



A shared journey

Insights from the
Banksia Younger Onset Dementia Support Group

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2015



**Brotherhood
of St Laurence**

Working for an Australia free of poverty

The Brotherhood of St Laurence is a non-government, community-based organisation concerned with social justice. Based in Melbourne, but with programs and services throughout Australia, the Brotherhood is working for a better deal for disadvantaged people. It undertakes research, service development and delivery, and advocacy, with the objective of addressing unmet needs and translating learning into new policies, programs and practices for implementation by government and others. For more information visit www.bsl.org.au.

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Finally, we hope that the evaluation illuminates the importance of developing services which work in partnership with people with YOD to enable them to live well with dementia.

Abbreviations

AAV Alzheimer's Australia Victoria

BSL Brotherhood of St Laurence

DHS Department of Human Services

HACC Home and Community Care

PAR Participatory Action Research

YOD Younger onset dementia

Summary

The Banksia Younger Onset Dementia (YOD) Support Group in Frankston, Victoria, was created by the Brotherhood of St Laurence in 2013 in response to an identified gap in services. Funded through the HACC (Home and Community Care) Growth Fund, the pilot project recognises that the social and personal needs of younger people with dementia and their carers are distinct from their older counterparts due to their stage in life when dementia is diagnosed. Moving away from conventional 'professional' 'service provision', the YOD Support Group recognises members as individuals with expert knowledge stemming from their personal experiences of dementia. It assists them to initiate, plan and engage in activities, maintain social links and raise awareness of YOD in the community.

The evaluation used a Participatory Action Research (PAR) approach to gain insights into how well the Support Group had achieved its intended short-term outcomes (first 12 months):

- members' participation in activities that are aligned with their interests
- established links with the local community and use of local community support
- increased number of members
- established links with relevant agencies and services
- slowing progression and delaying residential care
- a documented model of social and personal support that is transferable across other YOD-specific Planned Activity Group (PAG) programs

Key points

Participants reported the following:

- **a sense of ownership and belonging:** as the YOD Support Group activities were initiated by members, they felt a feeling of ownership and a sense of belonging.
- **a place of hope:** members reported that they have created a social environment that fosters hope and positivity through meaningful activities and positive socialisation with others in the group.
- **maintaining continuity:** the group enables members to maintain their routine and to continue engage in activities that interest them.
- **meaning and enjoyment derived from activities:** activities are initiated, planned and organised by members and reflect their personal interests and aspirations as well as the overall goals of the group.
- **a shared journey:** members reported the emotional benefits of being part of the group which included peer support, sharing experiences, information and concerns. As a result, a collective identity has been built on friendship, cohesion and trust among members.
- **a chance to be heard:** the group provides a forum for members' voices to be heard, as they direct it and share their personal experiences of dementia with the local community in Frankston.
- **a strong bond between staff and members:** staff have developed close, reciprocal and sustained relationships with members.

Background

The term ‘younger onset dementia’ is used to describe any form of dementia that occurs in a person under the age of 65 years. In 2011, an estimated 24,700 Australians under the age of 65 were living with dementia (Standing Committee on Health & Ageing 2012). With the ageing of the population, this cohort is likely to grow in the future, with wider implications for research, policy and for services in the socioeconomic and healthcare landscape.

Many are likely to be in the workforce when they notice the early signs of dementia which may lead to forced retirement and decline or loss of income (Chaston 2010). They are also more likely to have multiple roles within the family (carer, spouse/partner, sibling) and to experience feelings of loss, neglect, marginalisation and feelings of social isolation (Harris 2002). However, most available services are designed for older adults, and are located in the aged care sector (Alzheimer’s Australia 2007).

The program

The Banksia YOD Support Group involves people diagnosed with dementia who are aged under 65 and live in the City of Frankston or the Mornington Peninsula Shire. At the time this evaluation was conducted there were eight members whose ages ranged from 55–65 years and who are in early to ‘early late’ stages of dementia.

The model is founded on three key service delivery approaches. Firstly, the Capability Approach articulated by economist Amartya Sen emphasises capabilities—the opportunities a person has to live a life they value. Secondly, the concept of co-production requires active involvement and decision-making by the service user. Thirdly, the HACCC Active Service model involves service providers working together with service users to provide holistic care and support to maximise autonomy so the person can continue living in the community.

The group meets once a week from 9 am to 3 pm at Brotherhood’s Banksia Day & Respite Centre. The members are supported by two part-time group facilitators. The YOD Support Group is part of the wider dementia programs overseen by a coordinator.

A set of pictorial ‘Who am I?’ cards, designed by one of the group facilitators, is used to prompt members to identify their personal interests and skills. Members then choose and plan activities by group consensus. On-site activities or outings have included gardening, producing a short movie about YOD (the DVD project), painting and fishing. Additionally, group facilitators work with members directly to support their personal goals.

The research

Our literature scan on YOD revealed a poor evidence base capturing the subjective experiences of people with YOD. Furthermore, the voices of persons with YOD have been neglected in research, policy reviews and submissions. Recognising the importance and value of involving persons with YOD, this evaluation used a Participatory Action Research (PAR) approach to enable members to discuss and develop a program logic framework for the evaluation together with group facilitators, the program coordinator, senior manager and researchers. This evaluation includes feedback from four members, of whom three have been with the Support Group for over six months. It also captures the impact of the Support Group on members, spouses and staff.

During the year, two rounds of interviews were conducted with participants to track developments. The Alzheimer's Australia Victoria YOD Key Worker was also interviewed about current YOD services in Victoria and her observations of the YOD Support Group. A short survey was conducted with members to explore their opportunities to maintain their capabilities and their enjoyment of the YOD Support Group. Members were asked about their health, level of control in life, opportunities to help others and level of social interaction.

Research findings

All four members who were interviewed expressed their satisfaction with the freedom and choice that they had to initiate and develop projects within the group. They explained that the difference between the BSL YOD Support Group and other programs was that the group's activities had meaning because they were aligned with the personal interests and collective goals of members.

A sense of ownership and belonging

Members claimed the YOD Support Group as a space to call their own. This sense of ownership is reinforced through the projects that members direct, such as creating a garden at the Banksia Centre with flower beds, a water fountain and vegetables that were used in the kitchen. One member said:

We go out, we go to different places and we source you know the right sort of materials to put in the dirt, get it right, make it flourish. (Richard¹, 62 years)

Members have developed links with the local Masters hardware store, a local church and Mount Eliza Secondary College. As a result, members have received donations and discounted goods for their projects. Through these activities, the Support Group has enabled members to increase and exchange their social capital with the local community.

A place of hope

A recurrent theme was that the group brought hope. Hope among members takes many forms: hope about delaying progression of the condition, hope about maintaining autonomy and personal dignity, and hope for the future. Members are optimistic that being involved in activities through the YOD Support Group is beneficial for their mental wellbeing.

As one member explained, the group made him more positive about things and 'accepting that I have got the condition but also learning that I can still do things'. While previously he associated dementia with 'people who had lost it', he knows now that 'it is not the end of the world'.

Maintaining continuity

A person with dementia undergoes constant changes in cognitive and physical functions which cause difficulties at the personal, social and emotional level. For members, continuity stems from having a routine and having a space where they can be who they are and pursue their own interests. As a result, group activities and outings promote a continuation of self.

Tom remembered his early days after diagnosis as suddenly aimless:

I [used to] get up one day, what am I going to do today? I couldn't do anything. You get out of bed, you have a shower, put a pair of shorts on, sit outside in the shade. That was it. Apart from when she took me to the doctors or the hospital, I sat there in that unit 24/7.

¹ Names used in this report are not members' real names.

Of the YOD Support Group, Tom said:

It works. It makes it more like I'm going to work again.

Meaning and enjoyment derived from activities

Reinforcing members' sense of autonomy, staff encourage each person to make decisions, initiate and organise activities—which members have been happy to do. As a result, activities in the group have multiple dimensions. Stimulating activities such as gardening and the DVD project have enabled members to maintain existing skills, exchange knowledge and/or discover new skills and interests with guidance by staff. As one staff member commented:

[the group] unfolds very nicely each week and keeps them tuned by stretching their capacity and their abilities. (Staff member A)

The activities match personal interests:

Coming here I could put some of the good things out of my childhood like doing the garden. I used to do the gardening to help my father as a child. (Tom)

The garden project has also brought back good memories. Frank (56 years) recalled: 'Me cousin and I used to do the gardening together'.

