

Dementia Post diagnosis support

The Dementia Action Alliance (DAA) is the alliance of over 150 national organisations across England who connect, share best practice and take action on dementia. Everything we do is in partnership, and informed by people living with dementia, and those that care for them. Through our work we are able to provide a crucial platform for the health and social care sector to come together to share good practice, to build meaningful partnerships and to work collaboratively. Our members commit to action plans based on the Dementia Statements and continue to make commitments, using their collective expertise to influence government policy and societal attitudes towards dementia.

We are very pleased to have been able to work with the Local Government Association (LGA), a valued DAA member, on this publication. You will see examples of some very positive post diagnostic support work by local authorities working in collaboration with other organisations. At a time when budgets are squeezed it is vital for organisations to find innovative ways in which to support people living with dementia and their carers. This report shows the positive work that can be produced and our hope is that this work will be replicated throughout the country to give good, consistent post diagnostic care and support to all people who need it.

Kelly Kaye

DAA Executive Lead

Introduction

Dementia is on the increase. It is estimated that there are currently 850,000 people with dementia in the UK, more than ever before, and this number is projected to increase rapidly over the next few decades. As age is the biggest risk factor for dementia, increasing life expectancy is the driving force behind this projected rise.¹

Receiving a diagnosis of dementia can be devastating for the person and their family and friends. It is important that, at this time, the person diagnosed receives appropriate and timely information, care and support to ensure that they and their carers can live as fulfilling lives as possible, and prepare for the future.

Local authorities have a unique role to play in supporting people following a diagnosis. As well as providing care and support on a statutory basis, they have a role to lead on prevention and early intervention by promoting good health and wellbeing. They also have responsibilities to provide good quality information and advice. Local authorities have an influential leadership and place shaping role in the community and have strong links with local partners.

Local authorities have now been under sustained funding constraints for many years and continue to be so. Despite such pressures, this publication produced in partnership with the national DAA highlights some notable and innovative practice by councils in supporting people living with dementia after their diagnosis.

Councillor Isobel Seccombe

Chairman, LGA Community Wellbeing Board

¹ <https://www.dementiastatistics.org/statistics/numbers-of-people-in-the-uk/>

Foreword

A diagnosis of dementia, like many other illnesses, can be a very traumatic experience for anyone to cope with. But if there is no support afterwards, life can become more difficult; that is why I am so pleased to hear of a positive piece of work.

I've heard stories of people after diagnosis who feel they have been left to fend for themselves and must fight for support, not just at the consultation but also in their community.

After my diagnosis in County Durham, my consultant told us about the illness and medication, and then told us to go to our nearest branch of the Alzheimer's Society, where we could get the extra support and advice needed to carry on with life.

The consultant also told me to try and remain positive, and never to look back at things I can no longer do, but to focus on the future, and get as much out of life as I can.

She also used these words "you either use it or lose it", meaning that by remaining active, you can help to keep the brain active.

I was told to write my life story, as a way of remaining active. It was recommended that I started with the diagnosis and then worked backwards, adding in memories as they came back. This is now widespread practice.

There is a common myth in dementia that if you have seen one person with the illness, then you know and understand everything there is to know about it. This is not correct, because we are all individuals with different problems and symptoms.

I do think that we must encourage people to do everything they can to stay active, and get involved with groups where they can discuss their problems with others in the same position.

I welcome this publication by the DAA and the LGA that highlights good work by councils and partners locally following diagnosis.

Ken Clasper

Lewy Body Society Ambassador and Dementia Action Alliance Affiliate

Background

In 2016 the LGA signed a national joint declaration² across government, health, social care and the third sector to deliver better quality services to people with dementia. This stated that post diagnostic support for people living with the effects of dementia and their families and carers should be personalised, flexible, culturally relevant and have regard to equality. It acknowledged that there is no one size that fits all, with different needs existing according to local needs, personal wishes and circumstances, the nature of the dementia and the course of the condition.

It is important that a person diagnosed with dementia is involved with their care and that they have the opportunity to have the choice and control to manage their condition as far as possible and to live as well as possible with dementia.

It is essential that the person with dementia and their close family and carers are able to talk things over with relevant services and professionals at the time of diagnosis and receive support afterwards. Presently, the quality of post diagnostic care, including access to carer support, can vary according to where an individual lives and the availability of services locally.

This publication highlights just some examples of recent good practice by local authorities and their partners in this area. If you have further examples of good practice in your council that you would like to publicise please contact kevin.halden@local.gov.uk

2 <https://www.gov.uk/government/publications/dementia-post-diagnostic-care-and-support>

Key learning points

1. Engage with people with dementia. A forum or regular meeting with people with dementia is an excellent way to build self-sustaining networks and help shape services. Local people often don't have an awareness of all support in the community. Ensure all feedback and actions from the forum are well publicised. By doing this people feel listened to and actions are taken as a consequence.
2. Offer information in a range of ways. Design information in partnership with people with dementia and/or representative organisations.
3. Build a dementia friendly community. Work with local partners in business, health, the voluntary sector and across local authority departments to ensure that your local area is dementia friendly.
4. The ability to work positively in collaboration across partners and establish common goals of practitioners is crucial.
5. It is beneficial to have an awareness of likely demand on service in order to plan effectively.
6. Consistent workforce development is essential for shared understanding and awareness of services across all sectors.
7. People with dementia and their carers are given the opportunity to think about what 'home' means and plan for their future housing needs, alongside financial planning.
8. Informal settings are important for delivering information to people who might not naturally identify dementia in themselves or a loved one.

