Brotherhood
of St Laurence
Working for an Australia free of poverty

Rebuilding connections

Creating opportunities for
socially isolated older Australians

Evaluation of the Brotherhood of St Laurence
Community Care Socialisation Program

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Foreword

Social isolation and loneliness are serious problems for older Australians. Yet the need for services and programs that help people remain connected to friends and family in later life has not received adequate attention from policy makers.

At the Brotherhood of St Laurence, we are committed to improving the capacity of older Australians to participate fully in the life of their communities.

We are aware that the there are many community organisations who are interested, like us, in the issue of social isolation. We welcome the opportunity to work with others to develop responses in this vital area.

Brotherhood of St Laurence staff encounter many people who are confined to their own homes, not having the physical, emotional, financial and social resources to engage in their local community. The experience of these staff is that 'it's immensely difficult for a person to have a decent quality of life when they no longer have anything to look forward to'.

This research was completed by the Brotherhood of St Laurence to explore and understand the experience of social isolation for people with complex care needs and their family carers, and to identify ways to address it. The study focused on clients and family carers receiving case management and community care services from the Brotherhood Community Care Program. These community care services include HACC, Linkages (Community Options), Community Aged Care Packages and Extended Aged Care in the Home.

The research shows the extent to which these people perceive themselves to be lonely and socially isolated as a result of managing a chronic illness, disease or severe disability, while living in the community.

The study details the Brotherhood's Socialisation Program service delivery model in developing people's social networks and social supports through community-based recreation, leisure and social activities. The report highlights the value of the care management framework, coupled with the provision of individualised support, in helping socially isolated people to regain the confidence to engage in their community.

Recommendations are made for policy changes to overcome barriers such as transport, lack of personal assistance and lack of emotional support and to reduce the social isolation of disadvantaged older people.

We trust that this report will contribute to community discussion and prompt governments to consider the policy implications.

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General Manager of Community and Aged Care

Acknowledgments

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Executive summary

A significant issue identified by the Brotherhood of St Laurence's Community Care Division is the social isolation of many clients and their need to rebuild friendships and social relationships. Staff are identifying this issue through their care management work, particularly with older clients and clients with a disability who experience multiple disadvantages. While building social friendships and networks has not historically been seen as a major goal of case management, the BSL experience suggests that this goal is of importance equal to or greater than other care management goals such as personal care, transport and health care. Loneliness and associated depression can limit a client's ability to focus on other goals.

Social isolation is a considerable problem. A recent Australian Bureau of Statistics report shows that people over the age of 65 years with moderate and severe disabilities spend 85% of their waking time alone.

The main factors causing social isolation and loneliness identified by the present research are as follows:

* Disability and illness lead to a loss of functional abilities that impose restrictions on people's activities of daily living, social activities and social participation.
* People can feel discriminated against by their community where they are negatively labelled by their disability and age.
* The high cost and the limited availability of wheelchair vehicles, especially taxis, reduces people's ability to access their community.
* Financially disadvantaged people cannot afford to engage in social activities necessary to maintain existing relationships with friends and family.
* People with low self-esteem and confidence find it difficult joining community groups and activities, especially if their disability makes them feel self-conscious, for example having difficulties with eating or being incontinent.

This report describes the experience of the Brotherhood's Community Care Division in the Department of Human Services' Southern and North and West Regions of Melbourne in responding to social isolation through its Socialisation Program. Drawing on the views of participants and care managers, the author evaluates the effectiveness of this approach in addressing social isolation and considers the broader implications for care management programs generally and particularly for leisure and recreational services for older people and people with a disability.

The Socialisation Program was designed to recognise the significance of supporting and improving client's social networks in improving a person's health and well-being. The program assesses clients' leisure and recreational preferences and organises individualised programs to address these preferences. An important component of people's engagement in community and centre-based leisure and recreational programs is their self-confidence and ability to build ongoing and rewarding relationships with fellow participants. The Brotherhood's staff have developed strategies for successful re-engagement of clients who have previously found it difficult to re-engage. Emphasis is placed on:

* engaging clients in health promotion activities that increase their physical activity and increase their nutrition and improve their mental health
* building on a person's life strengths and nurturing positive feelings of self-worth and life achievements such as past employment, hobbies and interests.
* using volunteer peer mentors to facilitate participation in leisure and recreational activities.

A central objective of the Socialisation Program is facilitating friendships within structured groups and encouraging contact between participants in external community settings. In addition, family carers who wish to join in group and recreational activities have been supported to do so, thereby enhancing the inter-personal relationships between the carer and the care recipient through the shared enjoyment of activities.

BSL Community Care Division staff undertook an internal program evaluation, collecting information through consultative forums and care management questionnaires. In addition, further exploratory research was undertaken by The Work Lab in 2006. Together these identified a number of benefits for clients, family carers and case managers, including:

- improved quality of life and sense of belonging
- motivation to participate and manage their illness or disability
- lessening of visits to medical specialists and health care services
- higher uptake of health promotion and recreational activities
- reassessment of personal needs (no longer seeking personal care attendants or care managers for friendship).

This report confirms the value of addressing social isolation amongst older people and people with a disability. It highlights the importance of this issue for care management practice and identifies the value of having specific programs that increase an individual's social connectedness. Funding to reduce social isolation and build social networks for lonely and isolated people should be further considered in the Home and Community Care and CACP Programs.

Summary of findings

The evaluation found that overall the Socialisation Program has had a positive impact on Brotherhood clients' quality of life and social well-being:

1. Care managers reported that the Socialisation Program improved older people's social networks, self-esteem/identity, and opportunities for respite and quality of life.

2. The major constraint on care managers was the time required to promote the Socialisation Program and provide the emotional and physical support to engage people successfully in the program.

3. Older people participating in the Socialisation Program perceive themselves as marginalised by their community directly as a result of their illness. Discrimination was a key reason stated for these people excluding themselves from their existing social networks and their community at large.

4. Family carers stated that participation in the Socialisation Program provided quality respite even when they attended the same leisure activity with the person they were caring for. Respite was more about taking a rest from caring duties as program volunteers and personal care attendants took over. Their major barrier to accessing the program was a feeling of guilt about also using the program for their own well-being.

Recommendations

1. That rebuilding social networks and increasing social connectedness be incorporated into program objectives and funding guidelines.

2. That the barriers to accessing health promotion and illness prevention programs for people with multiple disadvantages such as chronic illness, low socio-economic status and poor self-confidence be better recognised.

3. That an integrated package of measures to overcome barriers such as transport, personal assistance and emotional and social support be provided to reduce the social isolation of disadvantaged people.

4. That a case management approach to achieve good health promotion outcomes and improve quality of life for people faced with multiple disadvantages be better understood and further researched.

5. That funding be provided to promote the Brotherhood of St Laurence's Socialisation Program's service model and that similar programs be considered for other regions in Victoria.

6. That the benefits of enabling program participant's partners or significant others to participate in social support programs, particularly recreational and leisure activities, be recognised.

7. That social support services be encouraged to recognise participants' skills and abilities and be more proactive in encouraging participants to volunteer as mentors for socially isolated and lonely peers.

8. That further funding be provided to assist social support programs to address transport and access issues.

1 Social networks and social support

The importance of social networks, social support and leisure

Social inclusion theory, in relation to older people, emphasises the importance of leisure activities to improve an older person's social networks. Leisure and recreational events provide the opportunity for interaction between people. Social contacts in turn can influence the development of people's intrapersonal skills such as self-esteem, mood and self-efficacy.

The Australian Bureau of Statistics (ABS) in their review of social trends found that social networks are important both for their contribution to the well-being of individuals and families, and in creating and maintaining social cohesion and fostering a sense of community (ABS, 1999a). Social networks promote generalised feelings of psychological well-being that protect individuals from ill health. They provide members with a sense of predictability and stability and norms for behaviour, encourage positive affect and enhance feelings of self-worth and belonging (Cohen & Wills, 1985).

The same ABS review highlights a growing trend towards increased loneliness and social isolation (ABS, 1999a). The weakening of social bonds can in part be explained by high divorce rates over recent decades and a growing lifestyle preference for people across all age groups wanting to live alone. While spending time alone, even for long periods, need not be an indicator of diminished quality of life, feelings of loneliness and boredom that often arise from spending time alone are of concern.

The ABS (1999a) research used the measure from the Time Use Survey to determine the extent to which people report that they always or often have spare time, as an indicator of loneliness and boredom. The ABS found that feelings of loneliness increased with age and were higher among older people who live alone, particularly those with disabilities. In 1997, of people aged 65 and over identified as having a moderate or more severe disability, 21% of those living alone and 17% of those living with others felt that they always or often had spare time. These proportions were substantially higher than for the age group as a whole (12% and 5% respectively).

The ABS (1999a) also found that older people (aged 65 and over) spent the least time out of the age cohorts, talking and socialising—an average of one hour, 36 minutes per day). This reflected the significant proportion (32%) of older people living alone. This finding is also supported by the ABS (2005) profile of mature aged persons, which identified that in 2002 people in older age groups had lower levels of participation in social activities than all other age groups. When asked about social activities undertaken in the last three months, nearly 17% of people aged over 65 reported doing none of the activities listed.