For others, the group offered activities that they would otherwise not have pursued, such as painting:

That's what I have found with the Support Group. It's a place that I can go to where there was activity and do things I normally don't do on my own. (Richard)

At the collective level, activities present opportunities for members to make a positive contribution to others. This is evident in the sign that members prepared on the door that leads to the garden:

Please come out and enjoy our lovely garden.

This is further reflected in the comment made by one member about the garden:

The satisfaction of what we've created here as to what it was ... nicer when people start appreciating it. (Tom)

The short movie that members are producing has offered the chance to share their personal experiences of dementia with the community, while fostering empathy and hope for others living with younger onset dementia. Members are encouraged to steer the future direction of the group in a way that their goals and aspirations can be fulfilled.

Strong bond between support staff and members

An interesting feature of the YOD Support Group is the strong bonds that have developed between staff and members. One member described their relationship with staff as:

There is no us and them. (John, 64 years)

Taking on a facilitative role, the staff have ensured that members have the freedom to choose activities and outings. Richard commented:

They are just a guidance about what we need to do. It is more along the lines of how we are. What sort of things do you think you would like to do? They open the channels for discussion and thinking things through.

A shared journey in a supportive environment

The YOD Support Group has evolved into a place where mutual support, information and experiences are often exchanged informally. As a result, members have assumed a collective identity which has flourished ‘organically’:

One time in your life you really need people, when you get a diagnosis of dementia ... but you are also with other people who are exactly in the same situation as yourself. The only difference between them and me is that they have partners. (Richard)

Friendships, cohesion and trust have helped to create a social environment that is safe, inclusive and enabling for all members.

If you are wandering around the road a little bit and not quite sure what’s going on, someone in that group will find you and bring you back. It seems to work that way. (John)

Members appreciated the emotional benefits of peer support, sharing experiences and concerns, giving and receiving advice and learning about dementia. They have become interdependent, brought together by a common challenge.

A chance to be heard

Giving persons with dementia a voice is critical (van Genipp et al. 2014) and the YOD Support Group offers members the opportunity to exchange their life stories and their experiences of dementia with staff and with each other. It also enables members to play an educative role in the wider community. In this respect, interacting with students at Mount Eliza Secondary College has been valuable as members are collaborating with students to produce a short movie:

Even now the small interaction we have had with the kids, they have a far better understanding of dementia ... and if we can do that with the students, I think we have achieved an awful lot. They get an understanding, they talk to the parents ... so it sort of blends over. (John)

Discussion and opportunities for development

There are several services locally and overseas that are similar to the Banksia YOD Support Group model. For example, Melbourne City Mission Clubhouse for people living with an acquired brain injury and People Relying on People (PROP) in South Yorkshire, England, resemble the BSL YOD model in that they encourage the active involvement of members in the design and development of the group while supporting them to fulfil their social needs and interests.

A hallmark of the Support Group is the readiness of staff to incorporate member input to the model. The group mobilises the human and social capital of its members to promote shared learning between members and staff, which in turn leads to consumer empowerment. This has yielded positive outcomes such as close, sustained relationships built on trust and mutual support between staff and members, and also between members. It remains uncertain how the group will be affected by changes of members or facilitators.

The BSL YOD Support Group highlights the benefits of working with service users and their carers in partnership to understand and address their support needs and aspirations with the goal of supporting individuals to live fulfilling lives. It further reveals the need to shift from traditional service provision by recognising service users as individuals with expertise and assets.

During the interviews members suggested several enhancements:

- allow more time for members and group facilitators to plan and prepare for potential projects
- include timelines for projects
- allocate a weekly time for members to discuss with group facilitators private concerns related to dementia
- support members to plan and respond to changes related to dementia. It was suggested that a project on 'How to deal with the future' would encourage members to discuss and assemble information and resources.

A carer suggested that introducing an extra day would add to the benefits for members.

The evaluation identified several challenges which intersect at the social, personal and the organisational levels and which are worth considering in future development.

- Should age, stage and functional abilities matter for a YOD Support Group?
- How could the YOD Support Group support the needs (such as personal and social needs) of current members in more advanced stages (with different cognitive and functional levels) of dementia?
- How could the Brotherhood respond to younger people who are in more advanced stages of dementia?
- How could the YOD Support Group actively engage with carers to support members and carers through the progression of dementia?
- How could the YOD Support Group reflect the voices and opinions of its members who are in their advanced stages of dementia?
- How could the YOD Support Group involve members in refining the current model?
- How could the YOD Support Group ensure that the model is adaptable across other YOD services?
- How do intangible features such as staff attributes, personality, morale and culture impact on the model's adaptability and how receptive would other YOD services be to a model that is built on sharing power and decision-making with service users?)
- How can the YOD Support Group ensure the sustainability of the model?

The effectiveness of the BSL YOD model rests upon the receptiveness of both staff and members to a model that is built on sharing power, influence and decision-making. It is worth exploring how such factors would impact if the approach were to be replicated across other YOD services. The challenge for both members and staff in the long run is to ensure the success of the group is carried into the future.

1 Introduction

We dance together, each of us adjusting our steps as we adjust to each new challenge of dementia. And we need to watch the musicians – the care network. Professionals, family, friends provide cues and support for our dance with dementia. And they should be watching us dance, not playing their own music! ...

By accepting this journey of change and adaptation, we can dance with dementia and choose a new life in the slow lane (Bryden 2005, p. 165)

The Brotherhood of St Laurence (BSL) Younger Onset Dementia (YOD) Support Group was created in 2013 as a pilot project to provide social and personal support to people living with YOD. Response to an identified gap in YOD-specific services, it recognised that the social and personal needs of people with YOD and their carers are distinct from their older counterparts due to their stage in life.

The YOD Support Group is funded by the HACC (Home and Community Care) Growth Fund from the Department of Health, Victoria. The group comprises people diagnosed with dementia who are under the age of 65 and live in the Mornington Peninsula Shire or the City of Frankston. Members are supported to initiate, plan and organise activities related to their personal interests in a safe and comfortable environment, to maintain social and community links and to raise awareness of YOD in the community.

The Support Group model is founded on three key service delivery approaches: the Capability Approach, the concept of co-production and the HACC Active Service Model.

A participatory evaluation process was used to gain insights into the experience of members and their progress towards the outcomes that were initially set out by both members and staff. It drew on input from members as well as spouses, group facilitators, the program coordinator and the senior manager. The evaluation report provides a brief background to dementia, introduces the Banksia YOD Support Group and presents the themes that emerged from discussion of members' experiences. It then considers these findings in the light of the social needs of people with YOD and the gaps in current YOD services, and compares the Brotherhood's YOD Support Group with other local and international models. Finally it makes recommendations for the group's ongoing development.

Context

Dementia is used to describe a large range of illnesses that are characterised by cognitive deficits (American Psychiatric Association 1994) and affect a person's functioning (Alzheimer's Australia 2005). The condition affects a multitude of brain functions, including perception, memory, personality, thinking, behaviour and cognitive skills (AIHW 2012). The most common type of dementia is Alzheimer's disease, followed by vascular and other forms.

Dementia is both irreversible and progressive (Beattie et al. 2002). The stages of dementia can be classified as mild or early stage, moderate or middle stage, severe or late stage dementia (AIHW 2012). Dementia mainly affects older people but 2 to 10 per cent of all cases are estimated to start before the age of 65 years (ADI 2014). The term 'younger onset dementia' is used to describe any form of dementia that occurs in a person aged under 65 years.

The global prevalence and incidence² of younger onset dementia are uncertain, as ‘there is a lack of reliable epidemiological data’ (Beattie et al. 2002, p. 207). While there are notable gaps in the data collected in Australia (AIHW2014), in 2011 there were an estimated 24,700 Australians under the age of 65 living with dementia (Standing Committee on Health & Ageing 2013). Younger onset dementia is difficult to diagnose and it is often misdiagnosed by health professionals (Kinney, Kart & Reddecliff 2011) as depression or a mental health disorder (Alzheimer’s Australia 2007). Not only do difficulties and delays in diagnosis affect a person’s ability to access appropriate support services but also they can complicate the impact on an individual’s life and life decisions. Being diagnosed with dementia at an early age can affect a person’s social, emotional and financial situation.

