The Prime Minister’s Challenge on Dementia introduced under the last government emphasised the need to create “dementia friendly communities that understand how to help.” Similarly, a key focus of the National Dementia Strategy has been on reducing the stigma attached to dementia through promoting public awareness.

This has led to a number of dementia awareness initiatives across the UK, with the aim of presenting positive images and accurate information to demystify the condition and challenge pessimistic assumptions. The most notable national dementia awareness initiative has been the Alzheimer’s Society Dementia Friends campaign, which now has over a million members. And there have been several local initiatives, for example the Crawley Dementia Friendly project, a two year programme aimed at improving the experience of services and support people with dementia receive in the community, and, in Bradford, a number of culturally specific dementia roadshows delivered to raise awareness among minority ethnic communities (Parveen et al 2015). Such initiatives have generally been aimed at adults; however, there is also a need to educate the younger generation.

Atkinson and Bray (2013) report on an intergenerational exchange project where 22 pioneer schools promoted dementia awareness among pupils. Each school designed a bespoke curriculum to improve students’ understanding of dementia. Several beneficial outcomes were reported from this project such as increased awareness of dementia amongst students, reduced stigma and the recognition of the importance of learning about dementia in schools. But teachers also reported a number of challenges such as their own lack of knowledge about dementia and competing school activities. Atkinson and Bray go on to recommend that dementia awareness programmes in schools should have ring-fenced allocated time and be delivered by knowledgeable teachers. Students should also be given the opportunity to generate their own ideas on supporting people living with dementia. Based on these recommendations we developed ‘Dementia Detectives’.

**Dementia Detectives**

Dementia Detectives is a one-hour session dedicated to promoting dementia awareness and is designed for secondary school students aged 14 to 16 years. It aims to foster a positive attitude towards those living with dementia and to encourage young people to play an active role in ensuring that they live in a dementia friendly community. The session has been developed in consultation with young people aged 15 to 17 years. The metaphor of ‘dementia detectives’ is used throughout as a theme that connects with notions of finding out the truth and working as a team. The session, delivered by a knowledgeable facilitator with support from a teacher, can be incorporated into lesson time for existing subjects such as health and social care or citizenship. A slide presentation, using Prezi, has been set up to aid the delivery of the content and act as an online resource for students and teachers.

The session is structured as follows:

**Introduction**

The facilitator (Chief) splits students into detective teams: Team Sherlock, Team Quincy, Team Marple, Team Morse and Team Columbo. The students are provided with the following ‘brief’:

1. Bust the myths surrounding dementia
2. Discover how to support someone living with dementia.

**Operation PoD (Perceptions of dementia)**

This is an ice-breaker in which students are presented with the question “what is dementia?” and have five minutes to write down their thoughts in teams. This is then discussed with the rest of the group.

**Dementia myth-busting**

This 10 minute session draws on the best evidence about dementia to counteract myths and stereotypes. The facilitator talks about the nature of dementia, how lifestyles and other factors can put people at higher risk, the way dementia affects the life of the person, the way it might be noticed by family and friends and what can be offered to support people with dementia. The facilitator emphasises that the experience of dementia is unique to individuals.

**Operation Identity**

To challenge the stigma associated with dementia and labels of ‘us and them’, students are presented with five profiles of people who live varied lives and are asked to identify which of these people they believe to have dementia. The key message is that we cannot identify from the profiles which individuals have dementia and any assumptions made on the basis of stereotypes can be erroneous.

**We hope to gain Alzheimer’s Society accreditation to allow schools to be designated ‘dementia-friendly’**

**Living well with dementia**

To include real life narratives from people living with dementia, students watch videos of people with the condition discussing their experiences.

**Operation VIPs**

The final activity involves the facilitator reinforcing the message that people can live well with dementia if provided with the right support. Students watch the Dementia Friends video prior to working in teams to generate ideas they can implement to support someone living with dementia in their community.

**Case Closed**

The session ends with a lessons learned summary, which includes five brief statements that seek to reinforce accurate knowledge and positive attitudes.

**Dementia Detectives: busting the myths**

Sahdia Parveen, Jan Robins, Alys W Griffiths and Jan R Oyebode describe the one-hour dementia awareness programme they developed for secondary schools
Top tips for delivering Dementia Detectives

by “Chief Superintendent Robins”

- Have everything prepared and ready to use, make sure all papers are in order ready to give out quickly to avoid time wasting and disruption
- Be aware that young people may have a family member with a dementia diagnosis and the workshop may cause anxiety. Give young people the opportunity to speak to you in private after the session.
- Do not use jargon as younger people will quickly lose interest if they cannot follow what you are saying
- Be prepared to be challenged and questioned, but keep your answers short and concise
- Be sensitive to any signs of embarrassment or shyness with young people and treat gently
- Your adult humour may not be appreciated by younger people, so think carefully before you try to use it
- Avoid speaking for too long and use the video clips as much as possible
- Most young people are always hungry, so take in some biscuits or cookies, particularly if you are speaking to them just before break or lunch.

