

BANC PASS

Cross Sector Partnership: A successful collaboration and a pathway to better outcomes for people with Younger Onset Dementia



This research paper was prepared by Dr Constantine Tsingas with staff from the Neuropsychiatry Unit at the Royal Melbourne Hospital the North West ACAS and Baptcare. For further information relating to the content of this paper contact Rachel Breman, Head of Research, Policy and Advocacy, Baptcare: rebreman@baptcare.org.au

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Research Paper

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The invitation by the Neuropsychiatry Unit to observe the ward round meetings at the Hospital provided a unique insight into the benefits of a multi-disciplinary approach and of a forum for capacity building of staff that helps build on the distinctive competencies of each collaborating agency.

Contents

Abstract	3
Objective	4
Methods	6
Stakeholder engagement and case study selection	6
Interview instruments	6
Data collection	6
Results	7
A framework for understanding cross-sector collaboration.....	7
A cross-agency successful collaboration	8
Conclusion and implications for public health	13
References	14
A Successful Collaboration	14

Abstract

Objective:

To present a brief framework for understanding cross-sector collaboration, but more importantly to identify those elements of successful collaboration that improve outcomes for people with Younger Onset Dementia.

Methods:

A review of the literature, qualitative in-depth interviews involving key personnel, other key staff, case study reviews and a client interview to illuminate reader's understanding of the issue under consideration.

Results:

The initiative and experiences of key staff that formed the collaboration add critical knowledge that enhances the framework for understanding successful cross-sector collaboration within a Victorian context and how that framework could help improve outcomes for people with Younger Onset Dementia. Equally as important is to align skilful leadership and agency commitment with outcomes and accountabilities that ensure positive developments occur in a sustained way over time.

Conclusions and implications for public health:

Younger Onset Dementia is difficult to diagnose, it is life ending and more aggressive at a younger age. For these reasons, it is critical to keep people with Younger Onset Dementia active and stimulated to avoid rapid deterioration; obtain diagnosis early to allow for advanced planning, the timely involvement of support services and medical treatment.

Keywords:

Younger Onset Dementia, cross-sector collaboration, leadership, outcomes

Objective

Younger Onset Dementia is any form of dementia diagnosed in people under the age of 65 years. It has been diagnosed in people in their 50's, 40's and even in their 30's. Dementia in younger people is much less common than dementia occurring after the age of 65. It is not expected, thus often not considered as a possible differential diagnosis. For this reason it is frequently late in being diagnosed. The latest data shows that Younger Onset Dementia affects approximately 25,000 Australians^{1,2} and those accessed through the BANC PASS collaboration number around 20 people. The numbers are small but the experience gained through the BANC PASS partnership is important to capture for the benefit of this small cohort and learning.

Younger Onset Dementia often presents at a time when people are reaching the peak of their career. On diagnosis they may be physically strong, mobile and generally in good health. Their partner may still be in full-time employment, and there are often dependent children. Superannuation and life insurance schemes are difficult to access due to policy criteria restrictions related to age and yet people with Younger Onset Dementia may be financially responsible for their family.^{3,2}

As the disease is more aggressive at a younger age there is a need to keep people with Younger Onset Dementia active, engaged and stimulated to avoid rapid deterioration. Obtaining a diagnosis early is critical, as this allows for early planning, the early introduction of support services and medical follow-up, care and possible treatment.^{1,2} Antecedents that help delay deterioration include a stimulating job with low stress, a healthy heart, exercise or stimulating activities that occupy the brain such as learning to dance, continued social engagement, and involving people with Younger Onset Dementia in tasks that support reablement.³

The time spent with symptoms associated with dementia before diagnosis is, on average, two to three years. This delay is further prolonged in those with Younger Onset Dementia; because there is a mistaken belief that dementia is exclusively a condition affecting those aged 65 years and over.⁴ The symptoms associated with dementia can be more difficult to accept and manage in a younger person. Knowing it is a rapidly deteriorating, aggressive and life ending disease is difficult. For people with Younger Onset Dementia and their family, a number of issues may arise: a sense of loss associated with unplanned loss of income and a reliance on means tested support services they could ill-afford, adding further financial hardship; loss of driver's license; loss of self-esteem; loss of selfhood and personhood; loneliness associated with loss of social networks; genetic implications for offspring, particularly the knowledge of having a genetic predisposition or vulnerability to developing Younger Onset Dementia, and a future with diminishing options.^{2,3}

Other issues may include: adjusting to changes associated with family roles and responsibilities, the person's ability to cope with everyday life, stigmatising community attitudes and children's reactions to Younger Onset Dementia may also be difficult.^{3,2}

Access to home care services for people with Younger Onset Dementia is another challenge with existing eligibility criteria seen as restrictive and hindering access, especially as eligibility with Home Care Packages and residential care is determined by Aged Care Assessment Services (ACAS) compounded by local protocols associated with Disability Client Services, Victorian Department of Human Services. The protocols are variously implemented across the state of Victoria, and can be dependent on the interpretation of the protocols, the Disability Act 2006, and the interface between ACAS and the disability region.

