



Bigger Hearts – Needs Analysis

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More information

If you would like more information about the Bigger Hearts project please go to our webpage or contact the project coordinator Dr Catherine Barrett

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Introduction



Bigger Hearts was launched in 2016 to build a more dementia-friendly Ballarat. The inspiration for the project came from Ballarat residents Edie Mayhew and Anne Tudor who describe how their responses to living with Edie's younger onset dementia made their hearts bigger. Anne and Edie are real about the challenges of living with dementia and at the same time try to find the positive in each situation. They listen to each other and work at strengthening the connection they share. They have talked about their experiences at national and international conferences and been overwhelmed by the supportive responses. That got us thinking that sharing the Bigger Hearts way of thinking could be a great way of engaging communities to support the development of dementia friendly communities.

The importance of building dementia friendly communities was highlighted in a report by Alzheimer's Australia which describes how many of the 332,000 Australians living with dementia feel socially isolated and want the community to be more dementia friendly. In response Alzheimer's Australia launched a campaign for a Dementia Friendly Nation and a Community Toolkit emphasizing the importance of social connection and consulting people with dementia as experts in their own lives. This point is reiterated in Alzheimer's Australia Victoria's White Paper on Dementia Friendly Communities which highlights that the strength and success of dementia friendly communities lies in the active involvement of people with dementia.

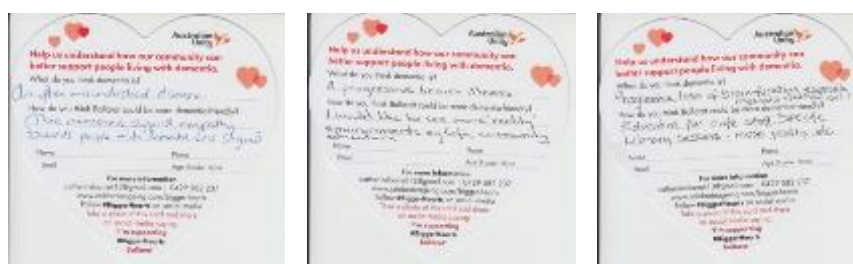
Bigger Hearts utilised creative arts and story based approaches to engage community members in building support for a Ballarat Local Dementia Alliance. The Alliance is a key step in the ongoing process of building a dementia friendly Ballarat.

The project was a collaboration between Celebrate Ageing, Alzheimer's Australia Vic, City of Ballarat, Australian Unity, The Ballarat North Community House and Carers Respite Service at Ballarat Health Service.

Needs analysis

To help shape the work of the Ballarat Local Dementia Alliance the Bigger Hearts project included a needs analysis. A series of heart shaped postcards were printed and asked community members: How do you think Ballarat could be more dementia friendly? The postcards were distributed through Bigger Heart Hubs - Ballarat businesses, services, groups and families are invited to become a Bigger Heart Hub. The hubs displayed a project poster and provided the blank postcards.

Blank postcards were also distributed through a series of face to face sessions at a local Café. A number of participants living with dementia and their family members raised strategies and asked the project coordinator to document their suggestions. The postcards were promoted over a three-month period.



This brief report outlines the major themes identified in the needs analysis. In particular, it analyses the response to “How do you think Ballarat could be more dementia friendly?” This report has been developed specifically for the Ballarat Local Dementia Alliance, to influence their strategies for creating a more dementia friendly Ballarat.

Results

How do you think Ballarat could be more dementia friendly? "People with dementia need to be part of the community, not apart from it."

A total of 159 postcards were returned to the Project Coordinator and thematic analysis identified seven recurrent themes. The most prominent theme related to the need for education. Education was further clarified as the need to better understand what dementia is, education to ensure that community members have the 'right attitude' to people living with dementia, and education of shop keepers so that people with dementia were able to interact with the community.

The second most common theme related to the need for more activities for people with dementia, followed by the need for more support and safety. A small number of postcards related to improved care and dementia assistance dogs.

In the following section 124 responses to the themes are outlined – in participants own words

Education

The predominant theme was the need for education. Subthemes were noted in relation to: understanding dementia, education for the right community attitudes and education of local retailers.

Understanding dementia

1. Education of the people about the effects of dementia
2. Education on what dementia is
3. We need more education. I think we have come a long way and educating people is the key
4. By making people more aware of the dementia and its effects it has on the brain
5. More knowledge, more education
6. More talking to people about dementia
7. Education and awareness. Programs to help people better understand
8. Education of the community, family and dementia support staff
9. We need to talk more about dementia, so everyone understands it better. Start with children
10. Awareness that dementia is not only for 'old' people
11. Take away the fear of uncertainty, fear of catching it, what it is
12. Understanding and awareness of what it is and how it affects people – to increase acceptance
13. Teaching younger people to understand it and be more aware
14. To understand what it is and how prevalent it is in Ballarat. To be accepting
15. Conduct workshops and get more information out in the community
16. More education in the community to allow a better understanding of this insidious disease

17. More education, more awareness in the community – early diagnosis for helping carers
18. More education, more awareness, isolation awareness for the families involved
19. More awareness and understanding, more encouragement to access the facilities and services available
20. It would be great if there was more community awareness
21. More awareness days like this
22. More preventative services to help educate the public
23. Recognise symptoms at an earlier stage.