Post-Dementia Detectives

Students can take home the lessons learned summary, which also contains clues (a QR code) to extra activities they can complete at home with friends and family. They are given a link to the Prezi which contains hidden activities that foster further understanding and empathy: There is a Twitter account (@demdetectives) for students and teachers to follow and regular messages are tweeted by the team. Students are encouraged to tweet the team their thoughts and ideas using the hashtag #dementiadetectives

The Cambridge case

Our first Dementia Detectives workshop was delivered in a secondary school in Cambridge by one of the authors, Jan Robins. To evaluate the impact of the session, 38 students were asked to rate their knowledge of dementia on a 10-point Likert scale, ranging from “1 – Nothing” to “10 – A lot”, before and after the session. Students’ perceived knowledge improved from an average score of 4.5 to 8. At the end, we asked students to rate out of 10 how easy the information had been to understand and we received an average score of 7.8. We also asked students to rate how much they enjoyed Dementia Detectives, for which we scored 7.9. Thirty six of the 38 students said they would recommend the session to their friends and others.

Students highlighted the “best bits” of Dementia Detectives as: learning about types of dementia, group discussions, the videos, discovering how to become a dementia friend, and finally the biscuits – an important lesson for future workshops! As this was the pilot workshop, students were also asked how it could be improved. The majority reported that they would have liked more interactive activities and physical activities. One of the students suggested that they would have liked a person living with dementia to attend the session in order to provide a face-to-face account of their experiences. Words most commonly used to describe Dementia Detectives are shown above right.

Future plans

We are in the very early stages of developing and delivering this exciting initiative. In the near future we hope to gain accreditation from the Alzheimer’s Society, which would allow schools to be designated ‘dementia friendly’ as a result of hosting Dementia Detectives. We are also conducting research with young people to explore perceptions and attitudes towards dementia, which will enable us to further tailor the sessions to challenge specific misconceptions. We hope to start a steering group of young people and people with dementia to produce a wide range of fun interactive activities. Although Dementia Detectives sessions are currently led by an experienced trainer, we hope that in the future teachers will be able to do it in partnership with people with dementia.

Finally we would like to roll out the initiative to more schools and conduct a formal evaluation of the impact of Dementia Detectives on the knowledge and attitudes of young people.

References


I Sahdia Parveen is a post-doctoral research fellow; Jan Robins is a dementia trainer and lecturer in dementia studies; Alys Griffiths is a research assistant; and Jan Oyebode is a professor of dementia care. The Dementia Detectives team is based at School of Dementia Studies, University of Bradford. We are grateful to the following for their support: Iffat Mamoon, Sanna Mamoon, Shireen Yousaf, Janine Hamilton, Stephen Morris, Maz Khalid and Heather Blakey.
Connecting Communities: sharing the learning

Sophie Leatherland and Alli Anthony report on the Alzheimer’s Society’s Connecting Communities project to increase dementia awareness within Black and minority ethnic communities in London boroughs, with a special emphasis on celebrating volunteers

The risk factors for developing dementia, such as high blood pressure and diabetes, are more prevalent among black, Asian and minority ethnic (BAME) groups. There are 25,000 people with dementia from these groups in the UK, and this number is set to rise. Despite this, people from BAME backgrounds are underrepresented in dementia services, often only engaging with services at a crisis point, and diagnosis rates for people from these communities are particularly low.

There are many challenges that prevent BAME people with dementia from accessing appropriate services. There is no word for ‘dementia’ in south Asian and some African languages; often words synonymous with ‘madness’ are used instead, adding to the already significant stigma of the condition. There is further fear of social isolation as a result of that stigma.

Although work is being carried out to redress the balance, there are still relatively few culturally sensitive dementia services available in local communities. There can be presumptions that family carers from BAME backgrounds would be uninterested in receiving “outside help”, as there is a strong tradition, particularly among Indian, Chinese and Pakistani communities, of children looking after their elderly parents. Such assumptions can mean health and social care professionals offer fewer opportunities for support to family carers

In my community people were saying my dad had gone crazy, and that the disease was payback for something bad he did in his life. I don’t blame them for not knowing about dementia, but it’s really important that they can learn about it in a way that is sensitive to their culture. Connecting Communities is great at doing this.