The rollout of the National Disability Insurance Scheme from July 2016 may add another complication.

People with Younger Onset Dementia experience high levels of non-cognitive (psychological and behavioural) symptoms. Individual packages of care services are required, which are often unavailable or underutilised by younger people, with family carers filling the gap. Dementia in younger people was found to have higher direct costs than in older people.⁵ It was also found that the impact of dementia on mortality in people with Younger Onset Dementia was higher than those with late-onset dementia.⁶

Younger Onset Dementia also has substantial adverse physical and mental health consequences for those caring for a person with Younger Onset Dementia. In addition, carers are at increased risk of experiencing financial stress and family conflict, as well as direct and lost opportunity income through their inability to maintain employment.⁷

According to Access Economics “appropriate counselling through all stages of dementia progression is very helpful for the individual and family. Education and participation in support groups can help the person and their family learn to manage certain symptoms, such as cognitive behaviour therapy to address mistaken beliefs (delusions), prevent depression or anxiety ... (and help cope with) personality changes”.⁸ Psychosocial interventions for caregivers have been shown to substantially delay (entry to residential aged) care by supporting the capacity of caregivers to continue to provide care within the home at low cost.^{9,10} These interventions also reduce the likelihood of caregiver stress and burnout and the associated risks of neglect and abuse.¹¹

There is a lack of evidence regarding prevalence, risk factors, presentation and appropriate management strategies for people with Younger Onset Dementia. There is also a lack of research that explores the economic implications incorporating the impact of preventive and early intervention initiatives, the direct financial costs

to the Australian health system, the costs of care, income forfeited by people with Younger Onset Dementia and their families and carers, due to absenteeism and early retirement.³

Against this background, and in response to the increasing number of people with Younger Onset Dementia seen by the Neuropsychiatry Unit (NPU) at the Royal Melbourne Hospital, North West ACAS and Bapcare, it became apparent to all three organisations that the needs of people with Younger Onset Dementia could not be met through the available resources of one agency alone.

Staff within the above three organisations having a central role in the delivery of services to people with Younger Onset Dementia understood that the challenges presented by the complex needs of this population could be addressed effectively only if several organisations collaborated. The aim of the collaboration was to meet the service gap for people with Younger Onset Dementia to access appropriate and timely support; and prevent premature admission to residential care settings.

Driven by their increasing understanding of the issues presented at the coalface and informed by the literature on cross-agency collaboration, key staff commenced a process for establishing the Bapcare, ACAS, Neuropsychiatry Collaboration – Partnership Across Service Sectors (BANC PASS) as a means of addressing more effectively the challenges presented by people with Younger Onset Dementia.

The collaboration commenced in 2012 and the three agencies involved in the partnership have gathered information which they are keen to share for the benefit of their own staff and more widely the health, disability and aged care sectors. This paper presents a brief framework for understanding cross-sector collaboration based on the available literature, but more importantly it identifies those elements of a successful collaboration that improve outcomes for people with Younger Onset Dementia.

Methods

This paper draws on the available literature to gain a theoretical understanding of the elements contributing to successful cross-sector collaboration. It also draws on the experiences of a limited number of cross agency staff directly involved in either establishing BANC PASS or assessing and supporting people with Younger Onset Dementia. Using in-depth semi-structured interviews, people interviewed to inform this paper, included: the three key leaders of the BANC PASS partnership; four regional Baptcare staff involved in the intake, case management, and the design and running of activities for newly referred clients with Younger Onset Dementia; a Comprehensive Assessor and Liaison from the North West ACAS; and the partner of a client with Younger Onset Dementia. Findings were analysed and grouped thematically.

Stakeholder engagement and case study selection

The preparatory stage involved interviewing jointly the three key leaders in October 2015. Activities included: relationship building; gaining an understanding of the need for, and role of, BANC PASS; clarifying expectations of the purpose of this paper; agreeing on data collection methods; drafting of participant information sheet and interview tool (tailored for informants); and approaches to be used to select cases illustrative of the efficacy of cross-sector collaboration. Permission was sought from the handful of clients to publish anonymously information about them.