Social networks, social support and health and well-being

The high number of older people living alone is a serious public health problem, given that research has found a strong relationship between social isolation and loneliness and ill health. For example, Berkman and Syme (1979) who studied the social connections of a random sample of 5000 British adults over nine years found that men with the weakest social connections had age-adjusted mortality 2.3 times higher than women with the strongest connections.

Social (or functional) support refers to a more specific notion than social network. Its assessment involves identifying those aspects of social relationships that promote psychological and physical well-being. Critically, support needs to provide individuals with regular positive experiences and a set of stable socially rewarded roles in the community (Cohen & Wills, 1985).

Social support also may influence physiological reactions to stress. A study of Japanese living in Hawaii found low social support levels predicted high blood pressure independently of other risk factors such as smoking and alcohol consumption (Joseph, 1981 in Berkman, 1984).

Social support may also moderate health-related behaviours such as seeking medical advice, smoking, alcohol consumption (Levy et al., 1990). Finally, social support promotes adherence to complicated medical regimes and life style changes (Gottlieb & Green, 1984; Zimmerman & Connor, 1989).

On the other hand, high levels of depression are associated with loneliness and isolation (e.g., Godfrey & Denby, 2004). Flemming (2003) reported high levels of depression among older people living in community and residential care settings. Loneliness and social isolation as a result of chronic illness are the main risk factors for developing depression in later life. The social support derived from friends acts as a buffer, reducing the risk of depression in the face of a physical disability. The Gospel Oak community-based study conducted by Prince, Harwood, Thomas and Mann (1997) entailed interviewing older people to examine their exposure to a wide range of risk factors for depression. The study identified a strong relationship between physical ill-health and depression, but this was mediated entirely through the loss of a person's functional abilities.

Further research by Prince et al. (1998) reinforced these findings and highlighted the vicious cycle many older people experience managing a chronic illness, with depression leading to further chronic illness and increasing disability. Prince et al. suggested immobility associated with physical illness is the significant factor in this cycle, as it leads to isolation within the home, limited contact with friends and neighbours; and consequent loss of intimacy and reduced sense of community, further exacerbating isolation and loneliness. Social, recreation and leisure programs can assist older people with physical mobility problems to remain connected to friends and family and therefore reduce their susceptibility to depression.

Recreation and leisure activities can often connect a person with friends and acquaintances. Such relationships improve a person's sense of well-being and are equally important for men and women (Jerrome & Wenger, 1999). Higher morale and lower levels of loneliness and social isolation can be associated with the availability of a confidant(e) (Wenger et al 1999). The pleasure that is derived from shared activities has a positive effect on well-being (Rook, 1990) and life satisfaction. Iso-Ahola and Park (1996), in their studies of the effects of leisure on health noted that:

> …theoretically leisure affects health in three interrelated ways 1) leisure becomes a tool by means of which health is pursued and obtained, that is leisure provides the time and environment in which health behaviours are practiced; 2) leisure is a way of life, that is, it is a cognitive orientation toward life and a lifestyle that promotes and is conducive to health; and 3) leisure has some inherent qualities and characteristics that are germane to health.
> (Iso Ahola & Park, 1996:169)

Policy responses

The World Health Organization has been a strong proponent of healthy ageing, stating that good health is vital to maintaining quality of life in older individuals and ensuring their participation in society (WHO, 2000). Healthy ageing is a policy goal shared by Commonwealth and state governments in their response to the projected health, social and economic demands that will come from Australia's ageing population (Ageing NSW Report, 2000).

Increased longevity and decreased fertility are the key factors increasing Australia's ageing population. In 1976, Australia had 1.3 million people over 65 years, representing 9 per cent of the total population. By 2004 that figure had doubled to over 2.6 million people over 65, 13 per cent of the total (Australian Institute of Health and Welfare, 2004). The population aged over 65 is expected to grow to between 6.2 million and 7.9 million by 2051, more than 25 per cent of the

total. The over-85 age group is expected to almost quadruple as a proportion of the population, the highest growth rate of all age groups.

Health promotion work in aged and community care has been spurred on by the health problems associated with older age. For example, people who are 65 years and over:

- use hospitals more frequently and for longer periods
- visit the doctor more often
- consume more medication
- make more visits to allied or other health professionals
- have more falls

than other members of the population. Falls are the single injury responsible for the greatest cost to the health system (Australian Institute of Health and Welfare 2004).

Housing and its relation to independent living is a central issue for healthy ageing. There has been a significant shift in the values and priorities of older Australians, which is transforming the patterns of future housing tenure, lifestyle and family relationships, as documented by Olsberg and Winters for the Australian Housing and Urban Research Institute (Olsberg & Winters, 2003). Some 7000 older Australians (50 years and over) were surveyed about their intentions for future housing, inheritance, and legacies for their children. The researchers found that many older people wanted to continue to live on their own. The proportion of mature age persons living alone increased from 7% in 1971 to 11% in 2001; and it was older women who were increasingly choosing to live alone.

Olsberg and Winters also indicated that older people had a strong preference for independent living and autonomy. Importantly it showed a widespread reluctance by older people to move in with their children once their spouse or partner died. The findings also revealed that living near friends continues to be an important priority in either ageing in place or moving location. Respondents who had successfully moved away form the family home had 'moved to an area where they already had friends or an area in which they had spent holidays in the past and knew local residents'; and these were 'the best guarantees for successful retirement lifestyles'. The respondents in this research, who were already living in a retirement village, stated that the 'best thing about their move had been the opportunity for social contact and social activities' (Olsberg & Winters, 2003: 96).

Healthy ageing as it is perceived by older people is now less underpinned by traditional notions of loyalty and proximity to family and more by lifestyle preferences and attachment to friends. There are, then, significant opportunities for government in the public policy area of healthy ageing, not just in the development of new forms of housing, but also in aged and community care services that aim to maximise a person's quality of life through their friendships and leisure preferences.

Both sides of politics support the importance of strengthening communities as a major policy solution to the problem of social exclusion (Johnson, Headey, & Jensen, 2003). While both state and federal governments have done considerable work in the policy areas of family, disability, multicultural and unemployment to increase people's participation in community social and economic life, the same cannot be said for the area of older people managing a chronic illness or disability.

Brotherhood of St Laurence response

From the research evidence, Brotherhood Community Care recognised the relationship between leisure and recreational experiences and health and quality of life. Clearly, participation in leisure activities by older people is good health promotion, especially when it improves the resilience and connectedness of individuals and communities (VicHealth 2005). As Long (1990) observes, leisure

is important in 'empowering people to derive satisfaction from the kind of retirement they have created or had imposed upon them … [and] … whilst leisure [is] used by some to secure change, it most commonly provide[s] a sense of continuity'(Long 1990: 70).

The Brotherhood of St Laurence supports Commonwealth and state government policies that recognise the value of recreation and leisure strategies in improving mental health and well-being for older people. Pursuing a leisure activity for which a person has a talent or interest and which offers opportunity to meet people with similar interests has been shown to be highly beneficial. These elements therefore are at the centre of the Socialisation Program's service delivery model.

The Brotherhood of St. Laurence, through its community care services, is encountering lonely and socially isolated people in increasing numbers. These are people with no friends and no contact with family and in many cases people who haven't been outside their home for weeks, months, or even years. The Socialisation Program was initiated by the Brotherhood in response to this trend. A decline in the number and quality of relationships, possibly due to illness or disability, is an unfortunate reality that confronts many older people. Good relationships with family and friends do matter to older people and it is important to consider strategies that support continuation of productive relationships or rebuilding of relationships with family and friends. .

The following section describes the Socialisation Program, from the perspectives of both the care managers and the clients and family carers.

2 The socialisation program

In 2003 the Brotherhood launched the Socialisation Program for people with complex care needs and their family carers. The key principles that framed the delivery of the program were the recognition that older people:

- cherished hopes and dreams

- continued to want a purpose in life

- retained strengths and life experiences that transcended their disability/illness

- aspired to belong to their community through valued social relationships.

Hopes and dreams

The Socialisation Program recognises that older people have abilities and experiences that at one time have made life fulfilling and enjoyable. Despite the physiological challenges that come with age, they should not have to discard these talents and abilities. The program assists people to nurture those areas of life where they have greater control, particularly their interests and leisure activities that are important to self-esteem and self-identity.

Life purpose

Personal meaning is espoused by the gerontologist, Paul Wong (2000), as the important dimension of successful ageing: having a positive meaning and purpose in life will not only add years to a one's life, but also add life to one's years. This is important at a time when older people are faced with increasing and severe losses and uncertainty. Such losses may include the death of a close spouse, a severe illness or disability leading to physical immobility, and the relinquishing of cherished and valued roles. As Jerrome (1989: 161) stated:

> Social participation is part of a strategy for survival. All are determined to keep going, either by denying illness or acknowledging it and coming to terms with it. Social participation is the battle against old age.

The Socialisation Program aims to help older people with complex care needs to continue to discover positive meanings in life even when their health is failing. The program recognises that it takes tremendous effort and willpower for a person with a chronic illness to get out of the house to be with friends and family. The person should be encouraged and supported to continue to participate in areas of life that they consider priorities.

Life strengths

The Brotherhood recognises that older people are unique individuals with specific life interests and abilities. Understanding these issues comes through developing a relationship, listening to a person speak about their life experiences and identifying areas that a person cares about, that are worthy of their emotional, physical and intellectual investment (Driscoll, 2004). Therefore, it's often about supporting a person to remain engaged with their passions, interests, and talents. It's also about considering leisure activities that might lead to other social opportunities, outside a structured aged and community care program.