Project volunteer

(Moriarty et al 2011). We know that having the right advice and support in place can better allow family carers to look after their loved ones without putting their own health or emotional wellbeing at risk.

In 2012 Alzheimer’s Society secured three years funding to pilot Connecting Communities, a dementia awareness project within BAME communities across eight London boroughs. The project is funded by the Department of Health (DH) with a focus on celebrating volunteers and volunteering, thereby contributing to the DH’s Strategic Vision for volunteering in health and social care and its integration into the delivery of their strategic outcomes.

Many different communities live in London with varying cultural perspectives on volunteering, dementia and local support services. Previous work to engage with less often heard communities has identified the importance of looking at communities individually. This project provides the opportunity to engage with diverse groups in a flexible way that addresses recognised issues around BAME engagement with dementia care services.

The project works in many ways to raise awareness of dementia, for example:

• Contacting and working with community leaders to engage local groups in thinking about dementia
• Contacting and working with health care professionals
• Delivering awareness raising talks about dementia in the community, covering signs and symptoms, common myths and where to go for help
• Holding information stalls at local community events.

Responding to different cultural needs

A flexible approach to delivering the project allows the specific cultural needs and concerns of a community group to be acknowledged and worked through - different methods of engagement can be used according to different traditions and social customs. For example, when working with a group of south Asian women the group leader suggested a half day focusing on food and dementia. The group began with a picture quiz of traditional dishes from across the world, listened to a dementia awareness talk (with the help of an interpreter so we could present in English and Hindi), then shared lunch with dishes from different countries before a group discussion on the stigma around dementia.

Connecting Communities also works to share its learning within Alzheimer’s Society by better enabling operational managers, who oversee the running of support services across England, Wales and Northern Ireland, to recognise the demographics and cultures of the areas they work in and equipping them with the tools to engage effectively with them. By understanding more about who lives there, operational staff can work towards ensuring that the demographic profile of the users of their services reflects the population there. The project is now engaging with local groups to seek views on how our own services and information initiatives can be better shaped to be inclusive and more accessible to all communities.

In some areas Alzheimer’s Society already provides culturally specific services. This includes our information programme for south Asian families, which has been piloted across 15 sites to increase the knowledge of family carers. We are making good progress, yet we know we still need to do more to ensure that our existing models of information provision and service delivery are culturally sensitive and accessible to all.

The project has also aimed to increase the diversity of our volunteers in our eight pilot London boroughs. We have had to overcome some challenges, for example, e-learning, advertising, and the very definition of ‘volunteering’ in some communities for whom the practice is less well established.

Key learning points

We have identified some other key learning points for raising awareness in BAME...
Connecting with a local mosque

Earlier this year one of the Connecting Communities volunteers worked with a local mosque in north London, enabling Alzheimer’s Society’s national awareness-raising bus to park on the site during a large family event. Many meetings and weeks of careful negotiations with the mosque leadership, as well as significant publicity before the event resulted in many people seeking out advice and information on dementia. Our volunteer reminded the team:

• to please have both female and male staff on the bus, as the female members would not go to the male section and vice versa
• to have leaflets in Gujarati and Urdu
• to please dress modestly, including head coverings if female staff entered a building on the site
• to confirm that there would be two entrances to the bus - female and male.

By respecting all these simple requests we were able to give advice and information to over 25 families caring for people with dementia or worried about their own or a family member’s memory.

communities. For example, it can take many months to build trust with a community. Small organisations may find it less of a priority to engage with a large organisation such as Alzheimer’s Society when diminishing funds, limited access to technology, significant time and staffing constraints are all everyday realities.

This should be taken account of in the lifespan of an awareness-raising project to ensure that sufficient time is given to open up a dialogue with community leaders. Community or religious leaders are often the key to bringing the issue of dementia to audiences that might never have heard the word before. Their trust and backing is essential.

Approaching the end of its pilot phase, the project is turning its attention to sustainability. How can best practice when raising awareness of dementia among BAME groups continue to be identified and replicated and how can the needs of people with dementia from BAME backgrounds continue to be a priority in dementia service provision?

Currently the project team are producing an information booklet on dementia that will be available in 12 languages and will cover the types and causes of dementia, symptoms, how to access help and support, and reducing the risk of developing dementia.

References

Sophie Leatherland is project administrator and Alii Anthony is project manager, Connecting Communities.

Journal of Dementia Care policy for involving people with dementia and carers in our events

The majority of our conferences are aimed at professionals who work in dementia care. They aim to give examples of best practice and current thinking and allow opportunities for professionals in the dementia field to share information and experiences.

We also want to make sure that wherever possible, we include presentations from people with dementia and their carers. This is a great way of raising awareness – helping people working in dementia services understand what it is like to live with dementia.