Interview instruments

From the joint interviews with the leadership group, questions were developed to guide the informant interviews. These were introduced in conversational style to allow flexibility to pursue a new line of questioning to identify those elements of the BANC PASS collaboration that improve outcomes for people with Younger Onset Dementia.

Data collection

The initial joint interviews with the three key leaders provided the background for the in-depth interviews with staff from Baptcare, the Neuropsychiatry Unit and the North West ACAS and the partner of a client with Younger Onset Dementia. Nine face-to-face interviews were conducted between October and December 2015.

Results

The initiative and experiences of the three key staff that formed the collaboration add critical knowledge that enhances the framework for understanding cross-sector successful collaboration within a Victorian context – presented below – and how that framework could help improve outcomes for people with Younger Onset Dementia. Equally as important, the views and perspectives of the few other staff involved in making the collaboration work successfully also contribute to that knowledge.

A framework for understanding cross-sector collaboration

Several theoretical frameworks discuss the elements that favour the formation of successful cross-agency collaborations. Foremost, is the recognition that no one agency can solve an important public issue on its own and the need to involve multiple agencies to provide the necessary combination of skills, resources and expertise.¹² Equally as important to successful cross-agency collaboration is the involvement of committed leaders, referred to in the research as sponsors and champions.^{12,13,14} According to Crosby and Bryson, for a cross-sector collaboration to be effective, leaders needed “formal and informal authority, vision, and long-term commitment to the collaboration, integrity, and relational and political skills”¹² to be able to influence decision-makers.¹² They also needed to be able to serve as linking mechanisms that are committed to building resources, strategies and tactics for dealing with power imbalances.¹²

Other significant leadership characteristics include sharing a “collaborative mind-set”¹³; having the capacity to see the problem as being significant to enable different collaborators to “understand its importance and relevance to them”^{16,13} and agree that it needs to be addressed.^{17,13}

Leadership also needs to be able to engage in the “problem-solving process”¹² and “set directions likely to result in widely beneficial changes”.¹²

Research has also highlighted other important drivers that facilitate successful cross-agency collaborations. First, there needs to be a willingness by collaborating agencies to enhance each other’s capacity “for mutual benefit and a common purpose ... by exchanging information, sharing risks, responsibilities, resources and rewards”. It also requires “considerable amount of time and an extensive sharing of turf”.¹⁵ Formalising partner willingness through an agreement would have the advantage of supporting good governance and accountability, avoiding complications and confusion concerning partner roles and responsibilities.¹³

Second, the role of prior relationships is important because it is often through these that partners judge the trustworthiness of other partners and the legitimacy of key stakeholders.¹³ Trust can comprise interpersonal behaviour, confidence in organisational competence and expected performance, and a common bond and sense of goodwill.^{18,13}

Third, communication, capacity building of staff, managing tensions, making use of each agency’s strengths while also finding ways to minimise, overcome, or compensate for each agency’s characteristic weaknesses are also important to the success of cross-sector collaboration. Planning that carefully articulates goals and objectives; roles and responsibilities; action steps and builds on the distinctive competencies of each collaborating agency also contribute to the formation of cross-sector collaboration.^{13,12,14,15}

Fourth, sustainable stable systems to minimise uncertainties arising from membership turnover as leaders leave, join or alter their level of involvement in the collaboration are desirable too. Success also appears to depend on developing a measurement system to document the results of the collaboration and how those results change over time. This would provide critical information to partner organisations and use that information to improve their operations.^{13,14,15}

A cross-agency successful collaboration

Baptcare, the North West (ACAS) and the NPU commenced their formal collaboration in 2012. The basis of this collaboration was established several years earlier when ACAS and the NPU collaborated with a view to addressing the needs of clients with acute mental health issues and the call for improved access to aged care assessments and services for this group of clients. As an increasing number of people with Younger Onset Dementia started presenting at the NPU, it became apparent to both services that they were falling through the gaps of existing restrictive eligibility criteria within the disability and aged care sectors.

By this stage, two highly committed professional workers, one at each agency started championing the cause of people with Younger Onset Dementia. One was the Senior Clinician at the NPU; the other was the Manager of the North West ACAS. Both kept building and sharing the knowledge and understanding they were developing about people with Younger Onset Dementia. They targeted colleagues and professional networks within the health, disability and aged care sectors. More importantly, they were on the look out to enlist the services of an agency that could support appropriately the highly complex needs of people with Younger Onset Dementia in the community.

Concurrently, the Manager of Baptcare's Northern Home Care Packages was re-calibrating and adjusting policies to ensure Baptcare was putting into practice its mission of "partnering for fullness of life with people of all ages, cultures, beliefs and circumstances", including people with Younger Onset Dementia, who were largely left to their own and the inadequate resources of their families to manage a 'phantom' disease.

