

1	share expert power,skill educating community and creating micro enterprise links	equilty and equity		refllect,plan,do,review and re_start	screanig,assesment,reffe r,community,organization and groups education towards disability	
<i>Response</i>	<i>Can you share some examples of great work being done to support people living with dementia, by projects large or small?</i>	<i>Which models or types of projects respond best to local and regional differences across the UK?</i>	<i>How can we successfully involve people affected by dementia so that their experiences and expertise shape projects and services?</i>	<i>What data is there that would help us understand what works, and what doesn't?</i>	<i>If you could do one thing to make a real difference for people living with dementia, what would it be?</i>	<i>If you had £10k, £100k or £1m to help bring about change for people living with dementia, what would you do?</i>

2	<p>north-east-england-and-cumbria-dementia-fund A three year project to support family carers thorough the north east of England and Cumbria http://www.festivalofideas.org.uk/ A one year project with a range of events to improve support for people living with dementia http://dementiamc.net/ Dementia masterclasses; a way of helping people with dementia through influencing politicians and the media http://dementia.stir.ac.uk/ideas/big-ask the Big Ask, a survey that will allow people with dementia and their carers to shape the future of dementia care http://dementia.stir.ac.uk/design/virtual-environments an on line resource that shows how the environment can make a difference for people with dementia</p>	<p>Models where expertise from around the world, not just the UK is used. Models where the learning is embedded in local people. Models that by pass the professionals when needed and work directly with the person with dementia and their family.</p>	<p>Avoid tokenism. Use researchers who have practice in involving people with dementia long after everyone else thinks that they can't communicate.</p>	<p>Too much to report here. Happy to discuss.</p>	<p>Give families and individuals the knowledge and information that they need to avoid hospital admission, survive hospital admission and maintain independence for as long as possible</p>	<p>£10k I would hold a masterclass £100k I would train 800 health and social care workers and families £1M I would hire the DSDC to provide an independent authoritative change programme</p>
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3	<p>We deliver a range of project to support people living with Dementia and their Carers These include: A weekly Dementia Cafe A monthly Tea Dance A Dementia Garden A ID Card Service in case of emergency A weekly Day Club Our website is www.silverlinememories.com</p>	<p>Small local third sector organisations that fully understand the community they serve and develop project to address the needs of that community, rather than fitting projects to meet fund criteria.</p>	<p>Academic articles have been written regarding evaluating services directed at people living with Dementia, and the efficacy of any data collected. I believe that in involving customers at every stage of service planning and delivery, collecting feedback is relatively straight forward and all data relevant. When verbal and written communication skills are affected it may be necessary to request additional support from Carers.</p>	<p>Due to the nature of Dementia there is a lot of debate about the validity of empirical research and methods of evaluation in formal research. Instead of focusing on research data I would go directly to Carers and people with dementia themselves - they are your best source of information as to what works and what doesn't.</p>	<p>Stop focusing on memory and definitely stop correcting people's perception of reality. Be with them in their moment, wherever they may be and whatever their reality or understanding of time and space.</p>	<p>I would create a Dementia Care Village modelled on those near Amsterdam - but it would need more than £1m or a scaled down version!</p>
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4	<p>great example of a large project and I've seen first hand the difference that the increased understanding and awareness Dementia Friends sessions Make to ordinary people, and people with dementia. Local Dementia Action Alliances is a huge project run by the Alzheimer's society and aims to help communities become dementia friendly - again, it makes a huge difference to a person with dementia to have help and support in everyday places such as the supermarket or on the bus. Life story work is vital to the well being of people with dementia as it helps them to retain their individuality and personhood. The TIDE (Together in dementia everyday) is an initiative set up to link and give support to carers and</p>	<p>locality or requires partnership working with the community. For example; Dementia cafes, Local Dementia Action Alliances, Carer support groups, community projects to build sensory gardens, Dementia Friends community work, intergenerational work where groups of people are working towards the same aim for the community - a good example is a project carried out by the Crawley bus company - people with dementia can have a specific bus pass so that staff know to take extra time and assistance if required to people with dementia who travel on their transport. The local library in Crawley also identifies customers with dementia and does not fine them for late return of books.</p>	<p>engagement and empowerment project) is a great example of how people with dementia can influence services and behaviour - through the Dementia Action Alliance they developed a ' call to action' called 'words matter' to challenge and change inappropriate language used to describe people living with dementia - the group that is made up of people with dementia published a guide and made suggestions for alternative words that can be used instead. There is a group of people with dementia in Kent called the 'Forget-me-nots' who frequently give talks at conferences. They also recently published a book called 'Welcome to our World' - a great read! Groups like these need help and support from individuals and/or</p>	<p>There is a wealth of data - I would suggest in the first instance information provided by the Alzheimer's Society, DEEP, University of Stirling, Association for dementia studies (university of Worcester), Joseph Rowntree Trust, Extra Care Charitable Trust, Kings Fund and many many more</p>	<p>Ensure that carers of people with dementia are provided with great training, support and pay. This would ensure continuity of care and the right expertise.</p>	<p>Its so hard to pick just one thing! In my current role, I would use the money to set up and support our own panel of experts (residents with dementia) to help shape our own services and new developments</p>