The most effective way of making sure that the experiences of people with dementia and carers are included in our conferences is to include them in the programme. We also encourage professionals who submit abstracts to include and involve people with dementia and carers as much as possible.

All presenters at our conferences, including people with dementia and carers who are part of presentation teams (in limited numbers), can attend our events at no charge for the day of the presentation.

People with dementia and unwaged carers who are not part of the event programme will be offered reduced rates to attend our conferences on a first come first served basis. The rate will vary for each conference – please see our website www.careinfo.org/events or contact events@hawkerpublications.com.

In addition, we understand that some people with dementia may need support to attend our conferences. Therefore, subject to availability of places, the fee for a supporter will be waived for any person with dementia who needs help to attend and / or present.
Adaptive clothing to help with vital personal care

Matthew Crooks describes how he and colleagues developed ways of adapting people’s own clothes for ease of dressing and undressing, especially helpful where, despite person-centred interventions, individuals remain resistant to personal care

Physical restraint is occasionally necessary even when there is a good care plan in place. Our challenging behaviour service regularly develops care plans that focus on assisting staff to attend to a person’s personal care. While difficulties can often be resolved with a purely psychosocial approach, it is sometimes necessary to include a contingency element for the use of physical restraint so that we can respond to a person’s essential intimate care needs (Sells & Howarth 2014).

Recourse to physical restraint usually follows episodes of incontinence when it has not been possible to reassure the person sufficiently to let staff assist them, and their health and dignity are deemed to be at significant risk. But staff in care homes have rarely been given the opportunity to learn how to use physical restraint appropriately and safely.

In consequence, a number of people in our area have been admitted to hospital because of their level of resistance to staff interventions for essential personal care, despite being settled at all other times. Moreover, there were inpatients whose only challenging behaviour was their ongoing resistance to personal care, but who could not be discharged as no other care environments provided their staff with the necessary skills to meet these needs.

Physical restraint training

Over the past 18 months the challenging behaviour team has been delivering bespoke training in physical restraint to staff in a range of care settings. Great care is taken to ensure that the interventions are always the least restrictive and have been formally assessed as being in the person’s best interests. The training involves a collaborative process with staff to identify the most suitable techniques to assist the person.

Typically, the final care plan sets out one or two restrictive interventions that must only be used with the person in question. Since a limited number of techniques were identified in these care plans, it was possible to give staff with no previous prevention and management of violence and aggression (PMVA) training the skills to respond effectively to people in deep distress. This training could usually be delivered in two or three hours.

Removing soiled clothing

However, while the person was now being attended to more safely, it left the problem of removing the person’s soiled clothing while being held. Releasing their arms so as to remove a shirt sleeve, for example, meant losing control and exposing everyone involved to an increased risk of injury and upset.

There are ways to remove a person’s clothing while they are in restraint but these can be complicated to learn and require staff to be able to utilise a number of additional techniques. It was simply not possible to teach those techniques properly in the time available so an alternative had to be found.

One common approach is to change the type of the clothing that the person wears. This usually involves dressing people in loose fitting garments such as T-shirts and tracksuit bottoms. This clothing can be removed more easily, although it doesn’t solve the problem of how to get it off completely without letting go. It may be a sensible approach in some ways, but it leaves lots of elderly people dressed in clothes that most of them would have been unlikely to choose themselves.

We felt that an alternative allowing people to wear clothes of their choice should be sought. We looked at the options for specialist adapted clothing, but found only a few retailers and they offered a narrow range of designs, making this a less than ideal solution. Several companies could have made alterations but quoted fees ranging from £35 to £50 for a single item of clothing. It was prohibitively expensive for most people so we began to think about how their own clothing might be adapted.

An alternative approach

Initially some samples were made up in the hospital sewing room. They did an excellent job but they could only adapt clothes for inpatients, including those being discharged with a relevant care plan into a care home. But most of our team’s work is done with people who are already living in a care home.

We have been very fortunate to find several staff in care homes who were former seamstresses or sewing machinists. Angela O’Connor, a carer from Blyth, was particularly helpful and looked at how different types of garments could be altered. She tried various types of fastenings such as Velcro, zips and press studs, and we had lots of discussion about how best to adapt the garments.

It was important to consider the comfort and aesthetics of the adapted clothing as much as the practical aspects. We didn’t want it to be immediately obvious that the clothing had been adapted. We also had to consider the make-up of the garments in the context of the kinds of physically restrictive holds that were likely to be used.