A survey of the literature shows that there is still a lack of consensus among researchers whether it is essential to have specialised services for people with YOD. While younger people with dementia experience different needs and challenges, the ‘distinctiveness’ of such needs tends to become blurry with the progression of the illness. Furthermore, it can be argued that having specialised dementia services based on age could promote ageism. This ongoing debate on the significance of age and stage in dementia is yet to be resolved (Kinney, Kart & Reddecliff 2011). Nevertheless, younger people experience distinct needs and challenges in addition to the needs that they share with others living with dementia (Harris 2004).

Therefore, it is important that service providers recognise that younger people in the early stages of dementia may not fit in to mainstream dementia services. Support networks and appropriate services play a vital role in counteracting the social consequences of dementia.

The hallmarks of a model of ‘good practice’ are seen in services that support individuality, encourage socialisation, member-driven activities, identify a person’s strengths, values and understand their life stage, interests, relationships and life history’ or in other words, services that are ‘flexible, holistic and strength-based’ (Thompson 2011, p. 18). A number of YOD programs have been credited by Thompson (2011) as examples of good practice. However, it is unknown whether some of these programs still exist.

Services that have been recognised as ‘good practice models’ in Australia include:

- Mercy Community Care Younger Onset Social Support Service and Day Program (Waitara, New South Wales)
- Chesalon Younger Onset Social Support in Avalon, New South Wales
- Hunter (region) Younger Onset Working Group
- Alzheimer’s Australia Linking Lives Project (Victoria)
- Melbourne City Mission Compass Clubhouse for people living with an Acquired Brain Injury.

Some innovative features of these programs are

- integration with other services so members and their carers can access counselling, carer support groups, dementia day care programs, etc.
- client decision-making about activities and outings, facilitated and supported by staff

² Prevalence is the proportion of those with the disease in a given population and provides a snapshot, of the impact of the disease at a given point in time. Incidence is defined as the rate at which new cases occur in that population and is therefore a measure of risk of developing the disease. Prevalence and incidence are closely linked, prevalence being the product of incidence and duration of the disease episode (ADI 2014).

- active involvement of users in the daily affairs of the service (for example assisting with administration)
- active involvement of members in all levels of decision-making and steering the future direction of the service
- age-appropriate activities
- the use of community support
- YOD-specific staff training
- positive social networks and peer support groups
- participants sharing experiences, building social relationships and maintaining or increasing physical activity.

All of the above-named programs are activity-based programs that encourage social participation and positive socialisation. They cater to the social needs and interests of people with YOD and those with cognitive impairments. The Melbourne City Mission Compass Clubhouse³, in particular, provides members with greater influence and a sense of autonomy by enabling them to work alongside staff. It also supports members to rebuild their lives by enhancing their work and life skills, to participate in the community and to be part of a peer support network.

Good practice overseas

There are several notable overseas services for people with YOD, particularly in the United Kingdom. PROP (People Relying on People) in Doncaster, South Yorkshire, The Clive Project in Oxfordshire (also known as YoungDementia UK), ACE Club (also called Glen Devon Day Club) in Denbighshire in Wales have been identified by Thompson (2011) as models of good practice.

PROP

PROP is a self-help group that was initiated by a nurse with personal experience of caring for a relative with YOD (Thompson 2011). Believing that service users should be given the opportunity to make their own care decisions and choose services they wish to receive, she encouraged users of YOD services and their carers to establish the PROP group (Chaston 2004). The group challenged the traditional assumption that people with YOD are passive recipients of services and are incapable of expressing their own views. PROP members directed their own affairs and were involved in directing the group. They promoted socialisation, engaged in social activities, exchanged peer support and gave presentations at local conferences. They produced a DVD, followed by a booklet to help the general public understand the needs and experiences of people with YOD and to reinforce a positive attitude towards them. They helped to redesign care plan documents by removing professional jargon, making them comprehensible for YOD service users. They also devised their own information leaflets and worked to demystify the terminology attached to YOD (Chaston 2004).

After more than 14 years in operation, PROP has been dissolved. Smaller community groups have emerged from the work carried out by PROP and it appears that these have reduced the need for a central organisation (RDASH NHS Foundation Trust 2015).

³ Melbourne City Mission, 2014, Compass Clubhouse, <http://www.melbournecitymission.org.au/services/disability-services/living-with-an-abi/program-detail/compass-clubhouse>

The Clive Project

The Clive Project, which began in 1998, was named after Clive Beaumont, an Oxfordshire resident who had been diagnosed with YOD in his forties and had found limited support that was suitable for him and his family. He died in 1999 at the age of 51. Clive's experience had revealed a considerable gap in services. Inspired by his story, a group of people convinced the local Alzheimer's Society to recruit a development worker to research the local needs of people with YOD. The Clive Project provides individual support for people with YOD. It also includes a family service, a club and a café. The project was renamed Young Dementia UK in 2010 (YoungDementia UK 2014).

The ACE Club

The ACE Club, which began in 2002, was developed by a mental health nurse commissioned by the local Alzheimer's Society. ACE stands for: Autonomous, Confident, Empowered; Activity, Companionship and Enjoyment; and Awareness, Care and Education (Thompson 2011). The club is for younger people living with memory problems due to Alzheimer's or other related conditions; and it also involves their partners and family (ACE Club 2015). Through a variety of social and recreational events, it offers members the opportunity to share experiences, develop relationships with others and exchange peer support (Thompson 2011). Members also give talks and presentations about living well with YOD, at community and professional events. Although the club lost its funding in 2009, it is currently supported by donations and funds raised by volunteers and members (ACE Club 2015).

All of these services provide ongoing emotional and practical support, information, referral and socialisation and are built on the themes of empowerment, confidence, enjoyment and companionship.

2 Methodology

The evaluation of the YOD Support Group used a Participatory Action Research (PAR) methodology. PAR involves a collective and self-reflective inquiry by both researchers and participants (Baum et al. 2006). It is a collaborative effort with the aim of producing knowledge and action that are directly useful for the community (Boulton & Gifford 2012).

The reason for using a PAR methodology in this evaluation is that it recognises the importance and value of involving people with YOD in research and evaluation design (Pipon-Young et al. 2012; Cantley, Woodhouse & Smith 2005; Brown et al. 2012; Cheston, Bender & Byatt 2000). While a number of literature, service and policy reviews on YOD have been conducted (see for example Thompson 2011), very few have actively involved people with YOD in the design. This represents a clear gap in the literature and the service delivery related to YOD.

Program logic

The evaluation is built on a program logic framework that was discussed and developed by members of the group, group facilitators, the program coordinator and senior manager together with researchers in September 2013. The first part of the meeting involved a visioning exercise to capture an overall shared vision for the YOD Support Group.

From a set of pictures, participants were asked to select one that matched their ideas about the YOD Support Group. They were then asked to describe the picture, explain how it made them feel, discuss what it said about the program and choose the most important word about how they saw the program. The exercise produced visions of the YOD Support Group from a number of perspectives.

This was followed by an open discussion on the personal and social needs of people with younger onset dementia, and their expectations for the YOD Support Group. Through this discussion a set of desired outcomes for the group was identified by participants.

Short-term outcomes

The short-term (first 12 months) outcomes for the Banksia YOD Support Group are:

- members' participation in activities that are aligned with their interests
- links established with the local community and use of local community support
- increased number of members
- links established with relevant agencies and services
- slowing progression and delaying residential care
- a documented model of social and personal support that is transferable across other YOD-specific Planned Activity Group (PAG) programs.

Longer term outcomes

The medium-term outcomes (1–2 years) for the group are:

- promotion of Banksia YOD Support Group through articles and other materials for publication
- established pathways between care, support and relevant services
- improved referral systems and support for people with YOD in the local area
- development of a practice guide for the use of other YOD services
- improved and measurable care support outcomes for people with YOD.

In the long term, the group plans to create greater understanding of the many aspects and experiences of dementia among people living in the community.

This evaluation report focuses on how far the short-term outcomes have been achieved.

Interviews

Subsequent to the program logic, one-on-one interviews were conducted in two stages (February 2014 and October 2014) with four members, two spouses, group facilitators, the program coordinator and the senior manager to track the development of the group and to gather data. An interview was also conducted with the Alzheimer's Australia Vic. YOD Key Worker to discuss the YOD services that are available in Victoria and her observations of the Banksia YOD Support Group. A short survey was conducted with members to explore the opportunities that they have to maintain their capabilities.⁴ Members were asked about their health, level of control in life, opportunities to help others and level of social interaction. The survey also included questions about the Support Group to determine the level of member satisfaction.