Friendships

The Program develops small activity groups around people's interests and leisure preferences. Friendships are often best founded on shared interests, rather than age and disability (Friendships Matter 1998). Activity groups are often situated close to where people live and in venues that suit the activity. For example, the Red Hill and Frankston Art Programs are situated in art galleries. Groups are well facilitated with emphasis placed on helping older people to get to know one another.

High-quality activity groups led by a skilled professional help friendships to develop, especially when people are working as a team on a project or developing new skills and talents. Participants are encouraged to meet outside the activity; for example, the program has installed MSN Messenger on fitness participants' computers so they can remain in contact outside the class.

The care managers' experiences

Brotherhood Care Managers in both North West and Southern Regions regularly encounter older people living on their own and managing a chronic illness, without the support of friends and family. Social isolation amongst our client group is a serious problem. Clients report feeling depressed and anxious and believing that there is nothing left to live for. Care managers often struggle to find, within the health and aged care system, practical solutions for lonely and socially isolated clients. This is especially the case for older people faced with multiple disadvantages such as mental illness (often as a secondary diagnosis), insecure housing, fragile physical health and scarce financial resources.

However, there are problems with social support being delivered primarily through health and community care services. These include care practice and cost issues.

Care practice

Assisting socially isolated older people to rebuild friendships and social networks is a time-consuming and demanding task. Care manager and personal care attendants cannot provide what informal social relationships and social networks can, as Peters and Kaiser (1985: 128) suggest:

> Kin, neighbours, and friends actually function in the capacity of support givers by being available and involved in ongoing relationships with older persons as to make meaningful support a possibility.

The time and resources that a care manager can direct towards a person's inter-personal relationship needs are often limited by the resources available under existing funding programs. The focus on pressing issues such as scheduling medical specialist appointments, attempts to find secure housing and managing home and personal care attendant visits often leaves insufficient time and resources for improving the person's social relationships and networks. Quite often, care managers or personal care attendants can become the person's primary source of social support.

Community care services need to do more to increase and complement, rather than replace pre-existing relationships (Dunn, Hooker, & Jenner, 1998). The Brotherhood of St Laurence believes that more needs to be done to create the conditions in which social relationships, social networks and social support can develop for socially isolated and disadvantaged older people. The crucial role of friendship in the lives of older people is recognised by care managers.

Cost

Care managers often respond to a person's needs by linking them into a HACC Planned Activity Group (Day Centre), or assisting them to join an informal community group based on their personal interests. This is difficult, however, due to the financial costs. The costs of community transport (e.g. taxis) and of personal care workers, as part of a client's care plan, can be prohibitive due to limited care package funds. In many cases, the package barely covers community care services such as home care, personal care, community nursing and meals on wheels, which are critical for a person to remain living independently. There is little left to address their social well-being needs.

This is especially the case for community care services affected by differences between the state and Australian governments' funding provisions: for example, the costs to a client for one day at a state-government funded day centre (based on full cost recovery) is nearly equivalent to the total weekly care plan of a Commonwealth-funded CACP package.

Experiences of clients and family carers

Every year Brotherhood Community Care runs a Client/Carer Consultative Forum to assess gaps in services, identify unmet needs and improve service delivery. A consistent message from these forums has been the importance of social connectedness, reflected by many clients describing their feelings of loneliness and isolation. What they wanted was a way to be more involved with their family, peers and community to achieve a sense of belonging and purpose in life.

Clients and family carers suggested that social support services needed to be delivered in familiar and valued ways that actively supported them in the pursuit of their own personal interests. Fundamentally, they did not want an aged care experience from their social services, they wanted a community experience. They wanted community-based activities that:

- were close to where they lived

- recognised and promoted their talents and personal interests

- provided opportunities to meet like-minded people (not always other clients) for friendship

- encouraged a spirit of volunteerism, the capacity to help others

- enabled their family and friends to be involved.

This presented Brotherhood with a dilemma because there were few aged and community care social support services available in the North and West and Southern Regions of Melbourne that could meet these expectations. One major problem was the lack of choices available. Day centres were often the only community option available to meet older people's diverse social, recreation and leisure needs. They were the only services with the staff and the supports (particularly transport) to assist older people with complex care needs.

Day centres and meeting the diverse social needs of older people

While there is an extensive network of day centre and planned activity programs across the state, many Brotherhood clients choose not to use these services. Some clients feel uncomfortable in the large communal settings or find the activities offered inappropriate for their requirements. It is difficult for one centre to address the different needs of clients, such as making friends, improving daily living skills and increasing independence at home (Driscoll, 2004).

Some Day Centres do not offer the variety and choice that attracts clients. Many social activities are generically structured rather than individualised, so they often meet only the minimal social needs of participants. This is especially the case where day centres are funded to support both people categorised with *high* needs and people with *core* needs.

Core group sessions are suitable for participants who are physically independent and do not require personal care, specialist dementia care or other specialist care in order to participate in activities. *High needs* group sessions are designed for people in one or more of the following groups:

- frail older people who require personal care

- people with Acquired Brain Injury (ABI)

- people with disabilities who have a challenging behaviour

- people with disabilities who require assistance with toileting, eating or mobility in order to participate in activities (HACC, 2003).

This presents a problem for day centres because *core* and *high* clients often have quite different levels of abilities, expectations and social well-being needs. At present there is no service to support people with low (core) needs into mainstream community activities, particularly when many day centres are focused on supporting people with complex needs (high) such as dementia (Gravell 2005). The activities take place within the day care centre, with little encouragement for participants to explore wider community offerings or to pursue friendships throughout the week,

for example by meeting for coffee. This is reflected in the *Frankston and Mornington Peninsula Social Support Directions Report,* which identifies the lack of integrative opportunities for participants to access existing community facilities, such as senior citizens' centres, community libraries and neighbourhood houses (Gravell 2005).

This lack of engagement of day centre participants in local community activities is problematic given that 50 per cent of all participants in the Southern Region of Melbourne live alone (Gravell, 2005 unpub.). As already indicated there is a growing body of evidence which underscores the benefits of social networks and relationships to older people, especially those who live independently in the community. Activities need to foster informal friendships for participants outside the structured program.

Conversely, to what extent are day centres inadvertently providing activities for people who are already well connected to their family and community, rather than engaging hard-to-reach socially isolated older people? What approach can be used to engage socially isolated older people, particularly if they have depression and anxiety issues, and do not have the social confidence to engage in a structured group activity?

Many day centre activities tend to be passive (cards, board games, afternoon tea) and to be more female than male oriented (Gravell 2005). There is a greater need for activities that are relevant to males and encourage life skills, such as cooking nutritious meals and developing physical fitness. People want activities that reinforce their personal worth and self-esteem, enabling them to give something back to their peers and the wider community at large. This can only occur when day centres involve their participants in the planning, development and monitoring of the recreation and leisure activities provided.

Limited research has been done to date to assess the effectiveness of the day centre program in meeting its purpose to 'maintain an individual's ability to live at home and in the community, by providing a planned program of activities directed at enhancing the skills required for daily living and providing physical, intellectual, emotional and social stimulation' (HACC, 2003: 122). There has been a lack of conceptual clarity around the implications of 'enhancing the skills required for daily living', and this is reflected in the limited emphasis day centres place on helping older people maintain and increase their own social networks and supports within their own local communities.

Further work is required to measure the effectiveness of day centre activities in meeting the following needs of individual participants, identified as critical in the HACC Program Manual:

- physical needs—the extent to which activities improve physical health, increasing daily functioning and self-care abilities
- intellectual needs—the extent to which activities are closely linked to lifestyle interests
- emotional needs—the extent to which activities improve mood, confidence and personal self-worth, reflected in participants' capacity to re-engage in their local community
- social needs—the extent to which activities increase friendships within and outside the day centre, and improve the intimate relationships that participants see as important to their quality of life.

Despite these shortcomings, day centres meet an important social need for older people, reflected by the fact that 75% of PAG users use only this component of the HACC service system. This does suggest that older people are actively looking for social support and meaningful experiences in their life (HACC, 2003).

The Program within a Case Management Framework

The Socialisation Program is integrated within Brotherhood's case management processes—that is, with assessment, planning, facilitation and review. Case management provides an individualised approach to meeting a person's health care needs; it also enables the Socialisation Program to provide the appropriate level and type of supports to meet an individual's social well-being needs (ACSA, 2006). These needs are related to existing life strengths and social networks.

Life strengths

The Socialisation Program emphasises the life strengths approach within care management practice. A *life strengths* approach:

> …maximises the physical, social and psychological well-being of the individual to achieve their optimal level of independence and assist in their participation in the community commensurate with their capacity and choice. Case management facilitates the personal development of clients (ACSA, 2006: 5).

Social networks

The importance of improving a person's social networks underpins the case management approach in the Socialisation Program. The program aims to devise activities that help clients maintain significant friendships and relationships—in most cases with their primary carer.