Soft-backed Velcro was our preferred option, especially as it is cheap and easy to use. We decided to alter the clothes as follows:

- Shirts are split and Velcro-ed down the front and back and sometimes along the sleeves so they can be pulled off in two pieces. Buttons are sewn back down on the front of the shirt to ensure that it appears unaltered.
- Trousers are split along the seam stresses or sewn with a carer from Blyth, was particularly helpful and looked at how different types of garments could be altered. She tried various types of fastenings such as Velcro, zips and press studs, and we had lots of discussion about how best to adapt the garments.

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- Trousers are split along the outside seams and Velcroed back together. A press stud tag is placed at the top of each seam along the waist in order to prevent the trousers from separating during normal wear.
- Dresses are altered in several ways depending on the material, although they are usually split along the seams down either side, or across the shoulders and down the arms, in order that the garment can be pulled off in one piece.
• Undergarments such as pants and knickers can be pulled down slightly and then removed from a seated position. The same applies to socks and stockings. If vests or slips are worn, these should ideally be loose fitting for ease of removal. If necessary, they can be adapted with press studs or Velcro.

Adapting people’s own clothing has kept costs to a minimum, although they are admittedly still significant. The fee is £7 per hour plus the cost of materials and utilities. Unpicking stitching can be time consuming so a pair of trousers might cost between £15 and £20, depending on how they are being altered. There is a similar cost for shirts but the cost for dresses varies.

Our approach has made a big difference by reducing the duration of interventions and associated distress

Overall, though, it is still much cheaper than purchasing a whole new wardrobe and it is expected to be a one-off expense. The number of sets of clothes required is based on the frequency of the need to intervene. For some people this might mean only two or three sets, giving sufficient leeway for laundering. But for others twice this number may be needed. Of course, it is less expensive still if people’s families or care homes can make the alterations themselves and this is encouraged where it is a possibility.

The project in action

So far feedback on the use of the garments has been very positive and staff are normally enthusiastic. In addition to the upset caused to the person receiving care, staff themselves often find physical interventions distressing and are keen to do anything to avoid or reduce the need for them. Most contingency interventions in care plans involve three staff, two of them holding the person’s arms while a third attends to their care as quickly as they can. The most difficult and prolonged part of the intervention is usually the removal of the clothing. Reports suggest that interventions that might have taken 10 or 15 minutes can be cut to five minutes or less if the adapted clothing is worn.

So our approach has made a big difference by reducing the duration of interventions and all the associated distress. It is a significant consideration in contingency care plans. The clothing also has the potential to be used more broadly to assist with less challenging difficulties around personal care, preventing the need for more restrictive physical interventions in the first place.

Where people unintentionally put on extra layers of clothing, adapted garments can help to deal with the situation. By starting to pull the garment apart and drawing the person’s attention to it, they will sometimes finish removing the clothing themselves. In other circumstances a staff member can engage them in conversation or distract them while clothing is taken off with the minimum of fuss.

In the light of our experience, there may well be an opportunity to use this type of clothing more widely. With this in mind we’re looking at how it can be produced efficiently on a larger scale while also ensuring that it remains affordable.

Reference


Matthew Crooks is a registered mental health nurse and challenging behaviour lead practitioner (community) at Northumberland Challenging Behaviour Service, Northumberland, Tyne and Wear NHS Foundation Trust.
The involvement of people in decision-making relating to their care and support is essential and people with dementia are no exception (Samsi & Manthorpe 2013). In health and social care education and training, the perspectives and aspirations of people with dementia are increasingly discussed (Tremayne et al 2014), but there is less evidence that they and their carers are involved as direct contributors to educational initiatives, particularly in higher education (Innes et al 2012).

Here, we discuss a project that set out to provide an answer to this lack. In September 2014 a new undergraduate course was launched at the University of Worcester – the Foundation Degree in Dementia Studies. Its aim, over two years, is to equip students with the knowledge, skills and values to enable people with dementia, and their families, to live well. The lived experience of dementia has been placed at the centre of the degree through a new role - the expert by lived experience tutor – that will enable people with dementia and family carers to make frequent contributions to teaching in both years of the course.

Design of the initiative
During the design of the course four meetings were held with people living with dementia and family carers, which were facilitated by Alzheimer’s Society and the local LINK group whose membership comprises carers and people with dementia themselves. The LINK group is affiliated to the Dementia Engagement and Empowerment Project (DEEP) and advises the Association for Dementia Studies at the University of Worcester on the design of teaching and training courses.

Two priorities emerged from these consultations. Firstly, that the Foundation Degree would be enhanced by the regular and frequent contribution of people with dementia and family carers, and to maximise this impact the same group of people should accompany the students as they progressed through the two years of the course. This would enable stronger working relationships to be established and would also assist students to better understand the progressive nature of dementia.