Bracknell Forest Council Dementia forum supporting local stakeholders to connect and co-design dementia services

Overview

Bracknell Forest Dementia Forum is a recurring multi-agency meeting hosted by the local authority. It is held every six months and is attended by between 80 to 90 people. It was initially set up to for a single purpose – enabling people with dementia and their carers in Bracknell Forest to provide feedback on services they had received in the area.

Today, the forum has evolved and is attended by a range of different stakeholders. It has a simple aim – to use the power of collaborative local expertise to co-design new and improved dementia services. Stakeholders include people with dementia, carers, the local authority, members of the local DAA, health and social care practitioners, local commissioners, GP dementia leads, hospital dementia leads, care homes, home care agencies, community groups (including faith groups), advocacy services and local health and social care college students.

The forum is well publicised through the DAA, local Community Mental Health Team For Older Adults (CMHTOA), memory clinic and dementia advisers.

How it works

The forum is a well-structured one day event. In the morning there are presentations from local organisations; at lunchtime the forum provides an opportunity for people to network; and the afternoon sessions are facilitated so people can make suggestions of tangible and accountable improvements to local dementia services.

Morning presentations always include an update on dementia service delivery in Bracknell Forest, including the work undertaken by the local DAA. Other organisations presenting at the forum have included the local clinical commissioning group (CCG) dementia lead, hospital dementia lead, commissioners and voluntary/community organisations. Community groups also use the morning presentations to highlight their services, which in turn reduces the demand on local authority services. Previous presentations have showcased befriending services available at local faith groups and a local film society developing a dementia friendly screening.

Information tables display literature on local support from health, social care and voluntary organisations. Publications include the Bracknell Forest Dementia Directory – providing information about support, benefits, services, advocacy and respite for carers. Literature also includes the Dementia Adviser Newsletter – with news about upcoming events in the area.

Members of the local community mental health teams and other health and social care practitioners including Alzheimer's Society, Healthwatch, patient advice and liaison service (PALS) and carers groups are all available to offer advice/signposting. Further support is also offered as a follow up at a later date if required.

The afternoon session starts with a summary of feedback from the last forum, and the resulting actions from the local authority. For example, some expressed at past forums their concern with the dementia pathway, suggesting that it was not clear what services were available for people at different stages of their illness. Bracknell Forest Council subsequently developed a leaflet which helps explain the different levels of support available through the memory clinic and the CMHTOA.

To structure the afternoon session each table of up to six people, including a facilitator, is asked three key questions:

- What has worked well?
- What has not worked so well?
- Ideas for service improvement?

Table top discussions are followed by a summary from each table to the rest of the forum.

Feedback from the forum is presented to the local Dementia Partnership Board. The Bracknell Forest Council Dementia Service Development Coordinator (a DAA member) leads on analysing feedback, and recommending and implementing service improvement.

To develop the forum further there will be a focus on potential sponsorship from DAA members. This will ensure the sustainability and growth of the forum through a multi-agency ownership.

Impact of the activity

The dementia forum brings a number of unique benefits. They are:

- greater community awareness of all services in the locality
- people with dementia and their carers feel valued and listened to
- development of person-centred support services
- increased level of peer support
- improved multi-disciplinary working
- responsive delivery of service improvements across health and social care.

The effectiveness of the forum is evaluated through regular feedback, which enables it to grow. It is owned by all agencies that coordinate and attend the event.

Key learning points

The forum needs to be well advertised. This may be best through the local memory clinic and dementia advisers.

Having a development lead ensures that feedback is analysed and improvements are well coordinated.

It's important that all feedback and actions from the forum are well publicised. This ensures that people feel listened to and actions are taken as a consequence.

Contact

Karen White

Dementia Service Development Coordinator
Bracknell Forest Council
01344 823220

karen.white@bracknell-forest.gov.uk or
karen.white@berkshire.nhs.uk

London Borough of Brent Community Action on Dementia Brent using innovation to develop appropriate dementia services in an ethnically diverse borough

Overview

There are approximately 2,500 people living with dementia in the London Borough of Brent. This number is expected to rise to just under 4,000 by 2030. Brent is extremely ethnically diverse, with approximately 33 per cent of the borough's population claiming South Asian heritage, 19 per cent claiming African and Caribbean heritage, and other ethnic groups making up 7 per cent.

Community Action on Dementia (CAD) Brent seeks to create a dementia friendly borough that enables improved wellbeing for all people living with dementia, and their carers. CAD recognises Brent's ethnic and religious diversity and its primary goal is to improve lives for everyone with dementia, regardless of background.

CAD's approach is to try innovative projects which could then be sustained or scaled up if it is proved that they work. They are a broad coalition involving the following partners:

- Ashford Place
- Brent Council
- NHS Brent CCG
- Brent Age UK
- Innisfree Housing Association
- Kilburn Primary Care
- Irish in Britain
- Asian People's Disability Alliance
- Alzheimer's Society
- Brahma Kumaris – a spiritual university.