Brotherhood recognises the importance of respite that is responsive and flexible to a family carer's needs. But respite needs to take into account the relationships that a chronically ill person relies upon for their emotional and physical support. For example, services that distinguish between the person receiving care and the care giver can inadvertently place a strain on an already fragile and stressful relationship. The program therefore provides activities that maintain the primary relationship—for example, enabling a husband and wife to go to the movies, often a rare treat for a couple on a limited income or reliant on taxis and community transport to get out of the house.

The Socialisation Program service delivery model

The model of service delivery is based on four stages: assessment, planning, facilitation and review. Figure 2.1 presents the model diagrammatically.

Figure 2.1 The Socialisation Program's service delivery

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                    ┌──────────────────────────┐
                    │  Clients and family carers │
                    └──────────────────────────┘

┌─────────────────────────┐              ┌──────────────────────────────┐
│ Case managers           │              │ Socialisation Program        │
│ • Assessment            │   ◄────►      │ • Matches clients with       │
│    Interests            │              │   similar interests and      │
│    Barriers             │              │   experiences                │
│    Networks             │              │ • Establishes leisure        │
│    Life experiences     │              │   groups                     │
│ • Planning              │              │ • Provides individualised    │
│ • Facilitation          │              │   activities                 │
│ • Review                │              │                              │
└─────────────────────────┘              └──────────────────────────────┘
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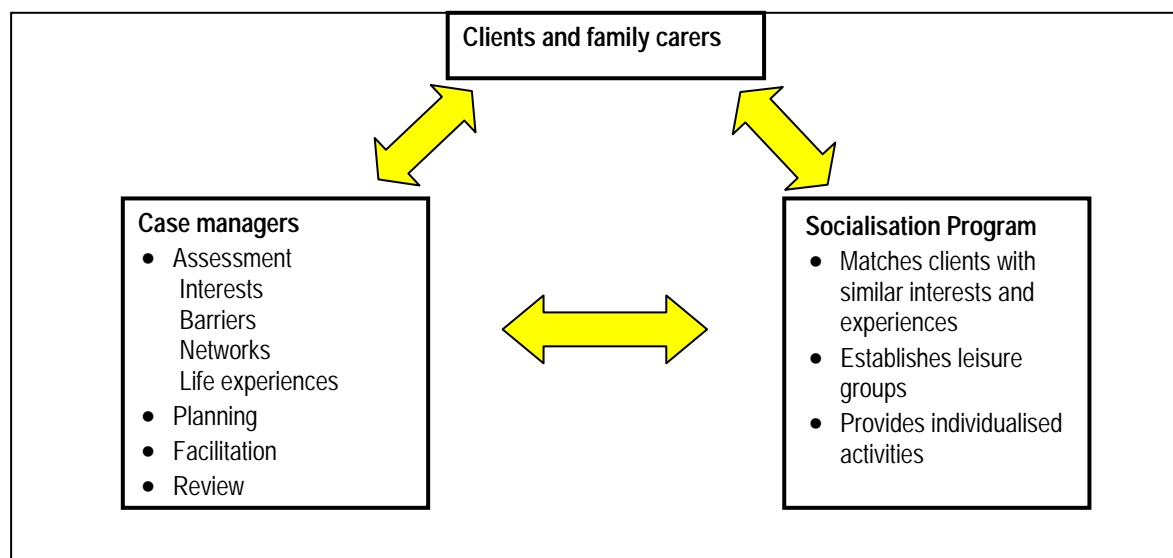
1. Assessment

The care manager typically meets a person or family in crisis. Serious illness or disability has either suddenly or over time reached a stage where the person is no longer able to manage independently.

The Brotherhood assessment process not only takes into account a person's immediate needs, such as access to medical specialists or public housing, but also their social well-being. These needs only become clear once the care manager gains a sense of *who* that person is and what is important to them. This part of the assessment process therefore cannot be adequately covered in a single home visit.

The care manager must develop a relationship with the client, built on respect and trust, that enables the person to feel confident and supported to reach longer term personal goals.

2. Planning

The care manager is required to develop a social well-being plan. This entails the following steps:
• Identify a person's interests (such as sports, leisure, arts and culture past times)

• Understand a person's life history and life course

• Determine their informal supports (i.e. family and friends) and the assistance received

• Identify barriers that prevent participation

• Establish specific individual goals to promote a person's well-being by:
    • reducing feelings of social isolation and loneliness
    • improving the person's physical health
    • improving the person's nutritional health
    • increasing their friendship circle
    • assisting the person to re-engage with their interests
    • strengthening the relationships with family and friends.

The care manager submits an assessment that includes this information. This information is entered into a database to enable the Program coordinator to identify clients with similar interests. The Coordinator is then able to develop social, recreation and leisure activities that closely match the interests of Brotherhood clients within their local communities.

3. Facilitation

Care managers are important mediators of each client's leisure involvement. Care managers are at the centre of understanding both the constraints and facilitators (intrapersonal, interpersonal and structural) that influence the client's participation in leisure and recreational activities.

For an older person who has been socially isolated for some time, taking the first step back into community can be a daunting experience. Moving from the safe, predictable and comfortable surrounds of the home to a community environment can initially be frightening. For example, a care manager might be aware of a client who would enjoy the Red Hill Art Program, but who has lost confidence in their mobility (intrapersonal constraint) as a result of a fall and will not attend. By reassuring the person that a personal carer or wheelchair (structural facilitators) will be provided, the Care manager may then influence the person to join the program. If the person still remains anxious, the care manager may suggest that their family carer (interpersonal facilitator) accompany them to the art group, which may help the person overcome their fear.

Care managers are important in the negotiation and facilitation process, which is often needed to link an isolated older person with the community. The care manager needs to make the person aware of the value in participating in an activity that they previously enjoyed. This encouragement needs to reinforce the following messages about the Socialisation Program:

- comfort and safety (there will always be someone there to help the person at the events and activities)
- good transport and wheelchair access (the Program's activities are local and easy to get to)
- no pressure for an ongoing commitment ('give it a try and see if you enjoy it')
- health comes first (if a person is not feeling well on the day they can cancel at short notice)
- fun and enjoyment comes with participating in a social, recreational, leisure activity
- continued investment in health through exercise and nutrition.

4. Review

Once a client is engaged in a group activity, the facilitator or responsible carer monitors progress in terms of:

- level of enjoyment
- quality of the interaction with other members
- willingness to contribute to the group activity.

This information is relayed to the care manager to determine whether their social well-being goals are being met. Also, the review process identifies new goals or provides new opportunities for personal growth and autonomy. For example, once a person attends a lunch group a couple of times and feels more socially confident, then the person may be willing to participate in more intensive activities, such as art, music, or day trips. (See the Appendix for Socialisation Program activities.)

3 Methodology

The research design was based on a series of focus groups facilitated by the Groupwork Institute of Australia to elucidate the experiences of 15 Brotherhood clients and 5 family carers accessing the Socialisation Program.

Further qualitative data was gathered through a survey of care managers from Brotherhood Community Care's northern and southern offices in Melbourne. The survey examined care managers' perceptions of social isolation and loneliness; the extent to which they perceived it as a problem; how they responded to the social well-being needs of their clients and family carers, and the extent to which they have linked their caseload into the Socialisation Program.

Participants in the focus groups

Although a sample of 40 participants was originally envisaged for the focus groups, 15 clients and 5 family carers were eventually able to take part. Client participants needed to be:

- aged 50 years and over

- clients of Brotherhood Community Care

- managing a chronic illness, disease or disability

- living in their own home

- engaged in at least one activity facilitated by the Socialisation Program.

Family carers needed to:

- be aged 50 years and over (since the socialisation program was aimed that age-group)

- provide informal care to a person receiving services from Brotherhood Community Care

- have engaged in at least one Socialisation Program activity.

Focus group facilitation and questions

Separate focus groups were conducted for clients and family carers and all participant responses were recorded on butcher's paper. There were no Brotherhood staff present at the focus groups, to prevent bias or influencing participant comments or views.

The same six questions were posed by the facilitator to both groups. The questions, and their purposes, were as follows.

What was life like before the Socialisation Program?

This aimed to understand the perceptions of clients and family carers about their quality of life e before the Socialisation Program, particularly the effect of illness and caring responsibilities on their perceived level of social isolation and loneliness.

What is your experience of the Socialisation Program?

The second question addressed the outcomes of the Program, especially on quality of life, health and well-being. Also, the question explored what dimensions of the Socialisation Program clients and family carers have found most valuable.

Why did you join the Socialisation Program?

The third question explored the main reasons behind a person deciding to participate, particularly whether it was an intrapersonal (person's attitude or belief) or interpersonal (encouragement from care manager) facilitator that assisted the person to join the Program.

What makes it difficult for you to participate in the Socialisation Program?

The fourth question aimed to identify the key barriers that prevent a person with complex care needs and family carer from participating in social, recreation, and leisure activities.

What are your suggestions for improving the Program?

The fifth question canvassed the processes (referral, awareness, information provision) and content (types of recreation, leisure activities) areas of the Program that can be improved.

Participants in the care manager surveys

Eighteen care managers from a sample of 23 completed questionnaires. This sample comprised 19 care managers in the Southern Metropolitan Region, and four care managers in the North and West Metropolitan Region. The Southern team, based at Carrum Downs and Mornington, manage both state government funded Linkages Packages and Commonwealth funded CACPs, EACH, and EACH Dementia Packages. The North and West team, based in Preston, manage CACPs packages to older people, many of whom are homeless or at risk of being homeless, and/or come from non-English speaking backgrounds.