The second priority was that the local Alzheimer’s Society should help identify potential candidates for the expert by lived experience tutor role. It was recognised during the consultation process that this risked appearing paternalistic. However, the people with dementia with whom the course design was discussed were consistently clear that the initiative would not suit everyone and that there was a high risk that people would be disappointed if they found they were unable to perform well in the role.

Consequently we adopted the strategy of using local knowledge of possible candidates to inform the recruitment process. Rather than advertising to everybody, suitable candidates were selected from the memberships of groups run locally by Alzheimer’s Society and LINK with the result that four people with dementia and two family carers were recruited as tutors. Essential criteria (designed in consultation with the groups) were used to help identify the tutors. These included:

- Experience of living with dementia, or, experience as a carer for a person with dementia.

Launch of the tutor role
After initial introductions at the students’ university induction, tutors then went on to take part in four tutorials during the academic year in which they discussed study topics with small groups of students. Additionally, tutors assisted in the assessment of a poster assignment exploring the theoretical basis for understanding the experience of dementia, and gave feedback to students on their work.

Learning from the initiative
We have been carrying out research on the first year of the Foundation Degree as it has progressed. There are two phases of the research. The first explores tutors’ motivation for involvement in the initiative, and their aspirations for it. Detailed results have been gathered from this and are discussed below. The second will look at tutors’ experiences of participation. Alongside this, we are also exploring the value the initiative has had for student learning.

Motivation for involvement
It was clear from the research that people’s contemporary contexts are important to them; the expert by lived experience tutor role does not exist in a vacuum. Tutors said that they would need to convey prominent aspects of the experience of dementia to students as a key part of their involvement.

For example, dementia brings a sense of loss, manifesting itself in different ways. There might be a feeling of loss stemming from having to stop doing things or being unable to do the things that you used to do. A tutor said: “I used to do lots of stuff, lots of...”
How one class worked

Four tutors living with dementia met with the 11 students on the Foundation Degree for two hours. The students had prepared a topic each that they wanted to discuss in small groups, each involving one of the tutors. The topics were:

- What assists with communication? i.e. What should people without dementia be aware of and do to make sure they communicate well with people with dementia?
- Are people in general more aware of dementia?
- What is the best way to protect your own rights?
- What is important to you about maintaining your own feeling of dignity?

A plenary session followed the small groups in which learning from each topic was discussed. Finally, students returned to their small groups to explore in more detail matters arising from the class as a whole.

Things I can’t any more…and it is pretty awful actually. I mean it is pretty awful.” The impact of change was another factor tutors wanted to get across, the fact that dementia meant you had to make changes in your life and that you had to adapt. For example, mental activity required an accompanying period of rest to recover strength in a way that was unnecessary before dementia.

The significance of demonstrating competence and the value of support were other issues they wanted to raise with students. Tutors said that, on a daily basis, it felt as if it was essential to show to people that you could continue to achieve a great deal, but also consistently said that partners and families provided invaluable support. One said: “I’m a very fortunate person and have a lot of support; I don’t think it’s hit me as hard as it would be if I was living alone.” The same person recounted that peer groups were also invaluable to a feeling of being supported, the example being her local D EEP group.

Clear reasons emerged from the research as to why participants wished to be tutors. The most significant and consistent was the importance of making a positive contribution. Tutors related their aspiration to share knowledge about their own experience of dementia to help the students learn. As one said, “...this is just a small way of putting a little something back...this is a little way I can do something...” Studies in other contexts have highlighted this as a significant motivation too, e.g. Keenan (2014) which explored the involvement of service users in cancer professionals’ education. Additional reasons for participation included boosting tutors’ own feelings of confidence which some felt they had lost since diagnosis. Carers also reported this as their motivation. Clemison and Moseby (2013) found that “service users” could boost their confidence by contributing to programmes in higher education. Later in the programme we will explore whether people living with dementia, and family carers, experience similar outcomes.

Having the opportunity to enhance one’s own learning about dementia, and the opportunity to reflect upon one’s own unique dementia journey through engagement with the course, gave another reason to take part. As a tutor told us: “It could be very interesting I think, to understand a bit more...part of it will be good for me to show my understanding about it and to be involved in it and I am very happy for that.”

Tutors agreed that the benefit of the initiative would be genuine insight for students, but they identified challenges too. First-hand knowledge was put firmly in the plus column. As a tutor said: “Well I think for a start they know we know what we’re talking about. Because if you’re going through something, experience is the greatest teacher of all, and so therefore my experiences will be true ones, they won’t be made up ones or something I’ve read from a book. I think there’s nothing quite like it being real to get through to your students. You know, you’re not just spouting it from a book or anything.”