Research ethics

The evaluation project was approved by the BSL Human Research Ethics Committee. All research participants were presented with a plain language statement outlining the purpose of the research and a consent form explaining their rights.

Limitations

At the time the evaluation was conducted, eight members were active in the YOD Support Group. This evaluation is based on the views of four members of whom three had been with the group for over six months. By chance these members were all male, so the study cannot shed light on any possible gender differences in response to the program.

An issue that members, particularly, wished to examine through the evaluation was whether services such as the Brotherhood's Banksia YOD Support Group could delay the progression of dementia. While this is an important aspect of dementia services that requires attention, it is beyond the scope of this evaluation.

⁴ Most survey questions came from the interview questions used for the Brotherhood's Enhancing Capabilities project.

3 The Brotherhood's Banksia YOD Support Group

Central to the YOD Support Group was the recognition that there was a lack of services specifically for people with younger onset dementia. People living with YOD are a relatively small group and are often overlooked by service providers. As a consequence, most people with YOD are either absorbed into dementia programs developed for older adults or fall through the cracks of the service system. Equally important for the creators of this pilot project was the recognition that people with YOD have a distinct set of needs, challenges and experiences due to their stage in life. Moving away from the conventional roles of professional service delivery, the Brotherhood's YOD Group recognises members as individuals with expert knowledge to offer stemming from their personal experiences of dementia.

The YOD Support Group meets once a week from 9 am to 3 pm at the Banksia Day and Respite Centre in Frankston. Activities and outings to date have included gardening, fishing, excursions (a visit to a motor show, walks) painting and producing a short movie about YOD (DVD project). These take place both on site and outside the Centre to accommodate the interests of all members. The group facilitators also work directly with members to support their personal goals. Members choose activities and outings by group consensus.

Members

At the time the evaluation was conducted, eight members (five men and two women, all aged 55–64 years and living within reach of Frankston) were participating in the Support Group. Most were living with their partners/spouses.

Six members had been diagnosed with Alzheimer's disease and the remaining two were unable to specify their type of dementia. Members had received their diagnosis between 2008 and 2014, and the average age at diagnosis was 56 years. Members represented stages of dementia from early to 'early late'⁵. Of the eight members, two had been in the group since its beginning, two for over six months, and the remaining members for less than six months.

Two of the group members also participate at the Men's Shed in Carrum Downs and another member in the outings program at Brotherhood's Nexus Community and Respite Disability Services.

Although the group had started slowly with just two members, it had grown to eight by late 2014. This increase was due to staff liaison with external services. The group receives referrals from the Cognitive, Dementia and Memory Service (CADAMS), AAV YOD Key Worker Program and Commonwealth Respite and Carelink Centre in the Eastern region.

During the year a couple of members with more advanced dementia had dropped out of the group after a short period: one moved into permanent care and the other was introduced to the Banksia Centre's dementia day program after staff noticed that she became anxious during group activities.

Staff

The group is supported by two facilitators and is overseen by a program coordinator and the senior manager of the Banksia Day & Respite Centre, which delivers a range of dementia care programs including overnight respite and in home support services. Both group facilitators have extensive

⁵ A staff member used the term 'early late' stage to describe the onset of the third, advanced, stage of dementia.

experience in providing dementia care. They are employed part-time and work with other dementia day and respite programs at the Banksia Centre as well as in the community.

Principles underlying the model

The Brotherhood’s YOD Support Group is governed by three principles. Firstly, it is modelled on the Capability Approach of Nobel Prize–winning economist Amartya Sen. At its core is the principle of enabling members to maintain their capabilities to live a life that they have reason to value. Secondly, the group is based on the concept of co-production, which ‘emphasises that people are not passive recipients of services but have assets and expertise which can help improve services’ (Needham & Carr 2009). From its very beginning, the group was shaped by the input provided by its members; it was also envisaged that members would be actively involved in its future development. Thirdly, it follows the HACC Active Service model, which is built on the notion that services should work in partnership with the service user to provide holistic care and support to help them gain the highest level of independence so as to continue living in the community (Department of Health 2014).

A model based on the Capability Approach

The Capability Approach was originated by Amartya Sen, Nobel prize–winning economist, as a way of better understanding how to recognise and address disadvantage. According to Sen, capabilities are the opportunities a person has to live a life they have reason to value and to choose to be and to do what makes their life worthwhile and meaningful.

The Capability Approach has four key elements (see table):

Table 3.1 Key elements of the Capability Approach

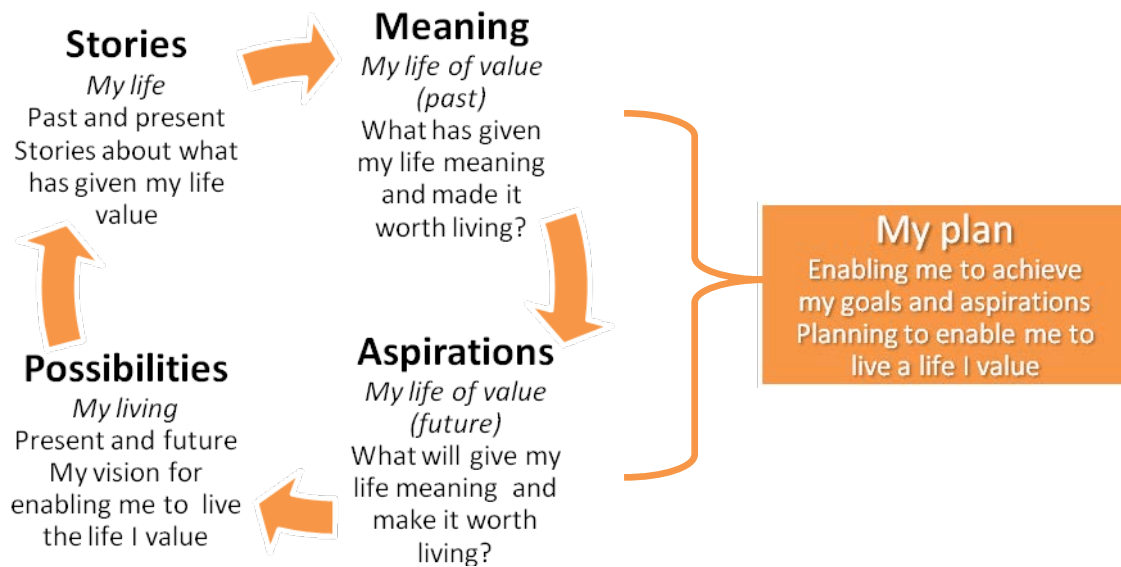
Opportunity	to be and do what you value
Choice	to have multiple opportunities to choose from
Freedom	to live in an enabling environment
Agency	to decide what’s best for you

Source: BSL Retirement and Ageing Division 2014 (unpub.), Practice guide: The Enhancing Capabilities Approach for working with older adults.

Sen does not specify what the most important capabilities are, but argues that they depend on culture and context; however he warns against what he terms ‘adaptive choices’, which people may settle for because they see no other possible opportunity or think they are not worthy of better (Nussbaum 2011).

The Brotherhood of St Laurence Retirement and Ageing Division has chosen the philosophy and principles of the Capability Approach to establish the ‘Enhancing Capabilities model’ and training program for all staff (see Figure 3.1).

Figure 3.1 The Enhancing Capabilities model



Source: BSL Retirement and Ageing Division 2014 (unpub.), Practice guide: The Enhancing Capabilities Approach for working with older adults.

At the heart of the YOD Support Group is its emphasis on enabling and enhancing the capabilities that are valued by people living with younger onset dementia. One application of the Capability Approach is the use of ‘Who am I?’ cards, a set of pictorial cards designed by one of the group facilitators to discover the skills and interests of members, what they valued in the past, and what they would like to be involved in now and in the future. The pictures encourage members to reminisce, reflect on what gives life meaning and what they value in their lives. Interests are often identified through members’ life stories. Group facilitators work with each member to develop a ‘My Plan’ that explores the activities and options which they could take part in either within or outside the group and which would help them achieve their personal goals and aspirations.