4 Personal stories of clients and family carers

Living together against the odds: Rhonda and Rod

Rhonda (54) and Rod (67) are clear from the outset of the interview that they don't have the time for social workers (broadly defined as any health professional that has any control or influence over their life).

Rod, a big man, spent most of his working life down a mine, and succumbed to chronic back pain late in his life. Rhonda is a petite woman who suffered a stroke in 1997 due to high blood pressure. Before her stroke, she managed a busy restaurant. Rod was a keen greyhound trainer and he collapsed when his back 'caved in' while walking his dogs. Both ended up in Hampton Park Rehabilitation where they developed an enduring friendship.

Rhonda's stroke left her severely paralysed down one side and impaired her walking, and as often after a serious illness, her marriage failed. Hampered in her ability to care for herself and having no close family to care for her, Rhonda entered hostel level residential care.

When he first met Rhonda Rod had been happily married for 33 years, but after a long battle with illness his wife passed away. Rod did not want to live by himself and wanted Rhonda to live with him as a result of the special bond they had formed through their rehabilitation.

Rhonda spent nine months in a hostel and Rod visited her monthly, recognising a decline in her mental and physical health. Rod was shocked by her unhappiness and the way some of the staff treated Rhonda. He decided that her life would be better if she came home to live with him, but he met with considerable opposition from the hostel, and Rhonda's family.

Rod's capacity to care for Rhonda's needs was questioned. Rod reported that 'People would tell me that Rhonda will be dead in no time flat, how are you going to help shower her and organise her meals?. But I had no choice, as Rhonda was going down hill fast, and I was prepared to take the risk, rather than see her so unhappy and neglected'. The dispute culminated in a Guardianship Hearing that paved the way for Rhonda to come home and live with Rod.

It was tough for Rod and Rhonda early on, especially as the house was not well suited to a wheelchair , and they were both struggling with their chronic illness and disability. Despite the challenges, both were determined that Rhonda would not re-enter residential care. The Brotherhood Community Aged Care Package helped them considerably with their independence, particularly the home and personal care services.

Fiercely independent and loyal to each other, Rhonda and Rod both see exercise as a way of remaining fit and out of the clutches of the health and aged care system. They recognise the value of physical fitness to their own health and well-being. Being older than Rhonda, Rod wants to keep in shape, so he can provide the best level of care to her: 'I work out at least an hour a day and often more if I am feeling motivated. Being active is the best way I can guarantee that I will be able to manage Rhonda's daily care needs'. Rod recognised that Rhonda's electric wheelchair was a mixed blessing which gave her greater independence, but unfortunately made her less active. No longer using her leg and arm muscles to manoeuvre a manual wheelchair, Rhonda's strength and flexibility declined. 'I found myself sitting in a chair all day and I felt my body getting weaker and weaker.'

Rhonda found out about the physical activities provided by the Socialisation Program through her care manager. She commented: 'I was really interested in the water aerobics and Adam's Fitness, but I was nervous at first about joining. What pushed me was the desire not to sit at home and vegetate. I wanted to get out and meet people'. Rod's involvement made it easier for Rhonda to participate in Adam's Fitness as there was someone to encourage her: 'Exercise isn't easy for me as

I am always in pain due to my arthritis. I don't like exercise. I used to walk short distances unaided but now I need help. Walking makes me feel good and motivated—that's why I like the water aerobics as it takes away the fear of falling.'

Friendships are the biggest other benefit Rhonda and Rod have received from the physical activity groups. Rhonda says I have found the groups to be a safe and supportive space where I have made some friends. I find myself giving encouragement to my friends around me to keep going with their exercise'. Friendship and exercise go hand in hand for Rod and Rhonda; a place to work out and keep fit, as well as social activity during the week to look forward to.

Sharing a table with friends: Gordon and Leonie

Leonie is a mother of four and the grandmother of seven children. Aged in her 70s, she has been managing multiple sclerosis for the past five decades. At 23, six months pregnant with her third child, Leonie became aware of her MS when she started to experience terrible unexplained symptoms. Blindness, fatigue, depression and a loss of sensory feeling ('I'd jump straight into boiling hot water and not realise it') became common experiences.

As expected, Leonie's MS has progressed and she is now confined to a wheelchair. Leonie lives at home with the help of her husband Gordon. 'I'm getting slower and I can't always do what I want. It's frustrating—I can't wash my hair; these little things.' Gordon and Leonie have been receiving care management services for the past 10 years from the Brotherhood of St Laurence.

Gordon and Leonie have been assisting the Socialisation Program since its inception two years ago. They are volunteers with the monthly social lunch groups held at the Provincial Tavern in Rye. Gordon, a retired manager of a local plumbing company, has always been community minded and jumped at the chance to help engage more socially isolated and lonely people in these groups. Gordon and Leonie facilitate the lunch by helping shy people enter into conversation. Gordon is a big believer in name badges and ensures that every person who attends wears one: 'Names are so important when it comes to meeting people; as we only meet on a monthly basis. There's nothing worse than asking a person who has been two or three times what their name is'.

Friendships have developed between many of the couples who attend the lunch groups. 'If people have missed a couple of gatherings we often give them a call to see how they are going. We find ourselves getting to know people well and if we can, we try and help, even if it is lending them a kind ear.' The lunch groups have become a starting point for many people who have been isolated to resume socialising, which often leads into other recreation and leisure activities. As Gordon explains: 'I remember Ivan. He was 90 years of age. He started coming to the Rye lunch group and over time his social life blossomed. David, a volunteer he'd met at lunch, started visiting Ivan regularly and he began attending Fleur's Music Group. It made such a big difference to his life, as in the past Ivan rarely received any visitors'.

The twice yearly Christmas functions that the Socialisation Program organises, Christmas and Christmas in July are special occasions on people's social calendar. Gordon, a founding member of the Client/Carer Group and a key organiser of past Christmas functions, has enjoyed the fact that people from the monthly lunch group sit together at one big table and share the festive cheer: 'I find it really special that we all want to be together on these occasions. It makes me feel good seeing all these people socialising; people that Leonie and I consider as friends'.

5 Findings

Clients and family carer focus groups

A number of themes emerged consistently across the client and family carer focus groups, and the material has been organised to identify both the different and common perspectives of clients and family carers in terms of their:

- experiences of social isolation and loneliness
- insights and understanding of the Socialisation Program
- reasons for participating
- personal barriers that prevented participation
- ideas about key improvement areas in the Program.

The dominant message from clients and family carers was the extent to which they valued the friendships they had gained through the Socialisation Program. Also, both groups perceived the same health and social well-being benefits from the program's recreation and leisure activities.

The major distinction for clients was that they felt marginalised by the wider community as a result of their illness or disability and they perceived their social isolation and loneliness as resulting more from this devaluation than from the physical limitations. Family carers, however, rarely mentioned care recipients' feelings of being marginalised or treated differently. Their own reasons for being social isolated and lonely centred on the multiple losses that came with the caring role, such as loss of friendships, independence and the intimate relationship they once had with the person they were caring for.

Life before the Socialisation Program

Clients

Clients perceived that their illness/disability had resulted in the wider community devaluing them:

> *I use a wheelchair. Some bits of me are 'missing', but not all of me. I'm still a person.*

> *If you are ill, you are on the shelf as a 'frail person'.*

These were common sentiments expressed by clients from the focus group. Disability and illness became the defining feature of who they were. This made it hard for people to remain connected to social networks that they had prior to becoming ill and disabled. They felt that friends could not get past the fact that they had a disability and were unable to continue with the relationship.

> *Friends say to call in anytime. But when I turned up on the doorstep one day, they did not introduce me to others who were there. My friend was embarrassed. I have never seen this friend again.*

> *Because I am ill, I lost contact with people I used to see. They don't know how to deal with my illness. They avoid me.*

> *People talk about you in the past tense.*

> *People don't know how to react to my illness. They take off—they walk across to the other side of the road to avoid me.*

The collapse of relationships that people had relied upon for emotional support led many into depression and to the feeling of being cut off from everyday social, recreation and leisure activities that they had once taken for granted. In one case, the daughter of a client was excluded from a birthday party:

> I overheard a mother speak to her child. This child wanted to invite my daughter to her birthday party. The mother of the girl didn't realise that I could hear them. She said '...you can't invite X to your party as X is 'not right'. I responded saying 'Your daughter is a better a person than you will ever be'. What we have is not contagious.

Many expressed the challenge of remaining mentally well in the face of this social exclusion.

> I was stuck in one room wondering 'what will I do?' It was sheer isolation which led me to despair.

> Spent a lot of time feeling sad.

> Depression. A real downward spiral.

> I was unable to go out. I was sociophobic.

Many clients were confronted with discrimination and hostility especially from neighbours, and in one case from a customer at a supermarket.

> When I got a walker [frame] and went outside my next-door neighbour said 'You should be in a home'.

> I was slapped by a child in a supermarket trolley because I was in a wheelchair. The mum did not apologise or take any action.

> My neighbours have made my life difficult—they taunt me.

Many felt as if they were a burden on society, had a contagious disease, or were directly responsible or at fault for their illness/disability. Clients considered that they had little choice but to remain at home and to go out only when it was absolutely necessary, such as for doctors' appointments, hospital visits, and rehabilitation. Several clients described their life and the choices that their disability afforded them as similar to the experience of a prisoner.