To the NPU and North West ACAS, Baptcare was the community link they were seeking. It was a provider of home care packages and had a champion with a particular interest in meeting the support needs of people with Younger Onset Dementia. It could complement their model of care.

To Baptcare, the NPU and ACAS could potentially unpack the vagueness of the condition befalling people with Younger Onset Dementia by offering a firm diagnosis, timely intervention, professional development regarding this rare disease, and extending eligibility rules to minimise cross sector inflexibilities.

The breakthrough came at a network meeting where two members of the future tripartite partnership were present. The manager from Baptcare mentioned the Organisation's interest to "do something creative particularly looking at the needs of people with young-onset dementia". The North West ACAS manager set in motion a meeting for bringing together all three key stakeholders. Each service provider had a different set of professional knowledge, skills and services to offer that could complement each other's service approach, making it possible to deliver a comprehensive set of services able to meet the complex needs of people with Younger Onset Dementia.

The NPU is an outpatient and inpatient statewide service that offers neuropsychiatric, neurological, medical, nursing and allied health assessments. The Unit specialises in the diagnosis and ongoing care of Younger Onset Dementia, as well as other rare neurodegenerative disorders, and their neuropsychology team also provides cognitive/behavioural management strategies. Without this level of assessment there is a risk that Younger Onset Dementia may take longer to be diagnosed or possibly miss being diagnosed.

The North West ACAS is based at The Royal Melbourne Hospital and is a community and inpatient service within North West Metropolitan Melbourne. The team is multidisciplinary and provides a comprehensive assessment to assess eligibility for commonwealth funded programs including Home Care Packages and residential care; assess for all restorative and potential care options; and support older people and their carers to identify what kind of care best meet their needs. People under 65 years will usually first require an assessment for eligibility for disability services. This ensures people receive the most age appropriate services.

Baptcare in its Northern Melbourne metropolitan region could offer Home Care Packages (HCP). The service provider could work in partnership with people with Younger Onset Dementia and their families to identify their needs and goals. It could also work with them to co-design the best ways to deliver the care and support services to enable them to live a more active and independent life. Specifically, using a home care package it could provide support services, such as house cleaning; personal care; respite care; nursing, allied health and clinical services; individualised service coordination, expert case management and diversional therapy.

As this symbiotic relationship evolved into a powerful partnership, their respective strengths proved integral to successfully supporting people with Younger Onset Dementia, who otherwise may have gone from crisis to crisis and possibly entering long-term residential aged care prematurely.

Foremost, the presence of three leaders who individually recognised that the complex needs of people with Younger Onset Dementia could only be met successfully, if they collaborated with other agencies that could complement their respective expertise, skills and resources. All three were highly committed to, and passionate about championing the needs of people with Younger Onset Dementia. They also had the capacity to frame the presenting problem so that key stakeholders within their respective agencies and potential partners could understand its significance and relevance to them.

All three leaders were highly confident in advocating both inter-organisationally and externally for the needs of people with Younger Onset Dementia. They were supported by their capacity to network and build relationships; their willingness to collaborate and be accountable; offer consistency of action and reliability; and their ability to articulate the goals of the partnership, roles and responsibilities. All these attributes and capabilities, as well as having ideas, being creative, tactful and politically savvy increased support for the partnership within their agencies and strengthened the trust of each other.

While on their own these skills were useful, years of professional experience and acumen had taught them that in order to achieve best practice outcomes, a sustainable partnership needed to offer value to their respective organisations. It also needed processes, structures and a common vision for the partnership to help equalise knowledge imbalances, build legitimacy, facilitate governance of the partnership and help implement the partners' agreement. They formally endorsed a project proposal which identified the partnership aims, the deliverables, the benefits and resources. All three agreed that the collaboration is continuing to go from strength to strength for the benefit of people with Younger Onset Dementia because they:

“had synergy. And part of that is about our personalities. We’re all fairly strong headed, fairly determined, incredibly passionate about what we do. Very committed to the agencies we work for. And fly the flag for our consumer group. ... We are leaders in the field.

(The collaborators).

Other enablers that promoted the collaboration included the backing offered to the partnership by the respective organisations and the support of individual teams, as well as having open channels of communication to cut through possible barriers. Equally as useful were the realisation that Victoria needed a new service system to support an emerging issue and the uniqueness offered by the NPU being a statewide service. The former provided the focus around a common issue, that is people with Younger Onset Dementia, and the later offered a window of opportunity to capture people with Younger Onset Dementia who have possibly been misdiagnosed and unsupported.