CAD Brent worked with the social enterprise Innovation Unit to develop two ideas: a peer support programme and dementia friendly Brent programme entitled 'A Whole Street of Support'.

How it works

Peer Support

Facilitated by the local authority working in partnership with CAD Brent, this programme seeks to connect people diagnosed with dementia, enabling them to provide peer-to-peer support and to engage in activities of mutual interest. A group for carers of people living with dementia runs alongside the peer support service in partnership with Brent Carer's Centre.

The service formally launched in March 2017 and to date 10 peer supporters have been recruited. The project is at the beginning of its prototyping journey.

A Whole Street of Support

This person-centred project explores how people in the community can contribute to making the area dementia friendly: an environment where people with dementia feel safe, confident and involved.

It started with an ethnography – detailed life story research – gathered by walking people living with dementia through their day, life and background, finding out about their interests, what matters to them, and what they would like to see in the local area.

A multidisciplinary team was then formed including service providers, residents, members of the council and a design facilitator. Together, the group embarked in an exciting eight week prototyping 'sprint' to try out potential activities based on the ethnographic research that could develop and grow into fully formed services suitable to the area. The group were tasked with seeking 'live' feedback on the idea rather than evaluation at the end in order to identify the things that don't work early on, and tweak them to ensure the final programme grows into something suitable for all.

Two pilot areas in Brent were chosen – Mapesbury Ward and South Kilburn – where the group had strong local knowledge and connections. The project began with exploratory prototyping phase in order to define aspects of the idea that could be refined through further prototyping. The team then approached individuals and people working in local organisations/businesses to test different ways of creating potential volunteer ‘activists’ – to create energy and behind the dementia-friendly Brent movement and create tangible change, and ‘connectors’ – to build relationships and connect key stakeholders in the community. Trust was built through regular contact and a personal approach – using prompts and gifts to build interest and gain buy-in. Since then scouts, local hairdressers, faith groups and housing associations have shown an interest and are willing to learn more about how they can make a difference to and with people living with dementia in the area.

Evidence of this is the newly formed Community Action on Dementia Brent Alliance website at <https://www.brent.gov.uk/your-community/community-directory/community-action-on-dementia-brent>

CAD Brent is now exploring how to ‘package’ the approach in a simple way to help the area become dementia friendly, through empowering people living with dementia and residents to bring positive change.

Impact of the activity

The programmes have enabled the local authority to engage in integrated working for the first time. This has included:

- partnership working/collaboration between organisations towards a shared ambition
- innovation capacity building in organisations
- increased social interaction/reduced social isolation
- reduced feeling of stigma for people with dementia in ethnic communities.

Key learning points

- Storytelling is an effective way of communicating the need for change.
- An aspirations based approach to dementia services means that people feel valued and able to contribute.
- Innovation means you can rapidly turn ideas into action: prototyping and developing ideas in real time.

Contact

Ajo Clua

Service Designer

ajo.clua@innovationunit.org

Doncaster Metropolitan Borough Council

The Doncaster Admiral Nurse Service

Overview

The Doncaster Admiral Nurse Service was established as a pilot service with the aim of providing a high quality multi-disciplinary family support service for people in Doncaster with dementia and their families/carers. The purpose of the pilot was to respond to the identified need to offer a point of contact, care and support to dementia families' post diagnostically making links to community resources and building resilience and formed through a partnership arrangement involving health, social care and voluntary sector organisations.

The service was co-designed by Making Space and Dementia UK working closely with the CCG and the council. The service was instigated by the CCG and Doncaster Metropolitan Borough Council through joint commissioning arrangements for dementia, which enabled current investment to be redirected into a new service through contract amendments with current providers. It was commissioned as a pilot service for a 14 month period, February 2015 to March 2017 including a one-month set-up period. The pilot has now been extended to March 2018 and positive evaluation suggests it is likely to be continued.

How it works

The service is delivered through a team of admiral nurses (AN) and dementia advisers (DA) via a single point of access.

People newly diagnosed with dementia are referred to the service to support effective discharge and/or ongoing holding, maintaining and care functions. If the person with dementia or their family/carer requires support from other services, then those services will understand and know how to access the Admiral Service.

The Admiral Service operates with three levels of case management: holding maintaining and caring, supporting care coordinators and the person with dementia with the delivery of their co-ordinated care package as appropriate.

Impact

Personal outcomes for people with dementia and their family and carers include:

- people have personal choice and control or influence over decisions about themselves
- people know that services are designed around their needs
- people have support that helps them live their life
- people have the knowledge and know-how to get what they need
- people live in an enabling and supportive environment where they feel valued and understood
- people have a sense of belonging, of being a valued part of family, community and civic life
- people know there is research going on which delivers a better life for them.

Other outcomes which have been achieved on a strategic level are:

- reduction in carer crisis episodes
- reduction in A&E attendances
- reduction in non-elective admissions to acute
- reduction in re-admissions to acute
- reduction in mental health trust emergency contacts (in hours).

Key learning points

- Partnership working and leadership across partners is essential. The ability to work positively in collaboration across partners and establish common goals of practitioners is crucial.
- It is beneficial to have an awareness of likely demand on service in order to plan effectively.
- We need consistent workforce development to ensure shared understanding and awareness of the service across all sectors.