Co-production

The YOD Support Group is also grounded in the concept of co-production, which calls for ‘active involvement and decision-making by the person using the service’ and ‘outcomes [that] are achieved through person-centred relationships on the frontline rather than mechanised service-centred delivery’ (Needham & Carr 2009, p. 3). For co-production to be effective, both providers and service users need to be empowered; they should be open to sharing power, resources, partnerships, and be open to the risks and possibilities of this transformative process (Needham & Carr 2009). Group members initiate, plan and organise activities and projects that bring meaning to their lives. Most importantly, members are able to steer the group towards fulfilling their goals.

The Victorian HACC Active Service model was influenced by service delivery models found in England, New Zealand and Western Australia. It is centred on the provision of care and uses a combination of approaches (restorative care, family and person-centred care, active ageing). It supports service users to maintain their independence, improve physical and mental health and make their own care decisions (DHS 2008).

4 Findings

This section presents members' perspectives on the YOD Support Group, complemented by input from spouses, staff and the AAV YOD Worker. The findings are based on information gathered during interviews.

A sense of ownership and belonging

Members claimed the YOD Support Group as a space to call their own. This sense of ownership is reinforced through the activities that they themselves direct, such as the garden project at the Banksia Centre which involved creating flower beds, installing a water fountain and growing vegetables to be used in the kitchen. The garden has been a very important project to which all members have devoted much time and effort. Many of the flower pots, materials for the vegetable beds and the water fountain were sourced by members with help from staff, as 62-year-old Richard⁶ explained:

We go out, we go to different places and we source you know the right sort of materials to put in the dirt, get it right, make it flourish

Members have reached out to the community to gather support, for example by creating new links with the Community Liaison Officer from the local Masters store. They have been able to capitalise on this relationship by seeking donations and discounted goods for their garden. Members also secured a baptismal font from a local church: it is now used as a water fountain in the garden. Through these activities, the Support Group has opened up opportunities for members to increase and exchange their social capital with the local community in Frankston.

This sense of ownership was underlined by a staff member:

[A member] organised his trailer to bring, get the water feature over here. So that was all done within the group. And the water feature actually turned out to be a recycled ... baptismal font from a church. So they actually then also spoke to the minister to ask if they could use this baptismal font ... then they told the minister about the group and what they are trying to do.

Activities also extended outside the group, as Carol, a carer and spouse, reported:

He had some seeds at home and because he hasn't really got time to do them here, he's made like a little lean-to with the help of my son-in-law and put them in some soil and got them starting and growing to be able to bring them here.

Members' feeling of connection with the physical environment has contributed to their sense of ownership and belonging. The Support Group was initially set up in a community house, which staff considered to be a more 'home-like' environment for members. Interestingly, over time, members preferred to base themselves in the Banksia Centre. It appears that the physical environment at the Banksia Centre offered more scope for creative activities both in the garden and indoors.

As the AAV YOD Key Worker mentioned, this sense of ownership is displayed by one of the members describing the group as 'his' Support Group. This indicates a degree of attachment, emotional connection and belonging that is associated with feelings of ownership.

⁶ Names used in this report are not the members' real names.

A place of hope

I think that hope that burns so brightly at the core of the group. It's almost like this flame, if you would like to say, of inspiration and 'We are here, we are together and we are, you know, going to make it, we are going to learn what it's like together'. (Staff member)

Hope and self-determination resonate through all the conversations between members. It has been observed that hope can be triggered in the face of uncertain and stressful situations in life and hope can also 'act as an energising and motivating influence on a person' (Wolverson, Clarke & Moniz-Cook 2010, p. 451). In the Support Group, hope can be seen in many forms: hopes of maintaining independence and personal dignity in the midst of changes, and hopes for the future (see Richard's story). The activities that members choose to take up have a very personal dimension. Members remain hopeful that being engaged in activities that require mental exercise and stimulation will play some part in delaying the progression of dementia. They are determined that being active and having social interaction can be beneficial for their mental wellbeing. In this regard, the DVD project has been interactive and mentally stimulating. The short movie will bring together members' experiences of diagnosis and living with dementia. The script is being written by members and the movie produced by students at the Mount Eliza Secondary College. Members are hoping to produce a longer version to distribute to the general public. When Richard was asked about the importance of the DVD, he replied that 'It makes you use your brain'. For him 'keeping himself busy and happy' is crucial and a diagnosis of dementia is not the end.

Richard

Richard, now aged 62, had a distinguished career in protective services, starting at the age of 17 and rising to a high rank. Talking about his experience during diagnosis, Richard reflected on the pain he felt when he was informed that he had dementia. Richard explains that being told to give up driving was what 'hurt me more than the actual diagnosis'. He says: 'It should have been the diagnosis that worried me more. Just not having that ability to drive a car around you know just hit me and I couldn't think it through'.

Driving, for Richard, represented independence, which he has now learnt to maintain by having an active life. He loves golf and continues to play with his friends. He retains a strong sense of self-determination and hope. For him 'the only weapon' he has against dementia is 'his positivity'. For Richard being independent and maintaining his personal dignity in the face of the disease is crucial. He is hopeful that the activities that he engages in at the YOD Support Group will contribute to delaying the progression of dementia.

Looking back, he recalls many encounters with people with dementia during his days in protective services:

If you had asked me even two years ago what does it mean to have dementia, I couldn't have told you. And I have dealt with people with dementia in my former career and I would have said 'people who had lost it'.

He knows now that 'It's not the end of the world to have dementia'. There is a clear shift from Richard's previous views on dementia which he associated with 'people just sitting in dressing gowns' in 'gloomy looking nursing homes'. The YOD Support Group influenced him to be 'more positive about things and accepting that I have got the condition but also learning that I can still do things'. He comments:

This support group has been the most important thing. I don't know how I would survive without one. It's the best day of the week for me. Just that one day of the week is worth the whole week.

Richard now has a new outlook on dementia. The message he would like to spread to others living with dementia is that 'really in the end, it's going to be about hope'.

Christine Bryden, who has lived with YOD and is an ardent advocate for others, was invited by members after they had watched a documentary about her on national television. Christine's visit was a deeply emotional affair for members because she is a source of inspiration and hope. Members regarded her visit as an opportunity to learn about coping and responding to changes related to dementia and to draw on her lessons of living with dementia.

Hope is not solely about the immediate present. Hope can also be 'a strong emotional longing directed towards something that is valued or important' (Wolverson, Clarke & Moniz-Cook 2010, p. 451) as seen in John's experience (see panel).

John

Before his diagnosis of dementia, John owned a lucrative advertising business and spent most of his time travelling in Australia and producing advertising campaigns for high-profile clients. He recalls the satisfaction he felt after a successful campaign launch, and how clients would send him expensive boxes of wine or organise a helicopter ride to the Melbourne Cup Day to show their appreciation. John now associates this same level of satisfaction with making toys out of wood. He said that 'there is a satisfaction in seeing the kids with the toys ... the kids love it and it's helping me.' John is filled with delight as he explains that he made toys last Christmas and has started on around fifty toys for this Christmas.

John then slips into his past, to the days when his son was growing up.. He speaks fondly about a wooden crocodile that he made for the boy. He describes how much the crocodile meant to his son and that he would refuse to go anywhere without it. With a smile across his face, John tells how his son referred to the crocodile affectionately as 'crocodilly'. This is a significant memory from John's past, and resonates with his future aspirations. John often says that his biggest concern is not being able to know his prospective grandchildren and to have a place in their lives. Making toys for children is associated with this deep desire. John hopes to realise this very personal aspiration by finding a way to pass on his life stories and memories to his grandchildren. He remains hopeful that this can be achieved through the help of others in the group.

Maintaining a level of continuity

A person with YOD struggles with the ongoing transitions which can cause complexities in personal and social spheres. Being part of the YOD Support Group has helped members to maintain a level of continuity with their life before diagnosis, by having a routine, having a space to be who they are and engaging in activities and interests that define them. Tom (61 years) for example, is outgoing and enjoys cracking a joke and being around people:

I've never been one of those people [who] walk into a party that drink and sit there in a corner. I talk to people.

His wife Carol described him as 'still young and a man who has always been fit, very, very fit and very active' and as a person 'who had a strong work ethic, who was hands-on and liked having a routine'. After his diagnosis of dementia, she recalled how 'It is his whole life that's changed'. Tom remembered those early days:

I get up one day. What am I going to do today? I couldn't do anything. You get out of bed, you have a shower, put a pair of shorts on, sit outside in the shade. That was it. Apart from when she took me to the doctors or the hospital, I sat there in that unit 24/7.