It is at this early point and most challenging time, when the Neuropsychiatry Unit offers a diagnosis that the collaboration is beginning to demonstrate its value to people with Younger Onset Dementia and their families. During this 1-2 week period inpatient admission, North West ACAS and Baptcare have a window of opportunity to conduct an assessment and to build in the necessary supports to help the family through the various stages of dementia.

Without this intervention, people with Younger Onset Dementia would continue to remain on waiting lists. Since deterioration of their health is quicker and the waiting time for home care packages is long¹, a delay in receiving home support services may in fact hasten their entry into residential care.

“It is that window of opportunity of trying to get support... by the time they’ve actually had their diagnosis they’ve probably been years out in the wilderness being misdiagnosed so they’re presenting with other issues. It is really just the timing and getting in there at the right time ... because their deterioration is quicker and the wait times for home care packages has been so long that if they go on a wait list and wait, by the time they’re offered anything they might be in care (residential care). It was ... probably one of the reasons (for) this collaboration.

(The collaborators)

The partnership did not bring additional monetary resources, but it recognised that existing resources could be reconfigured to allow for value adding. Baptcare and North West ACAS staff such as, assessors, care advisors, clinical practitioners, pastoral care workers and diversional therapists are invited to shadow staff at the NPU and attend ward rounds. Shadowing provides professionals a snapshot of how complex a diagnosis of Younger Onset Dementia is, while the North West ACAS Comprehensive Assessor and Liaison attends every week as a consultancy service providing information whether ACAS has a role, and if not, which service provider might within the community have a role. These arrangements strengthen the relationship between the three Organisations, create good will, facilitate the sharing of information, and safeguard the longevity of the collaboration as it is no longer dependent on only three key players for its survival.

More importantly, however, the above arrangements increase understanding of the need for timely access to support for people with Younger Onset Dementia and facilitate the synergy for helping people remain independent in their own home for as long as possible. It is for this reason that North West ACAS has made it a priority to dedicate regular staff time at the NPU ward round.

This provides for immediate access to assess newly diagnosed people with Younger Onset Dementia. It also allows ACAS to refer to the NPU someone aged under 65 years, knowing they will receive comprehensive assessment and follow-up.

Assessing people with Younger Onset Dementia while they are still impatient speeds up the process of linking them and their families to government-subsidised aged care packages. Receiving detailed information about the person with Younger Onset Dementia prior to visiting them at home, allows for increased understanding of the person’s behaviour and enables Baptcare staff to build an immediate rapport and trust with the person and their family.

When a referral is made by the NPU and a government-subsidised package is approved by North West ACAS, Baptcare already knows that the Unit and ACAS have had a conversation with the family about the features of the package and the relationship between Baptcare, the Unit and ACAS. Being highly recommended by the Unit and ACAS gives confidence to people with Younger Onset Dementia and their families that Baptcare has the capacity to support them well, builds trust and makes it easier for Baptcare to promote the Consumer Directed (CDC) package. It is also comforting to them that Baptcare recognises the names of staff at the NPU and ACAS and that all agencies will be supporting them together. It puts them at ease with something that is complicated.

Having the relationship with the Neuro-psychiatry Unit at and North-West ACAS it’s made that system work a lot easier ... , you know we’re already introduced to the client or the carer, so it takes some of that burden off the carer. It gives them that, ... , confidence, a little bit more at ease to say yes there is someone out there that can help us. ... that things will work out.

(One of Baptcare’s staff).

From Baptcare’s and ACAS’ point of view, the sharing of information proved to be a key to their successful engagement with the partnership. It helped their staff gain improved insights into the person with Younger Onset Dementia. It also helped build appropriate referral pathways and

¹ As of 7 April 2016 there were 1,765 people on the home care package waiting list for the North West Melbourne metropolitan region alone. People have been on the waiting list since 2012 (Source – North West ACAS).

a capacity to manage appropriately people with Younger Onset Dementia. Attending the ward rounds provided a unique insight into a highly specialised field that could and has broadened the capacity of staff to deal with a range of complex issues pertaining to older people and people with a disability, including managing challenging behaviours and the importance of having a clear understanding of the manifestations and implications of Younger Onset Dementia.

To Bapcare staff at the coalface, the NPU offers immediate access to its services for clients with Younger Onset Dementia, including assessment as an inpatient or outpatient, diagnosis, review of physical and mental health, as well as medication and strategies for managing challenging behaviours. Access to these, produce good outcomes for both the client and their family. The collaboration allows for an open communication and a consultative approach. It also broadens the multidisciplinary approach and opens up avenues for continuity of care.