Contact

Michele Clarke

Strategy and Delivery Manager, Doncaster Clinical Commissioning Group

michele.clarke@nhs.net.uk
01302 566363

Halton, Liverpool and Wirral Borough Councils Beyond the Front Door – what home means to people with dementia and their carers

Overview

Life Story Network (LSN) was commissioned by the Department of Health, as part of their programme to improve post-diagnostic support, to find out what 'home' means to older people and people with memory loss in relation to their sense of identity. This is particularly pertinent to the many people with dementia who find themselves spending longer periods in hospital before they receive support from social care or other resources. Often the next step will be taking up a residential care place and – if the individual was admitted in a crisis – they may never see their home again.

The emphasis on helping older people stay at home for as long as possible – retaining and enabling skills and activities of daily living, is hugely significant. Person-centred care is crucial in respecting older people's individuality and in enabling them to live the lives that they want, making choices and having control over activities and decisions. A big decision that most of us make is where we live, and how; 'there's no place like home' is a familiar adage, and if we stop to think about what 'home' is, we realise that it provides us with far more than shelter.

How it works

This project was designed to find out what 'home' means to older people and people with memory loss in relation to their sense of identity. Armed with this knowledge, the project's aim was to develop resources that would be useful to professionals, as well as older people and their carers, to enable issues of crucial importance to people's sense of identity to be taken into account when a transition from home is being discussed.

Geographically, the project was located in the Liverpool City Region and LSN worked across Halton, Liverpool and Wirral.

In total, LSN met with 60 older people, people with dementia and carers. Having collated their views, they also met with housing providers and other professionals to discuss the findings and their views on how they could improve their service delivery.

The objectives of this project were to:

- gain greater insight into the understanding of 'home' for people living with dementia
- develop awareness of what amongst professionals, particularly housing support staff, charged with supporting people living with dementia to continue to live at home
- enable better transitions to take place if someone living with dementia has to move
- contribute to the implementation of compassionate relationship-centred care and support
- develop a set of products that support staff in working with people affected by dementia across the range of agencies (housing, NHS Trusts, NHS and local authority commissioners), with responsibility for both commissioning and providing meaningful post diagnostic care and support.

LSN adopted a conceptual framework to help make sense of what people were telling them, such as:

- a sense of 'home' is important to people and contributes to a sense of wellbeing
- emotional connection and collaboration are essential characteristics in enabling and maintaining supportive and caring relationships
- people with dementia should live in their communities as equal citizens with their value recognised and respected
- the person with dementia is at the centre of decision-making and processes related to them and that they should be enabled to be self-determining as far as is possible
- the promotion of a human rights based approach
- the desired outcomes developed by people with dementia and their carers through the national DAA.

Key learning points

- Post-diagnostic support programmes can provide people with dementia and their carers the opportunity to think about what 'home' means and plan for their future housing needs, alongside financial planning, making a will and Lasting Powers of Attorney.
- Assessors could include discussions about what 'home' means to individual older people and people with dementia, particularly during transitions such as discharge from hospital, re-housing and admission to a care home.
- It is recommended that registered social landlords review the information they produce about the types of housing that they offer so they are clear to people with dementia. They could consider a 'settling in pack' for new residents.

- Local authorities to endeavour to include older people, people with dementia and carers in strategic development and service design.
- The 'top tips' for commissioners, hospital discharge staff, housing staff, social care assessors and people with dementia and their carers are in development.

Contact

Thomas Hughes

Life Story Network

0151 2372669

thomas@lifestorynetwork.org.uk

London Borough of Havering

Developing multi-agency capabilities through detailed and personalised training

Overview

The London Borough of Havering has the largest growing ageing population across the capital. The council recognised the need to implement preventative initiatives that were sustainable within the constraints of declining budgets and increased demands on adult social care services.

A key action was to ensure the highest level of care and support for people living with dementia in their own home, whilst also supporting the health and wellbeing of their family/carers.

Havering was successful in securing funds through the Skills for Care's Workforce Development Innovation Funds, to deliver a pilot study for care and support staff to receive training on dementia awareness and challenging behaviour.

How it works

Havering's dementia liaison officer and the carers commissioner worked alongside the workforce development team to design three training courses aimed to improve awareness of dementia amongst council staff, carers of people living with dementia, and specialist dementia workers.

The courses initially targeted specific learning areas – dementia awareness; behaviour that challenges; assistive technology; person-centred support planning; third sector and community support; joint working and the prevention agenda. After piloting and revisiting aims, further issues were identified around embedded learning, capturing the service user's voice and ongoing development of the project. Project delivery was adjusted to address these issues.

Havering approached training by targeting three specific audiences:

- **Frontline staff across adult and housing services** – to develop Interpersonal skills and an understanding of people living with dementia’s needs in designing services; staff are trained to work together to support and sustain residents tenancies, and are encouraged to be knowledgeable of all services within the community that support dementia clients and their families.
- **Identifying and creating ‘Adult Social Care Dementia Champions’** – in both adults and housing services to embed knowledge (these champions are different from the Alzheimer’s Dementia Champions who deliver Dementia Friends awareness sessions).
- **Ensuring staff across the services are well informed and updated on strategies and services.** The champions provide a robust foundation to help embed and communicate knowledge of the project, and this ongoing support to staff helps to provide sustainability of the programme. All Champions increase their skill set by undertaking QCF Level 3 Award in Dementia.
- **Identifying and engaging informal carers from Havering** who are affected by dementia. Havering supports carers by capturing their voice and views, helping the council to understand their needs. This has created a new communication channel with residents which can be continually accessed.