> After my injury, it felt like I was going to be contained within four walls for the rest of my life, incarcerated.

> I felt like a prisoner in my own home.

Clients' comments highlight the serious problem of social exclusion for people with complex care needs living in the community. The obstacle to engagement in community life was less the functional impairment or illness, and more the extent to which they perceived themselves as being marginalised and discriminated against by their own social network and the community at large.

Family carers

Family carers spoke about the difficulties of community engagement for themselves as well as for the person they were caring for. Considerable planning and preparation were always needed before venturing out. Many felt that the costs were too high when it came to the effort, and the feeling of pressure they felt they were under. Instead they remained at home.

A sentiment shared by many family carers is represented by this comment:

> *I had a reluctance to go out. There is so much to organise and set up. You have to prepare your loved one to go out (and that's all on me to do). It was easier to believe it was better to just stay home, to be housebound. You think is it worth it?*

A serious pressure was uncertainty about wheelchair access where they were going.

> *Access was always unknown. We had to do extensive 'homework' before you could go out.*

> *It was hard enough to access the bathrooms and doorways inside our own home, let alone contemplate access issues out in the community.*

Another common sentiment highlighted in the client group was the decline in friendships and the quality of family relationships.

> *We lost a lot of friends [post stroke/disability/incident]*

> *I changed from being carefree, dancing, laughing, entertaining visitors, to being very careful, worried and alone. I only felt safe at home.*

> *My family relationships became disjointed: my son will ring but he doesn't visit anymore—he just doesn't want to see his dad like he is now.*

> *I am alone. I have got no family.*

> *I couldn't have understood the isolation … if I wasn't living it. People stop coming. We had a full life, we'd been around the world and very active. It all stopped.*

Many commented on the overwhelming responsibility of becoming a carer and the new duties that came from changes to their life circumstances.

> *I was stuck—I had never driven before. My husband used to do it all.*

> *I used to go out for drives, but after [my husband's stroke] I could only drive around my own town. I was very nervous.*

> *Our social life stopped. We used to dance and we missed it all terribly when disability struck. I am still able, but my husband arranged all of our social life, so it stopped … for 10 years, until we got involved in the Socialisation Program.*

These accumulated disadvantages of caring for another—increased responsibility, social isolation/loneliness and the loss of a loved one's abilities—had important consequences for the family carer's physical and mental health.

> *My blood pressure was 230/150. I was in a bad way from the stress of everything and my doctor said I needed to be admitted to hospital—but my husband cannot be left on his own.*

> *I had a nervous breakdown two years after my husband's stroke. I thought I was coping well, but then I had panic attacks and needed anti-depressant medication.*

Experiences of the Socialisation Program

The experiences of the program shared by clients and family carers are similar in content. Both groups valued the friendships that they had made through the program above all other perceived benefits. Family carers emphasised how they enjoyed the time spent with their spouse participating in a leisure activity in the company of other couples who understood their needs. Clients highlighted the fact that they once again had some choices in their life and that the activities encouraged them to remain connected to their personal interests and to other like-minded people.

Clients

Some people valued the activities that they participated in and drew much of their worth from activities they had engaged in before their disability, while others uncovered new interests.

> *There is a great diversity of activities—I can reconnect with things I used to do. I grew up in rural Victoria with guns. When I went to the shooting range, I got a bullseye with my first shot. I was so chuffed.*

> *I have joined the Art Group. We had an art exhibition. We have sold art and had an art piece made into a postage stamp. It has made me feel so proud.*

> *I have discovered my talent in art, which is great for my self-esteem. I will keep doing art next year.*

Friendships were an important factor and lessened the stigma that often comes with a disability.

> *Everybody is on equal footing. I can relax more. There is no 'poor thing' attitude. We are sympathetic to other's disabilities. We can have fun with ourselves and laugh at ourselves.*

> *I have formed new friendships that I would not have otherwise have made. Most people are beautiful.*

> *We are family.*

> *People need to associate with others and we can.*

Clients noted the benefit of feeling more in control of their life.

> *It keeps us out of institutional care.*

> *It gives me inspiration to stay in the community, to do my best, to share and keep myself up to it, to have a go.*

Important program features identified by clients were the costs, transport, food, and the timing to meet their energy levels.

> *Great food. I go for the food.*

> *The program helps a lot with transport.*

> *Most activities are reasonably times (not too long or too tiring)*

> *Without the funding from Brotherhood I couldn't afford to do the things that I can in the Socialisation Program. I don't want charity, but sometimes I have no choice.*

The Socialisation Program meets client's needs on many different levels, providing leisure choices, closely matched to their interests, assisting them to overcome barriers and encouraging friendships within and outside the structured program.

Family carers

Family carers' experience of the Socialisation Program highlighted the feelings of belonging they gained from participating in the recreation, leisure and social activities. Many considered this to be respite from caring, even though they attended the activity with the person they were caring for. They highlighted the benefit of this type of respite in two ways.

Firstly, the activity was unencumbered by caring responsibilities

>*I can relinquish some of the care responsibilities—we share the care with paid carers and volunteers at these events.*

>*I like to be with my husband. I don't want to go by myself—we have a great time. It is the little things that make the program wonderful—there is the help from other people to push his wheelchair, move chairs out of the way. They observe me and offer help when I want it. It doesn't take so much effort when you have support. It is so social and wonderful.*

>*The program staff 'suss out' access—so I don't have to research anything.*

Secondly, it provided an outlet/escape from the caring role, particularly an activity that they could look forward to.

>*Movies are great for us. We sit back, relax and don't have to worry about getting frustrated—because my husband doesn't need to eat or speak (which is difficult for him), just relax and enjoy the escapism of the movie.*

>*I like to be with my husband. I don't want to go out by myself. We have a great time. It is the little things that make the program wonderful—there is help from other people to push his wheelchair, move café chairs out of the way. They observe me and offer help when I want it. It doesn't take so much effort when you have the support. It is so social and wonderful.*

>*It gives me something to get up for.*

The Socialisation Program over a period of time gave family carers the confidence to engage in community life and try different activities they would previously have avoided. The main reason for this confidence is knowing there is someone who can help. Family carers also appreciated the fact that care managers and the Socialisation Program staff would ring them prior to an event and encourage them to attend.

>*We need someone to give us a 'kick up the bum' and the program is just the thing I need to get out and do things.*

>*The program has extended my safety zone.*

>*The program has taken the fear out of going out—there's someone to help me. It gives me confidence.*

Social support was a key aspect of the family carers' experience of the Socialisation Program:

We enjoy going to a café after seeing a movie. We do smoke, so we sit outside—we used to sit by ourselves. It's such a lovely bunch of people we go out with. Now we are finding they will sit outside with us, so they can chat with us. It's lovely.

We learn that we are all in the same boat—we support each other.

We're already booked for the Christmas lunch.

I share my ability to help others—I can pick up another client and transport her to the Frankston Art Centre on my way.

Two of the family carers who often attend the Socialisation Program's physical activities such as swimming noted improvements in their health:

The program has had a definite positive impact on my blood pressure which was dangerously high. I have been swimming. I have accepted residential respite for my husband. I am still on medication, but today my blood pressure was a healthy 130/70.

My health has improved out of sight since joining the program. I have realised that my health is important. I have joined the exercise group two days per week—it is [for] over 60s. I am in a swimming program. I am firming up and I have lost weight.

Reasons for joining the program

Comments from clients and family carers made it apparent that the intervention of their care manager was a deciding factor in people joining the Socialisation Program. Family carers appreciated the encouragement from care managers and the time taken in talking through the activities that were on offer. Clients felt that their care manager gave them the push that was needed to get them started.

Clients

My care manager gave me the push. I was sick of the four walls and thought 'Anything will be better than this'.

I was heading toward being institutionalised while being cared for in the hospital. I joined the Socialisation Program to stop being put into an institution. The program is good for my sanity and therefore my independence.

Family carers

My care manager asked us to join. She said on her first visit that my husband could do something like clay shooting. He said 'No' and I said 'Yes it would be great'. Our care manager encouraged us and then my husband agreed. Our care manager put us on the Socialisation list.

At first we were overwhelmed—there was so much on the list to choose from. We were flooded with bits of information. It was easier[when the care manager] took the time to chat and then connected my husband's capacity, history and likes with the relevant bits on the program.

The pathway into the program for the majority of clients and family carers was through their relationship with the care manager. Importantly they trusted the care manager and this enabled the care manager to identify key areas where the Socialisation Program could add value to a person's quality of life.

Barriers to joining program

Clients and family carers emphasised different types of barriers that prevented them from engaging with the Socialisation Program. For clients these were was more structural barriers, such as lack of wheelchair transport and equipment. Family carer barriers centred on intra-personal barriers, such as feeling guilty about attending the program as they felt it should be more for the benefit of the person they cared for. They thought of respite as a chance to do tasks and jobs such as shopping rather than a break from caring.

Clients

Transport was the key barrier that prevented some clients from attending Socialisation Program activities; many clients in electric wheelchairs felt excluded due to the limited transport available.