When BANC PASS became involved with Ian², his partner was worn down by his obsessions, such as getting up very early in the morning and expecting his partner and children to wake up too, or what to wear every day for a month in advance. The home environment had become tense, chaotic and dysfunctional. With his input, various routines were developed to assist him to manage his obsessions. Once he understood these he was happy to follow through. For example, he agreed to wake up at 6:00am every morning, play on his iPad until 7:00am without waking up anyone else. This and several other routines developed by BANC PASS and being able to put that consistency of care in and to be able to work with other service providers, have made it possible for him to continue living at home and be part of the community

(One of Bapcare's staff).

Once Bapcare allocates a Care Advisor, they are invited by the NPU, with the consumer's consent, to attend the outpatient review together to provide either a written or verbal update about them.

That will occasionally occur when things are going well, and more often when there is a crisis, resulting in an immediate response by the treating team. This partnership not only allows Bapcare staff to consult directly with the treating team regarding the client and the disease progression, but it reciprocally allows the treating team to hear a professional perspective of the person's daily life and progress.

For ACAS the knowledge that a person with Younger Onset Dementia will be offered a home care package, soon after approval, allows more timely and informed feedback, creating a pathway to appropriate services and the opportunity to maintain independence within the community for as long as possible and prevents premature entry to residential aged care.

To BANC PASS, staff flexibility, commitment, consistency of care and longevity of the three partner leaders contribute to the success and stability of the partnership. To these leaders the collaboration, staff attendance at case conferences, sharing of information and views, having easy access to each other and maintaining the connection at the central core help build ownership, support and new champions; and more importantly, keep the momentum going in order to sustain the collaboration. To further strengthen the sustainability of the collaboration, the three leaders have recognised the importance of retaining the NPU and North West ACAS at the core of the partnership and expanding it to other Bapcare regions.

To the partner of and the person with Younger Onset Dementia, the NPU treating team was able to listen to their concerns respectfully, provide a clear understanding of the dementia, usually including the subtype of dementia, and provide information on strategies, management, treatment and illness progression.

² The name of the client has been changed to safeguard their anonymity.

With ACAS and Baptcare, together, they organised the necessary supports averting future crises.

When Kerry (Baptcare worker) came at home she saw that I was falling apart. She organised respite for Julia³. Two ladies came from ACAS and assessed her. People came to give her a shower, chatted with her and prompted her to eat. ... I wouldn't change anything about Baptcare with all the help that I got, the same about the Neuropsychiatry Unit and ACAS. They found what was the issue with Julia and what they were supposed to do they did it.

(Partner of person with Younger Onset Dementia)

An unanticipated benefit of the partnership is helping prepare for the eventual transfer of people with Younger Onset Dementia to the National Disability Insurance Scheme (NDIS). The NPU will continue to serve as an access point for people with Younger Onset Dementia, although, referral pathways may change while the NDIS is rolled out across Victoria over the next three years.

At this stage, it may be premature to state with certainty what referral pathways the Unit may have to change. It may also be premature to predict the likely impact on people with Younger Onset Dementia having timely access to support services. As discussed earlier, any significant delay in the delivery of services would most likely prove detrimental to their health and wellbeing and their families. During this interim period and until the NDIS is fully implemented in Victoria by 2018, people with Younger Onset Dementia will continue to be given timely access to assessment and support to avert rapid deterioration of their condition and a premature admission to a residential care setting.

BANC PASS recognises the importance of people with Younger Onset Dementia and their carers to be maintained in their social environment. This could be achieved through Planned Activity Groups (PAG) specific to the needs of this younger cohort; personal trainers, diversional therapies, educating carers and families about the disease, what to expect as the disease progresses and how

to keep people with Younger Onset Dementia active. There is also a need for residential care appropriate to the needs of people with Younger Onset Dementia.

BANC PASS is concerned that in Victoria, current traditional models of dementia services do not adequately take into account the life stage at which symptoms emerge and therefore may not be well equipped to support people with Younger Onset Dementia to remain living and participating in their community. Service options for people with Younger Onset Dementia are still bound to the aged care system which has largely been unable to meet the support, care and employment opportunities that more appropriately take into account the life stage, circumstances and expectations of this group. Supports specific to the needs of people with Younger Onset Dementia are required to maximise their capacities for participation in the activities that generally occur at this time of life, for example, family responsibilities, paid employment, and social and community activities.

BANC PASS is also concerned about the unintended consequences of means-tested supports offered through Consumer Directed Care (CDC) packages. This requires clients to make a financial co-contribution towards the purchase of services which they may not be able to afford and pose a significant financial burden. As a result, with the full implementation of the NDIS, people with Younger Onset Dementia may have access to funds but may opt out to purchase services that support their physical support needs to the detriment of life enhancement activities. Yet people with Younger Onset Dementia need to be kept active and stimulated to avoid rapid deterioration of their health.