Those days are long gone. Tom said: 'I enjoy coming here ... It works. It makes it more like I'm going to work again'. The Support Group is also a space where he can be himself and pursue his interests in gardening and fishing.

John (now aged 64 years) had a similar experience in his early days. His wife Rachel explained that the diagnosis of dementia forced John into early retirement; but with the support of the group, John is pursuing woodwork and painting which give him 'something of interest to occupy him'. Rachel said that John (64 years) has always had a strong work ethic and therefore, 'knowing his routine' was important for him.

Meaning and enjoyment derived from activities

We assist you with the things that you can't do so that you are able to do what it is that interests you. (Staff member C)

Activities in the group have multiple aspects such as maintaining existing skills and discovering new skills, utilising and exchanging knowledge, skills and expertise and enabling socialisation. A staff member commented that the group 'unfolds very nicely each week and keeps them tuned by stretching their capacity and their abilities'. In addition, members have been able to fulfil their personal and group goals. Each member chooses activities that match their interests and personal goals, such as the garden and the DVD project.

The garden has been a project that Tom holds dear to his heart: It has enabled him to relish some childhood memories:

Coming here I could put [to use] some of the good things [from] my childhood like doing the garden ... I used to do the gardening to help my father as a child.

The garden has also brought back good memories for Frank (56 years). He recalled 'Me cousin and I used to do the gardening together'.

For others, the group offers the opportunity to engage in activities that they would otherwise not have undertaken:

That's what I have found with the support group. It's a place that I can go to where there is activity and do things I normally don't do on my own. (Richard)

While some members said that they hadn't had much previous experience in gardening, they agreed that they have enjoyed it. Some have also been able to maintain their skills such as woodwork and others have developed new interests such as painting.

Some of the activities also represent a collective goal. There is a shared understanding among members that their participation in the group enables them to help others. As Tom expressed it regarding the garden, 'The satisfaction of what we've created here as to what it was ... [It's] nicer when people start appreciating it'. Members get a sense of fulfilment from knowing that they can still make a positive contribution to others. The garden, in this respect, is of value to members as it can be enjoyed by others who visit the Banksia Centre. The DVD project, on the other hand, provides members with an opportunity to offer insight from their personal experiences of dementia, while extending empathy and hope to others with YOD.

Although at the outset the YOD Support Group resembled a regular planned activities group program, the activities initiated by members are laden with purpose as they are aligned with their

goals and aspirations. As John summed up, the group for him is ‘more than going out for a hamburger for lunch’.

Strong bond between group facilitators and members

A feature of the YOD Support Group is the strong bond that has developed between group facilitators and members. Part of the group’s success is due to the commitment and enthusiasm of facilitators. The facilitators play a crucial role in influencing the culture, morale and the social environment; and they can influence the ways that service users perceive and engage with the group. As one staff member emphasised, supportive staff are a key to bringing out ‘the best in a person’. Facilitators have made members feel welcome, understanding each person and ensuring they have the freedom to initiate, plan and organise activities. As the AAV YOD Key Worker observed, facilitators have been ‘supportive and allowed people to enter the group under their own terms’.

Interestingly, there seems to be a collective attitude which has enriched the experience of the group. Members consider facilitators as partners rather than being ‘the dictatorial type of people’. ‘There is no us and them’ is how John described the relationship between facilitators and members. One facilitator said that ‘We genuinely get to know people as individuals’ and explained that ‘I don’t tend to make decisions about what goes on during the day without chatting with the guys first and taking their opinions’.

The other facilitator reiterated the importance of members having the right and responsibility to ‘make their own decisions’ and have control within the group. Richard described the role of facilitators:

They are just a guidance about what we need to do. It is more along the lines of how we are, what sort of things do you think you would like to do. They open the channels for discussion and thinking things through.

Facilitators have found their relationships with members equally rewarding. One staff member reported that working together with members in various projects has led him to learn new skills such as gardening. At an emotional level, staff have also been moved and inspired by the courage and perseverance that members have displayed. This is reflected in a conversation at the Centre: when John told a staff member that Christine Bryden inspires him, her reply was ‘You inspire me’. Support staff appear to have a natural ability to develop relationships with members while bringing their own personalities into the group. While one staff member is encouraging, empathetic, attentive, other brings ‘energy and spark’. They are also committed and caring towards members and have proved to be a good fit.

A shared journey in a supportive environment

The common challenge of living with dementia has led to a collective identity that has been formed ‘organically’ and gradually among members. Members have also developed friendship, cohesion and trust in a safe and supportive environment:

Everyone seems to have that sort of trust. Okay, we are all in it together. (Tom)

One staff member observed that the development of cohesion and trust within the group is:

particularly an exciting aspect that appeared very naturally. I think it's just the way that the environment has been created. I think it just almost fell in to that kind of more support group type thing.

Another staff member believes that this collective spirit originates in members being 'strong in their vulnerability and sharing it, and that's what is different about this group'. She believes that it is the 'emotional soul of the group that makes the difference'.

Members themselves identified the emotional benefits of being part of the group.

being a small group, we all get along quite well. I've noticed that the group as a group tend to be very supportive. If you are wandering around the road a little bit and not quite sure what's going on, someone in that group will find you and bring you back. It seems to work that way. (John)

That's what I like about everybody out there. They are all caring. They can see things through different windows. (Tom)

Richard explained that 'We do talk about our worries and anything that might be changing in ourselves. We don't do it in a formal sense'. Mutual support is fostered through the relationships between members. These relationships have also flourished outside the group, as Richard noted:

...when he [John] was still driving he would drive me up to the railway station at the end of the day. Now we walk up together at the end of the day and we probably talk more about personal things at that point rather than sitting around here because we do tend to have activities going most of the time.

Richard explained how his personal experience of being told to give up driving had enabled him to provide emotional support to John: 'He's just recently stopped driving his motor car so I guess he took a sort of lead out of what I've done'.

One of the staff noted that members have much to share with each other:

The one thing they lack in their lives is to be able to talk to people who really know what they are going through; and no doctor, no staff member, no family or friend or relative knows really what they are going through.

This is affirmed in Richard's comment:

One time of your life you really need people when you get a diagnosis of dementia ... but you are also with other people who are exactly in the same situation as yourself. The only difference between them and me is that they have partners.

A chance to be heard

It has been noted that 'the first person voice of individuals with dementia has long been neglected' (van Gennip et al. 2014, p. 1). While YOD Support Group members have the opportunity to exchange their life stories and their experiences of dementia with staff and with each other, the group has also enabled members to share their subjective experiences, needs and aspirations with the general public through the DVD project.

The DVD project displays the importance of sharing the personal experiences of dementia in a space where members feel supported and included. Equally important to members is making people understand what younger onset dementia is, in order to remove the stigma associated with it. A staff member remembered asking if John would like to speak to the Peninsula Dementia Action Group; John replied: 'When people don't understand dementia I get so nervous and then I can't find my words. When I know that they understand dementia I can talk'.

In this respect, collaborating with students at Mount Eliza Secondary Collage to produce the DVD has been valuable, as members played an educative role:

even now the small interaction we have had with the kids, they have a far better understanding of dementia ... and if we can do that with the students, I think we have achieved an awful lot. They get an understanding, they talk to the parents ... so it sort of blends over. (John)

It is rare that people with dementia are given the opportunity to extend their perspectives and views because, for the most part, services are built on the perspectives of health professionals and family members (Harris 2004). However, as Tom said: 'The main thing I get from here is that everybody listens to everybody'. The active participation of members was highlighted by the AA YOD Worker. During her multiple visits to the group, she noticed that 'the participants are really very active in saying what they would like to be involved in' which she believes 'makes it a really well run group'.

5 Discussion

While the preceding section focused on the interviews with members and staff about the YOD Support Group, this section presents the insights about living with dementia which were gained from members and staff in the earlier visioning exercise and compares them with the literature about YOD. It then considers how these perspectives align with the key characteristics of best practice YOD services, and the strength of the YOD Support Group model.