The challenges tutors identified to participation included worries about their own knowledge of dementia, and the mechanics of the course. They voiced concerns about the impact illness and feelings of low energy might have upon their ability to attend and contribute. But the response of students was also critically important, tutors consistently saying they wanted them to take a proactive and enquiring approach in class. They wanted students to show they were engaged and keen to learn. As one tutor said, “...it has to have a fair amount of dialogue...that’s the important thing...students actually asking me more than me telling them.”

Experiences of participation

Data on tutors’ and students’ experiences of participation will be fully analysed in the coming months when the first year of the course has concluded. However, early exploration of students’ views on the value of the initiative for their learning has revealed positive feedback. One student said they felt “privileged” to be given the opportunity while another said “it has been beneficial to hear the tutors’ experience of diagnosis and their journey so far.” A third student added: “The concept of role reversal was key (ie people with dementia and carers as tutors). It gave a picture of the paradigm shift in dementia care over the last decade.” Understanding the experience of dementia in a holistic sense is essential if people are to live well with the condition (Kitwood 1997; Brooker 2007). It is envisaged that the expert by lived experience tutor initiative will assist students to understand the condition by giving them a chance to engage frequently with the same group of people and their carers throughout their studies. The research will be analysed so that we can better understand the educational benefits of the initiative and use it to ensure the fullest appreciation of what is involved in life with dementia.

References


Chris Russell is senior lecturer in dementia studies at the University of Worcester and Dr Qiong Xuis visiting research associate at the Thomas Coram Research Unit, Institute of Education, University College London.
Forget me not: group support for younger people with dementia

Jacqueline Parkes and Alison Ward report on the development of a tailor-made social group to support people with young onset dementia and their families in Northamptonshire

Since its launch nearly two years ago, the Forget-me-nots Social Group for people with young onset dementia (YOD) and their carers has played an important role in our locality. It has come to provide a safe and non-judgemental environment where Northamptonshire people living with YOD can meet to discuss issues, share ideas, arrange events and activities, and have fun with their partners, carers and family.

Our social group was established after painstaking work by the University of Northampton and Alzheimer’s Society Northampton (ASN), and our purpose here is to set out why we came to the conclusion that it would make a valuable contribution to dementia care and support in this county, a conclusion that may well be applicable to other areas of the UK.

County-wide survey
To start with the university and ASN sent out a jointly designed county-wide survey to ascertain the need for a specific community-based social support group for people with YOD and their carers. The findings indicated a need for people with dementia and their carers to be more actively supported in rebuilding normal social networks following initial diagnosis.

Based on the initial findings, both partners agreed to support the development of the Forget-me-nots Social Group. Following 18 months of joint planning meetings, Forget-me-nots was launched at the University of Northampton on the 25th July 2013. Before going into more detail about our survey, it is worth noting that the broader context was also a factor in our decision.

Current conservative estimates of numbers of people in the UK with YOD are 17,000, but the true figure could be as much as a third of the total population for all types of dementia (Alzheimer’s Society, 2012). In the early stages, dementia in younger people is more difficult to recognise than late onset dementia (van Vliet et al., 2012). Factors contributing to such delays include the younger age at diagnosis and atypical presentations, behavioural non-cognitive and psychiatric presentations being common in this group (van Vliet et al., 2012).

The psychosocial and personal impact of the illness on a younger person is known to have “devastating consequences for productivity, family and society” (Bakker et al., 2008; Fardil et al., 2009, van Vliet et al., 2012), as individuals experience significant alterations to their sense of self, feelings of dependency, loneliness, and social isolation, and a “lack of meaningful occupation” (Harris & Keady, 2004). In addition, services are often aimed at an older age group and do not meet the social interests or physical capabilities of people with YOD (Beattie et al., 2002; Jefferies and Agrawal, 2009). Bakker et al. (2010) argue that services designed for this younger age group can be beneficial for both the person with dementia and their carers, through improved wellbeing.

Clearly, the physical, psychological, and social impact of the disease process on both the individual with a diagnosis and their family is enormous, not least in the resultant feelings of loneliness and social isolation. Kane & Cook (2013) say that 33% of people living with dementia have reported losing friends following disclosure of their diagnosis. The government has identified the need to reduce loneliness and increase social connectedness for people living with dementia in the community in order to improve quality of life. A range of strategies have been launched to enhance public knowledge and attitudes towards dementia, and promote social inclusion and normalisation (DH 2009; DH 2012).

Across the UK, there is little understanding of the unique needs of people with young onset dementia and therefore limited availability of specialist services, making it difficult to access adequate support (Kane & Cook, 2013). Northamptonshire has been no exception. In this county, there were 185 people estimated to have YOD in 2009, which was predicted to rise by 23% by 2025 (Northamptonshire Observatory, 2014). Against this background, the need for the Forget-me-nots Social Group was stark.