> *It is hard to get a wheelchair in and out of the car.*

> *There are not enough maxi taxis and they are not reliable.*

> *If I have to arrange my own transport, it is too stressful.*

> *There is a new rule saying that we have to transfer out of our wheelchair and sit on a seat in the taxi.*

> *You need a truck to move my scooter.*

Family carers

Family carers' comments regarding the barriers that prevented participation were wider ranging and complex. Many of the problems could be categorised as relationship barriers, particularly where they had difficulty negotiating with the person they were caring for to attend Socialisation Program activities. This often led family carers to feel guilty about their own participation in the program.

> *It is difficult to know what my husband will enjoy—I need to try to find that out.*

> *My loved one feels embarrassed—he wants to do things and help out, but he can't.*

> *My husband doesn't want to do much and so recreation and leisure activities need to come to him at our home.*

> *My husband is young in his early 50s—he likes sport, footy and stuff that younger blokes do—he is not into the theatre and meals out.*

These barriers led to family carers feeling guilty when it came to leaving the person in respite, or by themselves at home. They also felt uncomfortable about participating in the program for their own social well-being needs. Family carers' perception of how they used their respite time was governed by their responsibility towards the person they were caring for and the belief that activities and tasks undertaken during that time must be in some way related to the person's well-being.

> *The only time I go out and do not feel guilty is if I am doing a job (e.g. shopping).*

> *My four hours of respite is used for things I have to do out of the home—like shopping, doctor's appointments etc. It is not used for recreation or leisure as I don't have any hours left over for that.*

> *I feel guilty asking for taxi vouchers to attend.*

> *I feel guilt all the time. Even to go for a quick coffee, even if I go somewhere close to home and carry the phone to be instantly contactable—I feel guilty.*

Another barrier that prevented family carers engaging in the program was the schedule of their personal care services. This made it difficult to commit to any activities that might disrupt their care services, especially as many were dependent on this assistance.

> *Getting out can be tricky to fit in between morning and afternoon paid shifts. I can cancel the afternoon shift but then I have to try to manage by myself when I get home.*

Financial constraints were another factor determining whether a family carer would attend the Socialisation Program activities.

> *I would love to go to the exercise program at Carrum Downs (where I was previously a helper in the program—helping out and making teas and so on), but I had to stop because of petrol prices going up, plus paying $5 for the activity. I didn't mind helping out, but it is just too expensive now, especially as I don't get much exercise while I am helping.*

> *It is difficult to juggle our needs with the budget we have. We needed to decrease respite hours from four hours a week down to three hours because we needed to use an extra hour on meals (which became critical).*

Family carers' comments underscored the complexity of their role, especially the emotional demands of caring for a person with complex care needs, and the daily living pressures, especially the scheduling and juggling of costs of care services in the home.

Suggestions for improvements

Clients and family carers had rather different ideas on how the Socialisation Program could be improved. Clients emphasised the need for more choices in the activities, but also the need to provide activities targeted to housebound clients. Family carers highlighted the need for care managers to continue encouraging reluctant clients to participate in activities. They felt that care managers held more sway over care recipients than they did when it came to seeking a commitment to joining the Socialisation Program.

Clients

Clients highlighted the range of activities that could be offered through the Socialisation Program:

> *Go to the Aircraft Museum.*

> *Go to Scienceworks [museum].*

> *More country trips*

> *Scrapbook group*

They also valued belonging to a group and expressed the need to maintain friendships outside the program's activities:

> *Better communication between us.*

> *More phone calls to say g'day.*

> *It would be great to see more individual linking and connecting community members [buddy matching].*

Transport was highlighted as a key improvement area, especially in the provision of wheelchair transport.

> *Thinking about increasing capacity so more people can join in—more people want to go, plus more people are in wheelchairs so we need a greater capacity to transport these people. At the moment we are missing out.*

Family carers

Family carers stressed that care managers were pivotal to engaging hard-to-reach, reluctant clients. They highlighted the value clients placed on their relationship with the care manager, which made them more receptive to suggestions about attending an outing/activity.

> *A care manager can speak under different terms to the client. They are not emotionally involved so they can make suggestions that wouldn't be acceptable if they came from me. Care managers can dig for their interests (e.g. ferry ride, fishing, stamp collecting) then arrange the activity in the immediate future—you need to get the person to take the bait quickly, hopefully enjoying a positive experience (based on their interests) and leading them to be more likely to go out again. Care managers have a very important role.*

Family carers emphasised care managers' role in facilitating access to self-help groups, which many felt were important to remaining well as carers.

> *Care managers can encourage clients/carers to join self-help groups. Care managers could give us the information (e.g. contact person, phone number, meeting times and dates) and transport help if needed. This makes it easy to follow up (if we don't have to do the research ourselves). The care manager can encourage and nurture us to explore self-help groups. This can end up being another form of social and emotional links with peers where issues can be shared and weights lifted.*

Some carers were uncertain about their eligibility to attend the Socialisation Program as it was primarily marketed to clients. This made them feel hesitant about participating.

> *I need my care manager to encourage my loved one and to back me up. Brotherhood needs to approach and encourage people to get involved. Ask the client to go and explain that everything is set up for them. Offer it to us so we don't have to ask for everything.*

Summary of views of clients and carers

The comments from clients and family carers reflect the strength of the impact of the Socialisation Program on people's lives. Stories include: people avoiding entering institutional care; moving away from a suicidal state; making new friends; getting out of the house for the first time in a long time; having reduced blood pressure; supporting other people to participate; having a social life after 10 years of 'nothing'; having a reason to get up in the morning; and, of course, enjoying the activity and having some fun.

Client comments began with the social and personal damage caused by social exclusion. These views were very powerfully expressed and give a sobering insight into what may accompany disability or illness: it may start with isolation and being shunned and develop into suicidal thoughts. Accordingly, the Socialisation Program has had a dramatic effect on people's well-being:

it starts with lifting despair or depression and extends to people feeling proud of what they are achieving.

Carers agreed that care managers were a major influence in people's decision to join the Socialisation Program. Every carer said that they needed their care manager's encouragement and help to find out about the history, abilities and likes of their loved ones. The care manager then could suggest matched activities, and provide reassurance that their loved one's needs would be met. Care managers also helped to explain the necessarily complex calendar of events that was distributed every three months. Care managers held a big responsibility in supporting carers to encourage them and their loved ones to join the program.

There were various barriers which limited people from participating, or which made it difficult to do so. These ranged from emotional issues (guilt, lack of motivation, feeling ostracised) to practical ones (such as no money for petrol, toileting issues, being physically housebound, health issues,). Another important area for the family carer was respite care, particularly longer periods of in-home respite that carers could use for recreation. Currently many carers used respite to give them time for practical day-to-day household tasks, such as paying bills or attending to appointments.

Care manager questionnaires

The perceptions and experiences of care managers assisted in assessing the influence of the Socialisation Program on the older people's health and social well-being. It also provided an insight into the extent to which the program has changed existing Brotherhood care management practices.

The Socialisation Program was viewed positively among Brotherhood Care Managers, who listed the following positive effects for their clients and family carers:

- increases motivation to try new things
- increases self-esteem
- builds sense of belonging to a group
- improves social interaction, social networks — making new friends
- provides respite for carers
- provides good choices for social activities
- assists financially disadvantaged clients.
- through small group size, gives clients the feeling of being valued members of the group. For example, clients have said that they don't feel like they are on a 'disabled group' outing—they feel less obvious to public, more like a group of friends—not like 'monkeys let out of their cages' for the day (client's words).
- promotes independence, provides more choices-and control over their own lives
- aids loss of weight (through particular activities)
- increases muscle strength (through particular activities)
- increases interpersonal relationships
- enables clients to access outings with family members
- increases quality of life
- reduces feelings of isolation and promotes greater sense of connection with community
- increases enjoyment in life
- increases confidence in participating in groups now and also catching transport by themselves
- empowers clients who have taken on tasks to assist with organising (and learned new skills such as computer use)

- provides opportunity for discussion of daily events, when partners participate in different outings
- brings a feeling of normality back into a life.

Links between participation in the Socialisation Program and quality of life

Care managers perceive that there is a strong range of benefits for Socialisation Program participants, covering a number of quality of life domains:

> *Some clients may have increased their use of health care due to a confidence leaving their residence. Other clients, particularly with mental health issues, have significantly reduced admissions to mental health unit and suicide attempts.*

> *One client has requested for her one-on-one socialisation hours to stop as she is now more confident to join outside activities and attend her health appointments herself which are now less frequent.*

> *…no true data can be observed at this stage in terms of reduction of ill health. However, a general increase in self-confidence, happiness and motivation has been evident in most clients who participate in socialisation activities.*

> *In some instances [the program] supports increased feelings of self-worth and increases preventative care rather than mopping up a crisis.*

Encouraging a holistic view

Care managers learned about other aspects of clients' lives rather than seeing them only as program recipients:

> *It has put socialisation as a concept on the agenda, and encouraged discussion with clients about their activities and networks generally, i.e., been able to encourage non-socialisation program options.*

> *Reinforces the holistic assessment principles.*

> *My background has been in socialisation so my practice is more focused upon looking at the emotional/social well-being of clients rather than just viewing them from a physical health perspective.*

Care managers found that more of their time was spent encouraging and actively linking their clients into Socialisation Program activities. Nevertheless they viewed this as a good use of their time. Over the long term, they could reduce their case management of a person if the person is connected into a social group or activity.