Insights about living with dementia

At the visioning exercise which was conducted at an early stage of the program, members chose pictures which fitted their perspectives and what was meaningful in their lives. Tom selected a photograph of people in a hopeless and impoverished state, which appeared to reflect his feelings about the general lack of respect and support for people with YOD. Chaston (2010) documents feelings of loss and neglect among people with younger onset dementia. Alzheimer's Australia has produced a number of reports based on the subjective experiences of people with younger onset dementia, highlighting similar feelings of loss and neglect (Alzheimer's Australia 2003; Hodges et al. 2009). Persons with YOD report feelings of loss of selfhood (resulting from loss of purpose, meaning and relationships, activity and identity), loss of self-esteem (Roach et al. 2009), loss of family and social roles (Wolverson, Clarke & Moniz-Cook 2010), and abandonment (Phinney, Chaudhury & O'connor 2007).

John chose a picture that represented his personal goal to see and enjoy his prospective grandchildren. His choice encompassed important effects of younger onset dementia: the impact on family relationships and the feelings of hopelessness and confusion resulting from an unexpected diagnosis. A diagnosis of dementia in a younger person is considered out of time or 'off-time' as it is unanticipated. Unlike a diagnosis at an older age, 'it is often more difficult to accept [it] in the midst of life' (Tindall & Manthorpe 1997, p. 241).

Research also reveals family and social relationships change in a unique way following the onset or diagnosis of dementia at an early age (Pipon-Young et al. 2012; Harris 2004). People with YOD often have different social relationships to those of older adults: they may still be raising a family, have dependent children or be caring for their ageing parents (Thompson 2011). Loss or change to a person's role within the family such as being the financial provider, a parent or a spouse can lead to a loss of sense of who they are and their identity (Bakker 2013). Many fear being considered a burden, losing autonomy and becoming increasingly reliant on family (Snyder 2007). Added to these stressors are the pre-existing relationship dynamics, strengths and vulnerabilities within families that can become heightened by a diagnosis of dementia and test the ability of a family to adjust to changing circumstances (Snyder 2007).

John's concern about his grandchildren is consistent with life-course theory which suggests that a person's life is marked by social events that are loosely related to age; an unexpected diagnosis of dementia disrupts this 'inbuilt social clock' (Tindall & Manthorpe 1997, p. 240) creating great distress among younger people with dementia since progression is more rapid (Kinney, Kart & Reddecliff 2011).

Other social consequences of a diagnosis are workforce and retirement issues. At the onset of dementia many are still in employment (Alzheimer's Association 2006). Losing the ability to perform one's job can affect self-esteem and confidence; and over time, a person with YOD will be

forced to leave their job, resulting in a reduced income. Loss of employment can lead to a loss of the social contacts developed over the years, with subsequent boredom and a lack of meaningful occupation (Harris 2002), which, at the emotional level, leads to a loss of ability to give meaning to life (Bakker 2013) Losing social contacts leads to social isolation. Although feelings of isolation are expressed by people with dementia in general, for younger people the difference is the ‘depth of isolation they feel and the feeling of being marginalised’ (Harris 2002, p. 9).

As Kate Swaffer, a person living with dementia and a writer on YOD, explains, a diagnosis of dementia is usually followed immediately or soon after by a ‘prescribed disengagement’ of the person from the life they led before. She explains that it could have been different:

my employer would have assisted me to stay employed for as long as possible with the appropriate support for my disabilities and I would not have been given ‘prescribed disengagement’ from my pre-diagnosis life. (Swaffer 2014, p. 14).

As illustrated by members of the YOD Support Group during the visioning exercise, a diagnosis of dementia throws into doubt hopes and aspirations for the future. The diagnosis usually triggers early retirement (Harris 2002) and disrupts future plans and goals (Alzheimer’s Australia 2007). For John, the diagnosis of dementia led him to sell his lucrative business, forced him into early retirement and curtailed his travel plans.

Perspectives about services

Reflecting on the social consequences of dementia, members and staff commented on current services available for those with younger onset dementia. All of the visioning exercise participants, including the two members, pointed to the lack of specific support services. Many available services are designed for older adults and are located within the aged care sector (Tyson 2007); and access to appropriate care and support for younger people is extremely limited (Alzheimer’s Australia 2013). The AAV YOD Key Worker confirmed that although Victoria is leading other states in terms of YOD-specific services, such services are still scarce. A limiting factor is that YOD falls under both the aged care sector (funded by the Commonwealth) and disability sector (funded by state governments) but is not completely covered by either (Thompson 2011). This division between state and federal responsibilities makes it difficult for people with YOD to fit into the service system (Standing Committee on Health & Ageing 2013).

There are significant challenges to people with YOD at all points of the care and support continuum, but particularly with regard to timely diagnosis, social support and participation. Moreover, the generalised support programs available do not cater for individual needs (Brown et al. 2012). As numerous studies and reports point out, this is a serious service gap that has wider implications beyond the Brotherhood YOD Support Group (Tyson 2007; Brown et al. 2012; Thompson 2011; Tindall & Manthorpe 1997).

In their review of YOD services, Beattie et al. (2002) highlight that the lack of consultation with younger people with dementia by service providers, together with the limited documenting of the experiences of services, have resulted in most services being driven by the perceptions of professionals rather than of people with younger onset dementia. This highlights the need for service providers to value the subjective experiences of persons with dementia and place the interests, needs and concerns expressed by individuals at the heart of dementia care (Harris 2002).

Characteristics of best practice

The views expressed by people with younger onset dementia signify that they have important perspectives to offer, which in return can provide a feeling of empowerment (Chaston, Pollard & Jubb 2004). In the visioning exercise, empowerment was a theme identified by one staff member. Empowerment may take many forms, all of them relevant to this evaluation. Empowering people with YOD to make decisions about the care and services they receive has proved beneficial and this is a crucial ingredient for developing 'good' practice models of support (Chaston, Pollard & Jubb 2004). Services such as PROP (Thompson 2011) and the ACE Club in North Wales (Davies-Quarrell 2010) have been built on a philosophy of empowerment. They encourage and enable participants to continue living meaningful lives by sharing experiences and engaging in personally fulfilling activities.

Closely related to a sense of empowerment is the notion of courage, a theme identified by another staff member. The ability to overcome obstacles, to take the first step and embark on something new with the knowledge that one will be supported to do so, is crucial to the vision of the Brotherhood YOD Support Group. This too finds support in the literature. People with YOD benefit from services that create a safe and welcoming environment where they can be themselves, free from judgement and stigma (Brown et al. 2012; Reed et al. 2002).

Two further themes—support and togetherness—raised by the staff members find widespread support in the literature. Research conducted with people with YOD affirms the benefits of developing a collective social identity among people with YOD and the importance of sharing experiences of dementia: 'when people with dementia develop a shared social identity they also develop mutual support, this in turn, allows people to assume new roles and group identification' (Pipon-Young et al. 2012, p. 611). The ability to learn from others, provide interpersonal support and offer advice is recognised as a key indicator of 'good' practice (Brown et al. 2012). A group or collective identity may also support a person's self-identity, a key challenge in the experience of YOD (Harris 2004; Tyson 2007).

There is convincing evidence that people with YOD maintain a strong sense of hope and determination (Rostad, Hellzen & Enmarker 2013). Services that support and build on these qualities have proved of great benefit to people's wellbeing (Pipon-Young et al. 2012; Reed et al. 2002).

Strengths of the YOD Support Group

The Brotherhood YOD Support Group carries all of the traits of models of 'good practice'; however, the application of the Capability Approach distinguishes the group from other models. Another characteristic of the YOD Support Group that has only been noted in the PROP and the Melbourne City Mission Clubhouse programs is the active involvement of its members in the design and development of the service. Because of this, members of the Brotherhood YOD Support Group described the group's activities as having meaning and purpose. As Phinney, Chaudhury & O'connor (2007) explain, meaning in activities exists in the experience of enjoyment and pleasure, a sense of connection and belonging, and retaining a sense of autonomy and identity.

Tracing the YOD Support Group over a year, there is no doubt that it has evolved. It has received new members with diverse skills, interests and personalities, including those with differing cognitive and functional needs; and as a result activities and outings have been varied. At the beginning there were more physical activities (gardening, fishing and a visit to a motor show) that were aligned with the interests of male members who were in the early stages of dementia. The

group has now taken up other activities (pampering sessions and jigsaw puzzles) to accommodate the interests of female members with more advanced dementia. As one staff member described, 'It's almost like there are different seasons. There is a different season of the group and I have seen it change and unfold'. As observed by another staff member 'every person that comes through the door will change the dynamics. It seems to be in a good way. It really helps shape and form how the group is'.

The willingness of staff to value member input is another hallmark of the Brotherhood YOD Group. In addition, the group has fostered cohesion, trust and companionship, which have developed into a collective identity.

