, a colostomy and chemotherapy. He was referred to the service by staff who were concerned he would be lost and not have the treatment he required. With support from his navigator he received all his treatment, attends a Stoma support group and as a result of the success of his treatment will be having his colostomy reversed soon.

Case Study C

As a mother of three young children and with little family in Australia this lady was referred to the program for additional support. As a result of the cancer the family was under financial pressure as they had to survive on one income. Following a relapse the treatment proposed was not available under the PBS and the family did not have the money to pay for this. A CanCare Navigator linked her to another volunteer who organised a fundraising event. Through this event enough money was raised to allow her to have a choice between two different treatment options. The support she received contributed to her positive well-being.

Case Study D

An elderly lady who lived on her own with little family support was referred to the service to ensure she had additional support outside of the health care setting. This lady was too frail following her treatment to manage the coordination of her care. With the support of her navigator the lady was linked to a range of support services and put back in contact with her son who was going to provide ongoing support.