A further consideration in undertaking our survey was that, since its inception, the Dementia Research Network (DRN) at the University of Northampton has focused on early diagnosis and timely referral to appropriate care pathways for people living with dementia, while ensuring that their ‘voices’ and those of carers underpin all the work it undertakes. From early on, members of the DRN highlighted the apparent dearth of age-appropriate and accessible specialist formal care and informal support networks for people with YOD across Northamptonshire.

So our joint survey was formulated in partnership with ASN, Northamptonshire Healthcare NHS Foundation Trust, and St Andrews Healthcare, Northampton, to investigate the extent to which people with YOD and their carers would access specialist YOD support groups, if available. From February to April 2012, the dementia support workers at ASN distributed and supported people with YOD and their carers to complete the survey. A total of 17 completed questionnaires, (four from people with YOD, 12 from carers, and one not specified) were returned to the DRN for analysis.

Key findings
The most significant theme to emerge from the findings was the desire for a specific tailor-made service “because younger people have different social needs and preferences”. Sixteen respondents felt it would be beneficial to have a separate county-wide YOD service, while 10 respondents felt that the younger age of their loved one was a barrier to accessing current services, which were “more suited to older people”. Several views highlighted the “different issues and problems” arising before “retirement age”, and the desire for “still functioning as a younger person in society”.

It was suggested that a new specialist social support service “aimed at younger people would [not only] cater more for their interests and tastes”, but would also enable carers to relate to others experiencing...
similar issues, and get the most relevant support and advice available for their unique circumstances. One respondent commented: “As a carer, I find most people my age are caring for their parents and not partner. I would like to meet with people in the same age bracket and situation as myself”. And another carer said: “My husband is 60 years old with dementia and day centres are not ideal for him. I am younger and would appreciate some help and advice”.

A strong message to emerge from the findings was the desire to be socially connected to other people in a similar situation. Several respondents commented on the increased feelings of “isolation” and “friends disappearing” since diagnosis. People talked about valuing peer support from people of “similar ages and at different stages of dementia” and being able to learn and understand together what “younger people can and can’t do”. Such support, it was said, should “encourage hobbies, encourage interaction, meeting to resolve problems e.g. ‘why do I feel useless?, why can’t I work? Etc.’ Talk about these and other feelings. How to move forward.” Someone suggested that peer support could offer “anything that would help us as carers know/understand more about dementia and how we can care/support our family member with dementia and other family members i.e. our children”.

Respondents told us that the nearest services of the kind they described were in London and Oxford. Most respondents indicated a willingness to travel between five and 10 miles, two were prepared to travel between 10 and 15 miles, and two would have considered travelling over 15 miles to access a YOD social support group, if one was started locally. Nine people indicated that they would be happy to attend the group once a month and four wanted to meet fortnightly, while a majority indicated that weekday afternoons were their preferred time. Five respondents said that weekday evenings would also be acceptable, but only two plumped for the weekend option. Most said that any proposed social group meetings should last approximately two hours.

**Setting up the social group**

The findings indicated that people were prepared to travel significant distances to attend a YOD social group once a month. The Forget-me-nots Social Group was the result, the name being inspired by the floral symbol of the Alzheimer’s Society. The group designed and agreed a logo with the help of a local graphic designer and decided to meet from 4pm-6pm on the last Tuesday of each month. Initially, it chose to meet in a community venue in the north of the county; however, more recently the venues and activities have been negotiated and agreed by group members, and have ranged from a family Christmas meal and an Easter egg hunt through to afternoon tea, an evening meal, and bowling.

To date, 13 people with YOD and their carers have attended and there are plans to increase the number of regulars. Each meeting is supported by volunteers from the ASN and DRN. In the first instance funding came from ASN and the university, but subsequent funding has come via donations from the counselling and support network charity Stress at Work Northampton and the business network Business Women at Work Northampton.

An independent evaluation into the effectiveness of the group in supporting its members was completed in autumn 2014 and the report was due to be published as JDC went to press. Preliminary recommendations indicate that the group is seen very positively as a strong source of peer support for those who attend. The members are therefore extremely keen that the group should continue. But the challenge will be attracting new members, as the numbers attending have remained largely static. One suggestion has been changing the monthly meeting times to a slightly later time and planning a 12-month programme of activities. This would enable the group to be advertised more widely and help those wishing to attend to plan their commitments further in advance. These suggestions have already been actioned and further debate about the future is expected in the light of the recommendations.

**References**


Department of Health (2012) Prime Minister’s Challenge on Dementia. DH Publications; London.


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