Research shows that participation in a support group assists people to better understand dementia, to accept their diagnosis, to cope and to respond to changes related to dementia (Snyder, Jenkins & Joosten 2007). Studies of the subjective experiences of people with dementia have reported that 'a key element of the dementia experience is the struggle to preserve one's identity and sense of self and to maintain a meaningful life' (van Gennip et al. 2014, p. 1). Therefore, 'maintaining activities and relationships' are key to maintaining a sense of identity (Caddell & Clare 2011, p. 396).

Support groups such as the Brotherhood YOD Group play an important role: they encourage people to engage in activities and develop links with others and assist them to communicate and learn how to manage the different emotions that emerge from trying to cope with the challenges of dementia.(Caddell & Clare 2011).

In all of these respects, the Support Group has embraced the features of 'good practice' models.

6 Opportunities for ongoing development

This preliminary evaluation of the Brotherhood Younger Onset Dementia (YOD) Support Group pilot project has provided a range of rich learning opportunities. These include several challenges which intersect at the social, personal and the organisational levels and which are worth considering in future development.

Support for younger people with advanced dementia

- How much do the different categories such as age, stage, functional abilities matter for a YOD Support Group?
- How can the Brotherhood respond to younger people who are in more advanced stages of dementia?
- How can the Brotherhood YOD Support Group meet the needs of current members in the more advanced stages (such as social, personal and functional needs)? Do these people remain part of the Support Group?
- How are the different functional and cognitive levels of current members managed?

Engagement with carers

- How can the YOD Support Group support members and their carers through the progression of dementia?

It is suggested that the YOD Support Group could explore ways of supporting carers to maintain their care relationship. This could include engaging with carers to identify the aspirations and needs of members as they progress through dementia, with the aim of assisting them to continue living at home. Such additional support can be offered by collaborating with other service providers so that members and their carers can move smoothly along a given pathway of care and support.

Active participation of members

- How does the YOD Support Group reflect the experiences, opinions and the voices of its members who are in the advanced stages of dementia?
- How does the YOD Support Group involve members in refining the current model so that it can be taken up by other services for people with YOD?

Adaptability of the Brotherhood's YOD Support Group model

- How might the Brotherhood YOD Support Group model inform other services for people with dementia under the age of 65 and their carers?
- How do intangible features (such as staff attributes, personality, morale and culture) impact on the adoptability of the model across other YOD services?
- How receptive would other YOD services be to a model that is built on sharing power and decision-making with service users?

Sustainability of the Brotherhood's YOD Support Group model

- How would a member-directed YOD Support Group model impact on current Brotherhood service policies and practices?
- How can the group embrace members who may have differing opinions and perspectives?
- How will the model be sustained as the number of members increases?
- How will the YOD Support Group be affected by the complete implementation of the National Disability Insurance Scheme (NDIS) from June 2015? What challenges would changes to funding pose to the functioning of the Support Group and its future? What alternative funding possibilities should be considered?

Suggestions for improvement

During the interviews, both members and staff made suggestions about ongoing development which may address some of the challenges outlined above.

Member suggestions

Overall, members were satisfied with the YOD Support Group and the variety of activities and outings. They agreed that the group has met their expectations and therefore did not feel the need for major changes. A few suggestions were made by individuals:

- Allow more time for members and group facilitators to plan and prepare for potential projects and activities.
- Set timelines for projects to encourage a sense of achievement.
- Allocate a regular time each week for members to discuss with group facilitators private concerns related to dementia.
- Support members to plan for and respond to changes related to dementia. A project on 'How to deal with the future' could encourage members to assemble and discuss information and resources.

Carer suggestions

Although the two spouses who were interviewed appreciated the opportunity to provide suggestions, they believed that the members had the capability to shape the future direction of the group. One carer made a specific suggestion because of the mentally stimulating and meaningful activities:

- Provide an additional day for the YOD Support Group (also suggested by staff).

Staff suggestions

Staff members made a variety of suggestions which may inform ongoing program development:

- Recruit a volunteer as an extra hand to help group facilitators.
- Run a training course for support staff and members on using iPads in dementia care.
- Create a network of dementia mentors.
- Update the YOD-specific skills of group facilitators.

- Work more with members individually to support them in achieving the personal goals set out in the 'My Plan'.
- Develop a framework for assessing the unmet needs of people with younger onset dementia in order to reduce some of the changed behaviours.
- Define the role of the YOD Support Group within the broader service system by involving external service providers.
- Build on the relationships with other YOD services through the AAV Planned Activities Group network.
- Meet with external service providers to explore opportunities to create referral pathways. Such a discussion could reveal gaps in the service system and open up opportunities to campaign for more integrated and improved services for people with YOD.
- Set up early intervention strategies and planning processes to prepare members and their carers for and support through the progression of dementia.
- Develop a practice guide based on the YOD Support Group model, for other YOD services wishing to replicate the Brotherhood model.
- Formalise the current processes used for member assessment and for developing the 'My Plan'.

7 Conclusion

The Banksia YOD Support Group was founded on the belief that people with YOD have distinctive needs and challenges and that there is a lack of specialised services for them. Following Sen's Capability Approach, the model is essentially based on supporting and enhancing the strengths and the capabilities of the person with YOD. Grounded in the concept of co-production, staff and members work together to shape and steer the activities. The Brotherhood model displays many traits of good practice, including strengths-based, holistic and flexible processes which place the person with YOD and their carer at the heart of dementia care.

The YOD Support Group underscores the value of having services which acknowledge and are guided by the 'first person' voices of people with younger onset dementia, which are so often overlooked by professionals and services (Beattie et al. 2001). It affirms the need to recognise service users as persons with expertise and assets.

The YOD Support Group is attempting to redefine and challenge traditional methods of service delivery by recognising and mobilising the human and social capital of members and staff to promote shared learning, which in return leads to consumer empowerment. This has yielded positive outcomes such as close, reciprocal and sustained relationships built on trust and mutual support. Members have developed new friendships and an informal support network where they share and exchange information and experiences and learn from each other. They have also been able to harness support through new links with the community, thereby building and exchanging their social capital.

There is no doubt that socialisation and participation in mentally stimulating, complex activities can improve the mental wellbeing of people with YOD. While services such as the Banksia YOD Support Group may not be able to arrest the progression of the illness, they can transform the experience of dementia in a positive way by assisting both the person and their carer to live a full life to the best of their abilities. Such a model moves away from focusing on clinical or medical deficits.

Although the Brotherhood's YOD support model at the Banksia Centre displays many strengths, the evaluation suggests several opportunities for its ongoing development, which include reviewing the eligibility for membership, considering how the model can fulfil the needs of members whose dementia is more advanced, and examining the adaptability and sustainability of the model.

Despite the limited scale of this evaluation, the Banksia YOD Support Group can provide useful insight to the needs and challenges of younger people with dementia in their early stages. It is also hoped that the program will inspire other YOD services to explore the positive impact that various service delivery approaches can have on people with YOD and their carers.

Considering that YOD is still a relatively new terrain for services, researchers and policy makers, the Banksia YOD Support Group offers the opportunity to explore how services could best meet the needs of people with dementia. Until YOD receives the attention it deserves, providers such as the Brotherhood of St Laurence play a critical role in creating innovative models of service that support people with YOD and their carers to continue living lives that are both fulfilling and meaningful.

Appendix

Profile of Banksia YOD Support Group members

Sex	Age	Duration in the group	Living arrangements	Type of dementia	Age at diagnosis	Stage of dementia
Male	55	9 months	Not specified	Alzheimer's disease	Unknown	Early stage
Female	55	4 months	Living with spouse	Alzheimer's disease	50	Late middle - early late stage
Male	56	4 months	Living alone	Unknown	51	Early stage
Female	58	1 month	Living with spouse	Alzheimer's disease	52	Early stage
Female	58	1 month	Not specified	Unknown	Unknown	Late middle – early late stage
Male	61	16 months	Living with spouse	Alzheimer's disease	56	Early stage
Male	62	7 months	Living alone	Alzheimer's disease	62	Early stage
Male	64	16 months	Living with spouse	Alzheimer's disease	61	Early stage

Note: The term 'late middle to early late stage' was adapted from Alzheimer's Australia Help Sheets, *ReBOC: Reducing behaviours of concern guide* and the MMSE (Mini-Mental State Examination).

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