Adult Social Care Dementia Champions meet bimonthly at a forum facilitated by the dementia liaison officer. This gives a chance to update the course, practice, discuss issues, and provide opportunities for inter-departmental networking.

A second cohort of dementia champions has now been established including three members of the joint assessment and discharge team from the acute hospitals trust.

Impact of the activity

The project successfully delivered three programmes of training. Staff developed their knowledge and understanding of dementia; were informed of support available for carers and service users in the community and had the opportunity to discuss ways in which services can work in a more integrated way going forward.

Carer workshops supported families/carers to understand dementia and its effects, provided awareness of support within the community and provided a feedback platform for carers to voice their issues and concerns.

Service manager engagement between housing and adult social care has improved via the staff training initiative. It has bridged relationships between housing and social care and a formal management meeting is now regularly attended to ensure that synergies between the services are identified and actions addressed. This helps promote a seamless service experience to those presenting to frontline services. Dementia will be an on-going agenda item.

The programme is being evaluated through an annual survey to everyone diagnosed with dementia in Havering and their carers.

Key learning points

- GPs, health staff and frontline community services benefit from this development approach, and are in support of the prevention agenda.
- Prevention and early intervention are key actions for services, to ensure the approach remains robust and sustainable.
- By informing staff, building robust community services and working together across services to identify early help needs, individuals can remain at home for longer.
- Informal carers are a huge resource that all services have but do not support and utilise enough. Building on community activity and support, identifying carers at an earlier stage and developing staff to inform and signpost

family/carers provides service users with the opportunity to remain supported in their own homes for longer and support the health and wellbeing of the carers to do this.

- The three stage approach to training delivery, targeting staff and carers and building champions has proved to be a robust strategy. The training learning areas were the same for each group but Havering's approach ensured that training was meaningful and relevant for each group.

Contact

Jenny Gray

Commissioner and Project Manager –
Dementia
London Borough of Havering

01708 432318

jenny.gray@haverling.gov.uk

Kirklees Council

Establishing good post diagnostic support for people with dementia by raising local awareness

Overview

Kirklees has a population of just over 400,000 people who come from a wide variety of social, ethnic and cultural backgrounds. It is estimated that there are almost 5,000 people living with dementia across Kirklees, whose needs are championed by Kirklees Dementia Action Alliance (KDAA).

KDAA is a group of local stakeholders who come together create changes locally that ensure people with dementia feel understood, valued and able to contribute to their community. Members of the KDAA consist of Kirklees Council, local CCGs, faith groups, schools, housing associations, charities and community organisations including police, fire and rescue services and retail outlets. KDAA is working towards gaining formal recognition as a Dementia Friendly Community (DFC).

A number of different strands of work are taking place in Kirklees which are helping them to achieve DFC status. One particularly successful strand has been the hosting of a 'Dementia Friendly Saturday' event in Lindley, designed to raise awareness of the impact that good post diagnostic support has for local people with dementia and carers.

How it works

A number of events ran concurrently throughout Dementia Friendly Saturday including creating memory boxes in the library, physical activity in the Methodist church hall, and a 'Dementia Friends' session in the working men's club. The event was well supported by the mental health provider South West Yorkshire Partnership Foundation Trust who provided information and held one-to-one

sessions on the day for anyone concerned about themselves or someone they care for.

The event was an opportunity to shine a spotlight on post diagnostic support in Kirklees, and signpost people to community and primary care services that may benefit them. In one venue, St Stephen's church hall, a variety of stalls were set up offering advice and information on what services are available within Kirklees. These stalls included representation from Alzheimer's Society, Kirklees Council, Making Space, Age UK and KDAA.

Dementia Friendly Saturday ended with a masterclass to the public and health and social care professionals at Huddersfield Royal Infirmary, and was hosted by the Mayor of Kirklees. This masterclass aimed to demonstrate the power of first-hand stories in raising dementia awareness. It featured a service user and carer giving a personal account of their journey, and how they have adapted their lives to meet the progression of dementia.

KDAA aimed to make this event intergenerational to emphasise that dementia is 'everybody's business'. A competition was run by the local school asking children to paint/draw a dementia friendly flower. The KDAA Lead attended an assembly following the day to award prizes, and raise awareness of dementia amongst schoolchildren further.

KDAA have built on the momentum of Dementia Friendly Saturday by producing further materials to raise awareness of dementia support in the community, including a 'high street pack' which includes information and advice on how to operate a dementia friendly business.

Impact of the activity

As Dementia Friendly Saturday is a community event that is large in size, it is difficult to formally evaluate. However testimonials from the day suggest that both those affected by dementia and others who were keen to learn enjoyed the informality of the setting and the

ease of accessing information.

Kirklees' Mayor has identified dementia as her focus for her term and she is working towards all councillors becoming Dementia Friends. A number of subsequent 'Dementia Friendly' duplicate events have been identified as a priority for other communities by the local authority.

Dementia Friendly Saturday won an award from the local newspaper 'The Huddersfield Examiner.'

