

A shared journey

Insights from the Banksia Younger Onset Dementia Support Group

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The Brotherhood of St Laurence's Banksia Younger Onset Dementia (YOD) Support Group in Frankston, Victoria, was created in 2013 in response to an identified gap in services. Funded by 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, because of their stage in life when dementia is diagnosed. Moving away from conventional 'professional' service provision, the 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.

This summary reports on an evaluation that used a Participatory Action Research approach to assess how well the Support Group had achieved the following 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 of dementia 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 activities were initiated by members, they felt a feeling of ownership and a sense of belonging
- **a place of hope:** members of the Support Group reported that it has 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 Support Group
- **a shared journey:** members appreciated the emotional benefits of peer support and sharing experiences, information and concerns. As a result, a collective identity has been built on the 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 the group and share their personal experiences of dementia with the local community
- **a strong bond between staff and members:** the 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 people with younger onset dementia 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). Despite these challenges, most available services are designed for older adults, and are located in the aged care sector (Alzheimer's Australia 2007). Access to appropriate care and support is extremely limited for younger persons (Alzheimer's Australia 2013).

The program

The YOD Support Group comprises 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 to 65 years and who were in early to 'early late' stages of dementia.

The Support Group model is founded on three key service delivery approaches. Firstly, the Capability Approach articulated by a Nobel Prize winning economist Amartya Sen focuses on capabilities, which are 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 (Needham 2009). Thirdly, the HACC 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 (Victorian Department of Health).

The group meets once a week from 9 am to 3 pm at Brotherhood's Banksia Day and Respite Centre. The members are supported by two part-time group facilitators who work with other dementia services at the Banksia Centre and in the community. The YOD Support Group is part of a suite of 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 these people 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 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 had been with the Support Group for over six months. It captures the experiences and the impact of the Support Group on members and carers, as well as staff.

During the year, two rounds of interviews were conducted with participants to track developments. The AAV YOD Key Worker was also interviewed about the current YOD service system in Victoria and her observations of the YOD Support Group. A short survey was conducted with members to explore the opportunities that they have to maintain their capabilities and their level of enjoyment with 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 been offered to initiate and develop projects within the group. They explained that the difference between the Banksia YOD Support Group and other programs was that the activities in the group 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 are used in the kitchen. One member, when asked about that project, 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)

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. (Staff member)

Members have developed links with the local Masters hardware store, a local church and the Mount Eliza Secondary College. As a result, members continue to receive 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.

Activities which members were involved in also extended outside the group as reported by Carol, a carer and spouse:

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.

A place of hope

A recurrent theme was that the group brought 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 B)

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.

The determination to remain hopeful is evident from the visit by Christine Bryden, initiated by the group

members after having watched a documentary on national television. Diagnosed with dementia around twenty years ago, Christine has become an ardent advocate for people with younger onset dementia. Her experience illustrated the potential to live well despite dementia and her visit inspired the Support Group members to believe that 'if she can do it, we can do it'. 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'. Although previously he associated dementia with 'people who had lost it', he knows now that 'it is not the end of the world to have dementia'.

Maintaining continuity

A diagnosis of dementia can have a significant impact on a person's life. 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 and activities. As a result, activities and outings undertaken in the group promote a continuation of self. Tom, for example, is outgoing, enjoys cracking a joke and being around people. As he explained:

I've never been one of those people [who] walk in to a party and drinks and sits there in a corner. I talk to people. (Tom, 61 years)

His wife added that Tom had always been very fit and very active. After being diagnosed with dementia, she recalled how 'it is his whole life that's changed'. 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.

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, the staff encourage each person to make decisions, initiate and organise activities—which the 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

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

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 also 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 for Frank (56 years), who recalled: 'Me cousin and I used to do the gardening together'.

For others, the group offered the opportunity to engage in activities that they would otherwise not have pursued, such as painting and making a DVD:

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. A sense of enjoyment achieved through activities 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 YOD. 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. As one of them explained:

I don't tend to make decisions about what goes on during the day without chatting with the guys first and taking their opinions. (Staff member A)

This is reflected in the words of a member

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. (Richard)

A shared journey in a supportive environment

Although not initially anticipated by staff, 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, supportive, inclusive and enabling for all members.

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

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)

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.

As one member explained:

Having other people you can talk to and share like experiences where you can't with anyone in society. It has to be someone like yourself and that has been very, very important for me and I hope for them as well. (Richard)

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 the members are collaborating with students to produce a short movie about their personal experiences of dementia.

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)

Members are also acknowledged as individuals who have important insights to offer in shaping the YOD Support Group.

The main thing I get from here is that everybody listens to everybody. (Tom)

Discussion

There have been several services locally and internationally that are similar to the BSL YOD Support Group model. For example, Melbourne City Mission (MCM) 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 BSL group is the readiness of staff to incorporate member input to the model. The Support 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, reciprocal and sustained relationships built on trust and mutual support between staff and members and also between members themselves. Although strong relationships between members and staff have contributed to the group's success, 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 made several suggestions for enhancements:

- allow more time for members and group facilitators to plan and prepare for potential projects and activities
- include timelines for projects
- allocate a regular time each week 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.

Through the evaluation, a number of opportunities were identified for further development of the YOD Support Group:

- re-thinking the eligibility criteria. Despite the fact that the Support Group is for persons with dementia under the age of 65 years, there has been an ongoing discussion among members and staff about whether the group should be based on age or stage of dementia
- reviewing whether the group has the capacity to support the personal, social and functional needs of current members in the advanced stages of the condition
- considering how BSL might be able to respond to people in the more advanced stages of younger onset dementia
- supporting both members and their carers through the progression of dementia
- exploring how to reflect the experience, opinions and the voices of Brotherhood's YOD members who are in the advanced stages of dementia
- exploring how the group could collaborate with other YOD services to complement existing services.

Alongside these opportunities are several challenges for the YOD Support Group.

- How would a member-directed YOD model impact on current BSL service policies and practices?
- How can the group embrace members who may have differing opinions and perspectives?
- How will the group model be sustained as the number of members increases?
- How do intangible features (such as staff attributes, personality, morale and the culture between staff and service users) impact on the adaptability of the model to other YOD services?
- How will the YOD Support Group be affected by the complete implementation of the National Disability Insurance Scheme (NDIS) from June 2015? What challenges will the changes to funding pose for the future of the Support Group? What alternative funding options should be considered?
- How receptive would other YOD services be to a model which that is built on sharing power and decision-making with service users?

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 is to ensure the success of the group is carried into the future.

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About the project

Info about project partners and funders

For further information

The full report, *A shared journey: insights from the BSL Banksia Younger Onset Dementia Support Group* (PDF file, 356 KB) by Seuwandi Wickramasinghe, Ashley Carr and Helen Kimberley may be downloaded from the Brotherhood of St Laurence website.

For other relevant Brotherhood publications see <www.bsl.org.au/Publications>.

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