> *I have found that initially it takes more time assessing social needs and encouraging client to attend. Also time taking client to group and facilitating conversation initially. Reviewing and monitoring also time-consuming but this balances out when client becomes connected to others and involved in activity or and share interests and goals.*

> *More time initially equals less case management time dealing with sometimes petty issues that arise when client is bored and self-absorbed!*

> *I am definitely more aware and encouraging to clients about social program. It has broadened my thoughts regarding what services would be appropriate for certain clients. I am also more aware of certain clients who may be good to match with*

other clients. On assessment it is also a very good encourager for new clients as they always express keen interest. Might I add that it is more paperwork but I know it does pay dividends in long run.

My clients who have been involved with the program are more positive and seem to be more integrated into the general community. They appear to be more involved in their own lives. From a care manager perspective, I have found if the client is more socially confident, health status improves and they don't tend to rely and contact the care manager as often.

The value of the Socialisation Program to care managers

Care managers highlighted the following advantages of the Socialisation Program for themselves and their clients:

- The program is flexible, in terms of location of activities (for venue suitability) and the ability to cancel at short notice (due to client health changes).
- It allows friends or significant other/s to attend along with the client.
- Good lines of communication ensure issues arising around client supervision are effectively managed.
- The program supports holistic client care.

Improvements suggested by care managers

The care managers suggested improvements related to

- assisting participants to access activities independently of care managers
- more feedback about a client's functioning in Socialisation Program activities as a way of informing their care management. For example, if a client's self-esteem and self-efficacy increased as a result of the program, then the care manager could further assist the client to use these skills across other areas (such as contacting health professional or re-establishing family networks).
- developing training for volunteers, particularly for group facilitators. For example, since many clients had poor communication skills, activities could be socially awkward if the facilitator did not intervene. Managing and influencing group dynamics and communications are sophisticated skills. This task is even more complex when group members have differing levels of disability and health care needs requiring understanding and sensitivity.
- helping a person regain some social confidence before participating in the Socialisation Program. For example, a few care managers reported that they had [paid] carers take clients out for coffee and shopping, to help them feel comfortable in socialising.

6 Discussion and conclusions

This report has highlighted the problem of social isolation and loneliness for people with complex care needs and their family carers. Chronic disease and illness can weaken or reduce people's social networks and social supports that are essential to quality of life and well-being.

To improve the lives of disadvantaged socially isolated older people, particularly those with complex care needs, it is important that we encourage people to remain connected to their lifestyle interests and increase their friendship circles. This objective should be adopted as a component of case management goal setting and health promotion strategies.

The role of care managers in persuading clients and their carers to try activities that match their interests and to maintain their involvement can be vital in overcoming reticence and lack of self-confidence. However, it needs to be recognised that current funding levels are inadequate to meet the resource-intensive requirements of rebuilding such relationships. In addition, a number of structural barriers such as lack of wheelchair transport and personal care assistance limit community engagement.

Addressing social isolation needs to be given greater recognition within the residential and community care programs at the national and state levels. Socially isolated older people need to be recognised as a specific target population, and. specific pilot, training and evaluation strategies need to be developed and built into the state plan for the Home and Community Care Program.

Awareness of the relational and social network issues of socially isolated clients should be built into existing curriculum and training programs in the community care and care management sectors. The Case Management Society of Australia should be encouraged to consider the issue of social isolation and the development of case management practices as an area for program initiative over the next three years.

Consideration should be given by VicHealth and the Victorian Department of Human Services to funding training initiatives to raise awareness and improve the responsiveness of community care professionals to the problem of social isolation.

More generally, health promotion and active ageing strategies need to incorporate a social well-being framework into their scope of attention.

Conclusion

This study of a small sample of CACP clients of the Brotherhood of St Laurence has highlighted the significance of social isolation as an issue facing some CACP clients. It has identified a number of attitudinal and structural barriers to addressing this problem within existing programs. It argues that the quality of clients' inter-personal relationships is an important contributory factors to their overall social well-being and that this relational component has received insufficient attention. Addressing social isolation should be an objective of the CACPs and HACC Program. This issue requires policy focus, the development of clinical practice guidelines and education and training focus. A more concerted approach is needed to address the requirements of what appears to be a growing target population. With Australia's population set to age rapidly and the numbers of older people living alone, it is critical that as a community we work towards reducing social isolation and loneliness. This will achieve both better health outcomes and higher levels of quality of life for older Australians.

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Appendix: Socialisation program, activities and events

The Socialisation Program has developed a suite of recreation and leisure activities to maintain and build the protective factors essential for an older person's quality of life, functional independence and well-being. Activities have been developed to implement the health promotion priorities set by the Victorian Department of Human Services and VicHealth, particularly in the key areas of mental health and well-being, physical activity and nutrition. These activities operate through partnerships with local community health providers, particularly services recognised for their health promotion leadership and experience in the areas of nutrition (Community Kitchens Programs) and physical activity (Peninsula Health's Ageing Well Centre).

Table A1 Socialisation activities

Priority: Physical activity	
Adam's 1:1 Fitness	*Program aims*: to improve the confidence, skills and capacity of an older person to engage in regular exercise *Outline*: Fitness instructor works intensively with a person for 10 weeks, in consultation with their doctor and with direction from the Ageing Well physiotherapist. *Individual goals*: • increased strength, mobility, cardiovascular health • weight loss • improvements in key areas of daily living • increased motivation to exercise • engagement in a local community-based exercise class (Age Strong and Staying Stronger for Longer) after the 10 weeks
Somerville Water Aerobics	*Program aims*: to improve aerobic endurance, strength, tone and mobility particularly for people with soft tissue injuries or mobility problems.
Adam's Tuesday Fitness Classes	*Program aims*: to provide a social and supportive environment that enables clients to engage in individualised exercises with support and direction from a fitness instructor. *Program outline*: Tuesday classes aim to introduce clients to a wide range of new and enjoyable exercises, such as martial arts, boxing and ball sports that not only improves a person's strength and cardio fitness, but importantly their motivation to continue exercising. The class is suitable for people with a wide range of disabilities and mobility impairments, particularly people in electric wheelchairs.
Pathway to Activity	*Program aims*: to link older people into accredited and evidence-based community exercise classes, particularly Peninsula Health's Staying Stronger for Longer and Age Strong Exercise Classes. *Program outline*: Structured referral process for health professionals, especially care managers and community nurses to refer clients into community based exercise classes. *Goals* • to remove the common barriers (transport and companionship) that prevent older people from engaging in regular exercise • to improve the confidence and capacity of health professionals to locate community exercise classes suitable to the needs of their clients with complex care needs.
Rosebud & Rye Coastal Walking Program	*Program aims*: to increase the strength, fitness and social opportunities for older people with chronic health conditions and their family carers. *Program outline*: Supported by a trained walk leader and Royal District Nursing Service nurse and health aide, the walking program is a structured, safe and supported exercise activity for older people with mobility and chronic health problems.

Priority: Nutrition	
Community Kitchens (the Rye Provincial Kitchen)	*Program aims*: to increase older people's capacity to cook simple, nutritious meals cheaply in a social environment *Program outline*: The Rye Community Kitchen situated at the Rye Provincial Tavern teaches clients how to cook two nutritious recipes every week for the cost of $5 (pays for ingredients) in a social atmosphere. The project is based on a strong partnership with Peninsula Health, and Peninsula Community Health Services (PCHS) provide dietitian support, training and assistance to Brotherhood volunteers to facilitate kitchens for older people with chronic illness and their family carers.

Priority: Mental health and well-being	
Creative arts	
Red Hill Art Program, The Art Shed Gallery and 37 Passionate Friends for Art Sake (Cube 37, Frankston Art Centre)	*Program aims:* to create environments that support or foster healing, especially helping older people with their self expression as the arts enable people to communicate thoughts and emotions that at times may be difficult to express. The Creative Arts Programs aim to provide clients with • emotional and social support • psychological strength • opportunities to contribute to community through the arts. The program activities place a significant emphasis on adult learning and the development of friendships through artistic endeavour.
Music programs	
High Teas Concert Series	*Program aims:* to develop a sense of community around a shared love of music, particularly the important sense of being connected, of belonging to others *Program outline*: Every three months, Brotherhood and the Mahogany Neighbourhood Centre facilitate a community concert for older people living on their own or in residential aged care. Community groups provide the music and afternoon tea is supplied by volunteers and local bakeries, ensuring the event is low cost.
Fleur's Older and Younger Music Groups	*Program aims:* to develop emotional well-being, physical health, social functioning, communication abilities and cognitive skills through music. *Program outline*: Facilitated by Fleur Smith, music therapist and classical pianist, the two groups meet fortnightly and include family carers.
Social Lunch Groups	*Program aims:* to provide a social and welcoming environment for older people who have been socially isolated and lonely. It enables people to gain the confidence to re-engage with their peers and their community *Program outline*: Lunch groups are run monthly in Rye, Mornington and Frankston and encourage couples, particularly clients and their spouses (family carers), to come together for friendship and emotional support.
Day Trips, Musical Matinees and Movie Programs	*Program aims:* to provide a range of leisure opportunities for older people who require personal care, financial assistance and transport to engage in community activities, such as outings to museums and cultural events. *Program outline*: Day trips, musical matinees and movie groups are run monthly and are promoted through the quarterly Social Calendar.