Key learning points

- community engagement is the key to success
- it is best to choose a community which is well connected to pilot the model
- staff generally welcome the opportunity to volunteer and are passionate about their work in dementia
- Informal settings are important for delivering information to people who might not naturally identify dementia in themselves or a loved one; this is particularly important for minority and culturally diverse groups.

Contact

Sandra Croft

Partnership Commissioning Manager:
Older People
Kirklees Council

sandra.croft@kirklees.gov.uk

Lancashire County Council

Raising awareness of dementia symptoms and encouraging people to see their GP

Overview

There are currently more than 10,000 people in Lancashire who have been diagnosed with dementia, but it is estimated that the actual figure of people with the condition could be much higher. This means that potentially thousands of people who have dementia aren't accessing treatments and support to help them live well with the condition.

This campaign delivered by Lancashire County Council, with support from the Alzheimer's Society, aims to increase the number of people with dementia who are diagnosed so they get the right treatments and support at an early stage.

The county council worked with the Alzheimer's Society and local expert groups in Lancashire to develop the campaign artwork and messages. The Patient Voices project was also commissioned which captured accounts from people with dementia and their carers.

The target audience is 55 to 75 year olds and the campaign focuses on encouraging them, through their friends and family members, to tackle memory problems.

The campaign made use of a variety of channels to reach the public, including posters, local media, radio, billboards, social media, and screens in some in doctor's surgeries in Lancashire. GPs in Lancashire also received a letter informing them about the campaign and requesting their support.

The adverts directed people to dedicated webpages on the Lancashire County Council website www.lancashire.gov.uk/health-and-social-care/your-health-and-wellbeing/staying-mentally-well/dementia where they could

find information and videos designed to help people identify worrying symptoms. They are also be able to find out more about the diagnosis process and start a conversation to encourage a loved one to visit their GP as well as pointing them in the right direction for groups they can become involved in.

One of the short videos was adapted for a TV advert which was shown on GP surgery screens and Sky AdSmart local TV advertising.

Campaign

The campaign advert was displayed in 38 GP surgeries in Lancashire. The campaign aired six plays per hour, playing out on 60 plays per day on average (per surgery). Total four week footfall across 38 sites was 81,500 with total unique views of 52,975.

On Sky AdSmart TV the advert was delivered to 41,766 households in the target area and was watched on average 3.5 times.

There was a marked increase in the number of visits to the Lancashire County Council website during the radio and TV advertising period. Media coverage during the campaign period reached more than 800,000 people, with coverage valued at £6,800.

The council will continue to monitor referral rates to the Memory Assessment Service; however as it will take some time to see whether campaign activity has resulted in an increase in referrals. Comparing six months before the campaign launch with six months after there was a 46 per cent increase in the number of referrals to the Memory Assessment Service and a 79 per cent increase in the number diagnosed with dementia in Lancashire.

To find out more about the campaign, please download the [briefing note](#) on the Lancashire County Council dementia campaign page. There is also a digital toolkit which can be downloaded from the website. It contains artwork and images that can be used on social media pages and a bank of messages which can be used to promote the campaign across social media channels.

Contact

Safika Munshi

Communications Manager
Lancashire County Council

saf.munshi@lancashire.gov.uk

Greater Manchester Sustainability and Transformation Partnership

Partnership working,
leadership and public
engagement

Overview

In April 2016 Greater Manchester became the first sustainability and transformation partnership in England to take control of its health and social care budget. Dementia was set as an early priority for the devolution programme with three key aims; to improve the lived experience of people with dementia and their carers, reduce variation in quality and access of services and to increase the independence of people with dementia whilst reducing the dependence on the health and social care system.

In January 2017 local authorities alongside NHS partners, the voluntary, community and social enterprise sector and other partners across Greater Manchester endorsed a five year dementia strategy known as Dementia United. Initial development work was co-ordinated by an executive group chaired jointly by Sir David Dalton (Salford Royal NHS Foundation Trust) and Pat Jones-Greenhalgh (Bury Council). The Executive also included Professor Alistair Burns (National Clinical Director for Dementia). A supplementary task and finish group led by Anthony Hassall, Salford CCG developed a set of standards and an implementation plan.³

The group was supported by four expert groups which included people with dementia, representatives from the strategic clinical network, CCGs, acute sector, local authorities, voluntary sector and academia. Dementia United (DU) is now mobilised for implementation and whilst it

³ <http://dementiaunited.net/wp-content/uploads/2017/04/Dementia-United-Implementation-plan-17012017.pdf>

continues to be supported by members of the original executive and task and finish group the governance of this large scale improvement programme is broader with wider representation across the 10 localities that make up Greater Manchester and interdependent work areas eg primary care, care homes and workforce via a strategic board, an implementation operations group and a range of expert groups.

DU offers a strategy that will celebrate and develop best practice, improve and/or change elements of dementia care that are not working well, and reduce demand and dependence on health and social care services. It will do this by working with a whole systems approach – by developing key partnerships, listening to the voice of people with dementia and carers, and offering the opportunity to have a ‘big conversation’ across Greater Manchester.

What it consists of

DU is comprised of four work programmes (WPs):

- **WP1** – locality delivery (the delivery system within localities)
- **WP2** – regional support (the regional support architecture)
- **WP3** – intelligence (the infrastructure for intelligence)
- **WP4** – innovation, research and evaluation.