³ The name of the client has been changed to safeguard their anonymity.

Conclusions and implications

The BANC PASS collaboration was established when it became apparent to leaders from the Neuropsychiatry Unit, North West ACAS and Bapcare that the complex needs and challenges faced by people with Younger Onset Dementia could not be met through the available resources of one agency alone.

Researchers have developed comprehensive theoretical frameworks for understanding cross-sector collaborations.¹³ Collectively, they reveal that support from the institutional environment is critical for legitimising cross-sector collaboration. They also reveal that a committed leadership with the authority, vision, integrity and political skills who are able to influence decision-makers and build resources, strategies and tactics are also important drivers that facilitate cross-sector collaborations.^{13,14,15}

Willingness by collaborating agencies to enhance each other's capacity and establish a formal partner agreement, trustworthiness, communication, capacity building of staff, managing tensions, planning and building on the distinctive competencies of each collaborating agency, as well as having sustainable stable systems and measurement systems also contribute to the formation of cross-sector successful collaborations.

The BANC PASS initiative provides important insights relating to the challenges of creating and maintaining successful cross-sector collaborations. The key challenge is aligning initial conditions such as skilful leadership and agency commitment to a common objective, as well as expertise and resources to meet that objective; processes and practices that generate confidence, trust and improved knowledge; structures and governance mechanisms such as channels of communication and formal agreements to avoid complications and confusion concerning partner roles and responsibilities.

Equally as important is to align these with outcomes and accountabilities to ensure that positive developments occur in a sustained way over time, so that a holistic, collaborative approach to meeting the needs of people with Younger Onset Dementia is established.

To further strengthen the sustainability of the collaboration, it is recognised that the NPU, North West ACAS and Bapcare need to remain at the core of the partnership. To improve outcomes for a larger number of people with Younger Onset Dementia it is important to expand the collaboration to other Bapcare regions, and explore how existing blockages, such as the co-contribution fee, in line with the current CDC policy requirements, could be reviewed and modified to take into account the financial difficulties experienced by people with Younger Onset Dementia and their families. Where the progression of the disease dictates 24 hour care, residential care dedicated to people with Younger Onset Dementia is currently missing and its development is urgently required.

Research is also required to ascertain the impact of caring for a person with Younger Onset Dementia, in particular the physical and health consequences, the needs of this group of people to remain living and participating in the community, the cost of caring and lost opportunity costs borne by families and the community. Further research is required to identify preventative measures that could potentially reduce the risk of developing Younger Onset Dementia or delay its onset, and ensure noticeable health and economic benefits for Australia.

References

1. Royal Melbourne Hospital [homepage on the Internet]. Melbourne (AUST): Neuropsychiatry Unit; 2015 [cited 2015 Oct 9]. Young-Onset Dementia Clinic. Available from <https://www.neuropsychiatry.org.au/page9/page22>
2. Alzheimer's Australia [Homepage on the Internet]. Canberra (AUST): Alzheimer's Australia; 2015 [cited 2015 Oct 6]. What is Younger Onset Dementia? Available from <https://vic.fightdementia.org.au/national/about-dementia/what-is-younger-onset-dementia>
3. BANC PASS. Interviews with BANC PASS leaders. Melbourne: unpublished; Sep–Oct 2015.
4. The Age [homepage on the Internet]. Melbourne (AUST); 2015 Dec 28 [cited 2015 Dec 28]. Grellman, R. We need more investment to stop the insidious creep of dementia. Available from <http://www.theage.com.au/comment/we-need-more-investment-to-stop-the-insidious-creep-of-dementia-20151228-glvh9.html>.
5. Harvey RJ. Young Onset Dementia: Epidemiology, clinical symptoms, family burden, support and outcome. London: Dementia Research Group/NHS Executive (North Thames). In: Access Economics. The dementia epidemic: economic impact and positive solutions for Australia. Canberra: Alzheimer's Australia; 2003. p.7.
6. Koedam ELGE, Pijnenburg YAL, Deeg DJH, Baak MME, and Van Der Vlies AE. Early-Onset Dementia Is Associated with Higher Mortality. *Dementia and Geriatric Cognitive Disorders*. 2008;26:147–152.
7. Thies W, Blieler L and Alzheimer's Association. Alzheimer's disease facts and figures. *Alzheimers Dement*. 2013;9(2):208–45. In: Mittelman MS. and Stephen SJ. *Translating Research Into Practice: Case Study Of A Community-Based Dementia Caregiver Intervention*. *Health Affairs*. 2014;33(4): 587-595.
8. Access Economics. The dementia epidemic: economic impact and positive solutions for Australia. Canberra (AUST): Alzheimer's Australia; 2003. p 20
9. Sorensent S, Pinquart M and Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist Affairs*. 2002;42(3):356-72. In: Mittelman MS. and Stephen SJ. *Translating Research Into Practice: Case Study Of A Community-Based Dementia Caregiver Intervention*. *Health Affairs*. 2014;33(4): 587-595.
10. Hall-Long K, Moriarty JP, Mittelman MS and Foldes SS. Estimating The Potential Cost of Saving From the New York University Caregiver Intervention in Minnesota. *Health Affairs*. 2014;33(4):596-604.