The right attitude

1. By being more aware and considerate
2. People can be more thoughtful of one another
3. More awareness, support, empathy towards people with dementia – less stigma
4. Remember I don't remember
5. By recognising dementia for what it is and provide opportunities to improve quality of life for those affected and their families
6. Be patient and understanding
7. People having an understanding of being patient with people who have it
8. Educate people to allow them to be kinder to each other
9. People knowing more about the condition, people being kinder and more patient
10. Be more aware, tolerant and empathetic. Create dementia friendly spaces for everyone to feel safe in
11. Education to understand what people and families are dealing with
12. Just accepting people as they are
13. Some people with dementia feel ashamed and isolate themselves. Tell them there is no shame
14. A Travis Price mural on dementia that challenges shame
15. People with dementia feel part of Ballarat, rather than apart from
16. People with dementia need to be part of the community, not apart from it
17. Tell people with dementia to give the best they can from their hearts
18. Stop isolating people living with dementia
19. Love the country feel – build on it
20. Smile and be kind to everybody

Educate shop keepers

1. Education for café staff
2. Better education in cafes and shops
3. More awareness about when people are in public so they can understand it better
4. Improved awareness and understanding by retail and hospitality sector of symptoms of dementia
5. Be respectful of anyone acting differently in the shops
6. Introduction of the PALZ group (professionals with Alzheimer's Disease). Education for staff in shopping centres and other public spaces eg: libraries
7. Professionals with Alzheimer's Disease Group – PALZ in Geelong
8. Engage with people with dementia and their families. Be welcoming and do not isolate or feel fear

9. Need to provide information to young people as culturally not like Japan – ageing viewed negatively
10. By informing people about dementia and how they can help if they find a confused person in the street
11. More awareness of facilities to help carers in Ballarat like Eyres House

Activities

1. Activities to go to that is dementia specific within the community
2. Specific library sessions – music, poetry etc
3. Community garden with raised bed and circuit for walking
4. Open a dementia café where people and their carers can meet
5. Eyre's House is not suitable for everyone
6. Special café full of old memories, furniture and music
7. Different Cafes involved in having social events in different areas of Ballarat
8. People with dementia meet regularly
9. Opportunities for people with dementia to meet regularly and for coffee and conversation
10. Ballarat City Council support people with dementia to meet
11. People with dementia meeting in the Community
12. Getting together like the sessions at the Turret Café
13. Bus trips – nice days out
14. Maybe a place like fun bags for kids – but for the elderly
15. Exhibitions – have art by people living with dementia at the library. And have music
16. Computer training for people with dementia at the library
17. Evening with dementia book authors at the library
18. The city can provide social events for people with dementia
19. Social get togethers eg: live music, meals
20. Provide dementia specific activities for people to participate in
21. Better transport
22. Have more exercise groups for the elderly
23. Dedicated space for people with dementia to meet informally
24. A meeting place – dementia club for people with dementia to meet
25. Dance groups. Oral history. Contact with animals

Support

1. More family support and for the person with dementia
2. Support for carers – offer respite
3. More GP and allied health services specifically for people with dementia
4. Provide better funding and support for patients and carers
5. More accommodation tailored to meet the needs of dementia clients
6. Have better thorough GPs who diagnose and treat infections properly
7. Development of more dementia specific programs to assist carers and educate the community
8. Increase volunteer activity in nursing homes and GEMS and to increase stimulation and to increase education for nurses
9. Social support
10. Bus services specifically for people with dementia

11. Day groups – social gatherings involving transport
12. Buddies for shopping/outings etc
13. Provide more respite for the families, group activities, experiences for the people suffering
14. Have a dementia meeting place with bulletin board
15. Share information for people with dementia who don't have the internet
16. Give us a central place to find out about stuff
17. Raise awareness through the radio and the Ballarat Courier
18. More media advocating on behalf of people with dementia and their carers
19. Provide more nursing homes just for dementia
20. App for phones for family or carers
21. Help Centre – in person or online
22. Support network via Info Centre re local facilities- continence aids for sale, brochures etc
23. More respite facility day care to give carers a break

Safety

1. ID bracelet/badge. Safe places identified on Ballarat map
2. ID bracelet to make people aware of the condition
3. Get them to wear a bracelet saying they have dementia
4. Have people with dementia wear some form of ID bracelets or such
5. More dementia friendly res care facilities, sensory community gardens
6. Create a Hogeway Village similar to the one in the Netherlands – even on a small scale
7. Build a dementia village as in Norway
8. Create a safe environment where people with dementia can go eg: care
9. City of Ballarat needs to provide more dementia friendly public facilities eg: disabled toilets, gardens etc with wheel chair access
10. Town maps on corner of streets
11. Occupational therapy in universal design
12. Work out how to give her space. He is abusive and she is isolated
13. Stop the social isolation for people with dementia who are in abusive relationships
14. Dementia friendly audits of public buildings
15. A dementia seat sponsored by the City of Ballarat
16. Have a Bigger Hearts sculpture – like the 'harmony' round about
17. Use simple pictures such as 'compic' to help explain or label things

Signage

1. Signage at shops and bracelet for wearer to identify
2. Clearer signage around town. Safe places where people can go for help
3. Public signage on buildings showing safe places. Café signs and signs at police station and hospitals
4. Bigger Hearts signs indicating that people with dementia are welcome here
5. Clearer signage around town; picture signs
6. Considerate signage
7. Good, clear signage and some quiet areas for public events

Care

1. Providing care
2. Quality care is no 1

Dogs

3. Get more dementia dogs
4. Teach people how to be with a dementia dog