Greater Manchester is supported by the health and social care partnership team through a programme management office (PMO). The team provide regional coordination and measurement and improvement support through robust project and programme management to make improvements and drive efficiency. In addition, with key partners, the PMO will bring together work programmes to manage operational delivery of DU, stakeholder engagement and supply chain management.

The PMO will identify new opportunities for innovation or barriers to implementation for consideration by the DU strategic board and

implementation operational group.

The team undertook visits to all 10 localities between October and December 2017 to learn more about the aims, aspirations, current work and challenges faced in relation to dementia care and improvement. The visits provided a rich picture of dementia work that is taking place as well as giving an opportunity to see where and how improvements could be made on either Greater Manchester, a cluster approach or within individual localities. This information will form a work plan to compliment the agreed strategy and will be aligned to the Greater Manchester dementia standards (ratified September 2016). The work plan was developed during late December 2017 and early January 2018 and updates will be provided to relevant governance groups during January and February 2018 alongside playing back the plan to the localities.

Each locality in Greater Manchester will appoint an executive lead for dementia who will have responsibility for representing the area in discussions about the strategic direction of services. Coordinated regional support through a partnership delivery model will ensure that learning between localities is optimised and variation in service provision is better understood through peer review and knowledge exchange.

Collectively localities have a number of key deliverable ‘products’. These include:

- **The Dementia Barometer.** This will be the primary mechanism through which the Greater Manchester system will establish a ‘big conversation’ with the citizens.
- **Innovative locality profiles.** The development of an infographic to display localised data. These will be produced by each locality twice yearly and used to inform the discussion at the peer review.

Impact of the activity

This programme is at the beginning of its journey. It is projected that the impact and outcomes of DU for localities and the wider Greater Manchester system will be social,

psychological, environmental and financial, by providing improvements for the communities and the populations they serve.

Evaluation of DU will determine success and impact against the aims of the programme. This will include multiple approaches such as developmental evaluation used to record and understand the decision-making process; formative evaluation used to understand how the programme is progressing during its delivery; and summative evaluation used at the end of the programme to understand its impact, the effectiveness of the execution method(s) and the extent to which it achieved its aims.

Key learning points

- Be prepared to meaningfully listen and learn.
- Engagement, engagement, engagement – you can never do enough. Expect to be criticised for what has been done.
- Don't be afraid to take a step back and spend more time than originally anticipated to get it right.
- Celebrate the successes and encourage best efforts.

Contact

Rachel Volland

Senior Implementation and Improvement Lead
Greater Manchester Health and Social Care Partnership

rachel.volland@nhs.net

Kim Wrigley

Senior Programme Manager –
Dementia and End of Life Care
Greater Manchester and Eastern Cheshire
Strategic Clinical Network
Greater Manchester Health and Social Care Partnership

kim.wrigley@nhs.net

Warwickshire's Living Well with Dementia website

Overview

Warwickshire is a geographically large county, with a county council, five district and boroughs and three CCGs. Feedback from people living with dementia, their carers and practitioners highlighted that it was difficult to find out about services to support them in their local area. To help to address this issue, one of the key features of the website is a map of services which enables people to find services and support in their local area (at district and borough level).

In addition, county council officers have recently been working with District and Borough colleagues to develop paper based dementia services booklets for local areas. These are also being promoted, where available, as an additional source of information. However the drawback to these sources of information is they cannot be as regularly or as easily updated as the website. Warwickshire's Living Well with Dementia website is an example of an online resource, providing information about dementia, including details of services and support available for people living with dementia and their carers in Warwickshire.

www.warwickshire.gov.uk/dementia

The website is designed for people with dementia, their carers, family and friends as well as practitioners supporting people with dementia and organisations who would like to know more about becoming dementia friendly.

Warwickshire County Council's public health, strategic commissioning and communications team relaunched this website in 2016, following enhancements based on feedback from people with dementia and their carers, consultation with local practitioners and best practice guidance. The enhanced website includes additional features to improve its usability and accessibility and includes a new support

and services map to enable people to search for dementia services in their local area.

Warwickshire County Council worked with a range of partners to ensure that accurate and relevant information is provided through the website.

How it works

The website is promoted and is accessible to anyone who would like to know more about dementia, with all areas of the website accessible to everyone. However, people are guided to the section that may best meet their needs through the tabs on the home page.

The website provides information on:

- services and support in the local area – at district and borough level
- living well with dementia – information for people in the early stages of dementia
- information for carers
- Dementia Friendly Communities and Dementia Friends
- reducing the risk of developing dementia
- links to social media, blogs and Twitter
- links to Alzheimer’s Society National Dementia Helpline and Talking Point (online forum)
- Warwickshire’s Living Well with Dementia Strategy.

The website was re-launched as part of Warwickshire’s refreshed Living Well with Dementia Strategy (2016-2019)⁴ and supports the work being done in Warwickshire to raise awareness and understanding of dementia. It also supports timely diagnosis and access to post diagnosis support.