11. Mittelman MS. and Bartels SJ. Translating Research Into Practice: Case Study Of A Community-Based Dementia Caregiver Intervention. *Health Affairs*. 2014;33(4):587-595.
12. Crosby BC and Bryson JM. Integrative Leadership and the creation and maintenance of cross-sector collaborations. *The Leadership Quarterly*. 2010;21:211–230.
13. Bryson JM, Crosby BC and Middleton Stone M. Designing and Implementing Cross-Sector Collaborations: Needed and Challenging. *Public Administration Review*. 2015;75(5):647-663.
14. Bryson JM, Crosby BC and Middleton Stone M. The design and Implementation of Cross-Sector Collaborations: Propositions from the Literature. Special Issue, *Public Administration Review*. 2006;66:44-55.
15. Himmelman AT. On Coalitions and the Transformation of Power Relations: Collaborative Betterment and Collaborative Empowerment. *American Journal of Community Psychology*. 2001;29(2):277–284.
16. Page S. (). Integrative Leadership for Collaborative Governance: Civic Engagement in Seattle. *Leadership Quarterly*. 2010; 21(2): 246–63. In: Bryson JM, Crosby BC and Middleton Stone M. Designing and Implementing Cross-Sector Collaborations: Needed and Challenging. *Public Administration Review*. 2015;75(5):647-663.
17. Esteve M, Boyne G, Vicenta S and Tamyko Y. Organisational Collaboration in the Public Sector: Do chief Executives Make a Difference? *Journal of Public Administration Research and Theory*. 2012;23(4):927–52. In: Bryson JM, Crosby BC and Middleton Stone M. Designing and Implementing Cross-Sector Collaborations: Needed and Challenging. *Public Administration Review*. 2015;75(5):647-663.
18. Chen B. and Graddy EA. The Effectiveness of Nonprofit Lead-Organisation Networks for Social Service Delivery. *Nonprofit Management and Leadership*. 2010;20(4): 405–22. In: Bryson JM, Crosby BC and Middleton Stone M. Designing and Implementing Cross-Sector Collaborations: Needed and Challenging. *Public Administration Review*. 2015;75(5):647-663.

A successful collaboration

Neuropsychiatry Unit

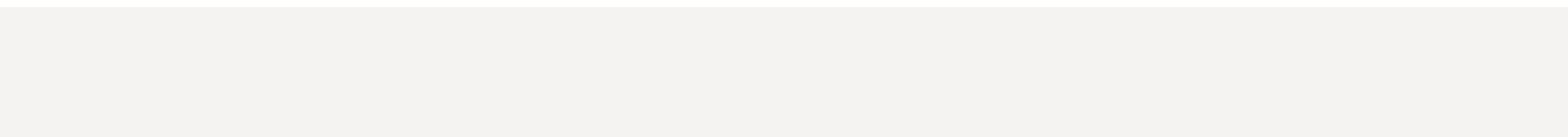
The Neuropsychiatry Unit (NPU) at the Royal Melbourne Hospital is an inpatient statewide service that offers neuropsychiatric, neurological, medical, nursing and allied health assessment. The Unit specialises in the diagnosis and ongoing care of Younger Onset Dementia, as well as other rare neurodegenerative disorders. Their neuropsychology team also provides cognitive/behavioural management strategies.

North West ACAS

The North West Aged Care Assessment Services (ACAS) is based at the Royal Melbourne Hospital and is a community and inpatient service within North West Metropolitan Melbourne. The team is multidisciplinary and provides comprehensive assessment to assess eligibility for commonwealth funded programs including Home Care Packages and residential care; assess for all restorative and potential care options; and support older people and their carers to identify what kind of care best meet their needs.

Baptcare

Baptcare proactively responds to human need to create positive change through advocacy, a diverse range of services and community engagement. Baptcare supports children, families, people with a disability, financially disadvantaged people and asylum seekers, and provides residential care and community care for older people. Baptcare works across Victoria and Tasmania.



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