The website is promoted alongside Warwickshire’s Dementia Navigator Service (which is commissioned by Warwickshire County Council) as the two key services that enable people to find out about all other dementia support. There is a focus on

promoting these two services to ensure that, on an ongoing basis, people have two key places where they can find out about all of the other services in their local area. The two sources of information complement each other, as the website is an online source of information whilst the Dementia Navigator service is delivered face to face or by telephone.

Impact of the website

The council have received extremely positive feedback from a range of practitioners, including general practice staff and front-line workers in a range of organisations across the county about these two key sources of further information.

During 2016 to 2017, when the enhanced website was launched, there were 5,244 unique users of the website; an increase of almost 800 unique users from the previous year. The website blog was accessed 189 times during Dementia Awareness Week in May 2017.

There is a further area of the website under development, which aims to create a more Dementia Friendly Warwickshire. When complete, this area of the website will provide information on, and access to, a range of dementia awareness opportunities and will be promoted to both individuals and organisations to encourage them to visit the dementia website to find out more about how they can become more dementia friendly.

Key learning points

The main benefit of the website is that information can be added or amended with relative ease and at little cost. However, ensuring that the website is up to date can be time consuming as information changes quite regularly.

The council recognises that not all people have access to the internet, and that some will not want to access information about dementia in this way. However, we have tried to address this by ensuring that information is also available through the Dementia Navigator Service and the booklets (where these are available).

⁴ <https://www.warwickshire.gov.uk/dementiastrategy>

Contact

Claire Taylor

Health Improvement Lead, Public Health,
Warwickshire County Council

01926 413782

clairetaylor@warwickshire.gov.uk

Katherine Herbert

Dementia Commissioner, Strategic
Commissioning, Warwickshire County Council

01926 742464

katherineherbert@warwickshire.gov.uk

Worcester City Council's Dementia Dwelling Grant An example of multi- agency working to enable independent living

Overview

The Better Care Fund (BCF), increase in Disabled Facilities Grant (DFG) resources and changes to the Care Act have granted local authorities the opportunity to design new ways to keep people out of hospital. In Worcestershire, specialist home adaptations are playing a central role in supporting 6,000 local people affected by dementia to live at home for as long as possible.

Through integrated service design with commissioners, providers and experts, Worcestershire developed the first non-means tested Dementia Dwelling Grant (DDG). Following a person-centred assessment and review of their environment, adaptations and adjustments are made to a person's home. Items provided include dementia clocks, touch lighting, contrasting coloured toilet seats, and identification stickers. The maximum grant a person can receive is £750.

This project led by Worcester City Council has been delivered by integrated working between health, social care and housing teams across six local authorities – Bromsgrove, Malvern Hills, Redditch, Worcester, Wychavon and Wyre Forest District Councils.

How it works

A multi-agency meeting was held with organisations involved in DFG delivery and those with expertise in dementia to gain an understanding of the gaps in provision, need, and to ensure all parties would support the programme. A dedicated service designer was then appointed, and partner roles were agreed.

A clinical engagement group was established to oversee the programme. Members include:

- Association for Dementia Studies University of Worcester (ADS)
- foundations strategy lead
- strategic housing officers
- local authority DFG project officers
- clinical psychology specialist occupational therapist
- older adult mental health team
- commissioning manager, dementia and mental health
- Age UK Herefordshire and Worcestershire – dementia advice and handyperson services.

A DDG Task and Finish Group has been formed who have been tasked with implementing a trial of the DDG, monitoring performance and applying learning. Partners at all levels have been kept involved through regular communication, being informed of outcomes and impact for beneficiaries.

For people affected by dementia, the referral pathway is clear. They are referred via the community mental health team, GP and early intervention dementia team to Age UK Hereford and Worcestershire Dementia Advice Service (DAS). The DAS supports households to claim the grant as well as providing other useful support, advice and information.

Impact of the activity

All partners involved in the DDG benefit through:

- being part of a unique and ground breaking service
- developing a cost effective solution to meeting the needs of people with dementia
- establishing new links and networks
- recognition of the role strategic housing can play in prevention.

The scheme is being independently evaluated by the Association for Dementia Studies (ADS) at the University of Worcester. It is expected that the evaluation will demonstrate a positive impact from DDGs on the lives of individuals living with dementia and also their family carers.

The evaluation will combine qualitative and quantitative methods in order to explore the effect of the DDG on people living with dementia at home and to provide Worcester City Council with robust evidence of the overall impact of the programme to inform its future planning and for dissemination to other local authorities and interested parties.

An interim report will be produced in the autumn of 2017 with a final report at the end of the pilot scheme.

Key learning points

Joined-up thinking meant that community, decision-makers and funders recognised the need for the DDG trial. This was a powerful asset.

Others considering a DDG scheme should:

- establish clear outcomes, objectives and roles
- manage expectations
- communicate often
- establish a clear governance and decision making process
- ensure that there is commitment and joint agreement at a strategic and operational level
- manage the risks both jointly and individually.

Contact

Nicola Matthews

Performance & Partnership Officer
Worcester City Council

nicola.matthews@worcester.gov.uk



Local Government Association

18 Smith Square
London SW1P 3HZ

Telephone 020 7664 3000

Fax 020 7664 3030

Email info@local.gov.uk

www.local.gov.uk

© Local Government Association, April 2018

For a copy in Braille, larger print or audio,
please contact us on 020 7664 3000.
We consider requests on an individual basis.

REF: 22.1