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5	<p>Thrive support in designing dementia gardens and giving social therapeutuc horticulture training. Sensory Trust also doing similar work. Learning through Landscapes own pilot garden design project in Herne Bay. The Dementia Friends free training for anyone.</p>	<p>Those that engage well with partners at all levels, i.e. are steered or overseen by a project partnership board covering areas such as local strategy, national sharing of good practice, delivery and evaluation.</p>	<p>By ensuring that any consultation is differentiated according to need and that ethics committee approval is secure when needed. We use a range of consultative tools including observation, informal focus groups, task led groups, notes of day to day conversation, mat boards, art activities such as secret gardens and traditional interview techniques with those earlier on the dementia and day care settings also have user committees which prove useful in this context.</p>	<p>There is a range of research reports and publications, Alzheimers Society probably hold the best and most comprehensive reviews.</p>	<p>make services more familiar and domestic and less clinical.</p>	<p>find ways to help them get outside more as they often spend so long in indoor settings and that limits their potentia and happiness.</p>
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6	<p>worked with people with dementia and their carers to develop a pop up dementia theatre to help communities become dementia friendly. Whilst most people generally understand that dementia impacts on memory and language, it is far less known that dementia also impacts on the senses. This can have a distressing impact on an individual through a process of sensory deprivation. Sensory deprivation is known as White Torture and is the worse form of torture. We help carers, family members, professionals and the general public understand the importance of sensory experiences in improving the quality of life and well-being of someone with a dementia. We do this through a hands on, fun</p>	<p>Inclusive models where families, carers, professionals and communities all understand the impact of dementia and what they can do to help.</p>	<p>dementia in developing the pop up dementia theatre by first involving their carers (professional and family members). We provided the carers with a structure to help enhance communication with their loved one (or people they care for). This structure was research based and boundaried - so it could help them put into context what was happening for the person with dementia in a way they could understand. This structure not only helped increase their understanding towards those experiencing dementia, but also their empathy, kindness and compassion. In addition, by involving nature based activities everyone in the family or ward or home could take part irrespective of cost. Nature can be freely enjoyed by everyone</p>	<p>We used data from three primary sources to create the idea of the pop up dementia theatre. 1. The research evidence on dementia, 2. the impact of nature, and our main evidence source was on 3. research studies on sensory programmes. We then compiled the evidence and data from three sources to create the idea of the pop up and then worked with carers and people with dementia to refine what we were trying to achieve. We continue to collect data to evidence change and outcomes relevant to our project.</p>	<p>style that is person centred and specific to the needs of each and every individual person with dementia. It doesn't have to cost hardly anything to create through purchasing expensive resources as nature is free at source . It just takes a little time, dignity, respect and compassion and willingness to reach out to someone with dementia in their world and learn to communicate with them through sensory language rather than words. To know about the impact of smell, touch, taste and sight and sound which will be different for each person as dementia fragments the brain. Sensory perception is hot-wired intensively throughout the brain so as the disease ravages certain parts of the cerebrum so</p>	<p>up sensory theatre experience in every region in the country in order to raise awareness of the very real distress that can be caused in those with dementia through sensory deprivation. Evidence shows deprivation can lead to hallucinations, agitation, aggression, poor sleep patterns, social isolation, withdrawal and depression. Ultimately it can lead to hospitalisation and care homes. By raising awareness of this with carers, family, professionals, organisations and communities we can demonstrate that some quite simple and free ways of using nature for sensory experiences can make significant difference to the quality of life for someone with dementia - and their</p>
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7	<p>Dementia Champions raising awareness to staff not just support staff admin, finance everybody including the general public. Supported living services rather than nursing care. Local communities have various projects Dementia cafes, memory boxes. Telecare</p>	<p>I think I may have discussed in the other answers person centered support is essential.</p>	<p>Experts by experience involve families friends share DVDS. Plans for the person involve in training. Ask them and their families questionnaires all ages. Respite for families which offers support from others look at holding workshops that looks at what is working and what is not.</p>	<p>People with L/D who have downs syndrome have baseline assessments to look at if their are signs of dementia it is picked up early most authorities will hold this data. Memory clinics</p>	<p>Everybody seeing the person not the Dementia and having empathy as to see what is going on for the person if people understand behavior then they will meet an unmet need. Prompt diagnosis of the disease correct medication</p>	<p>I would invest in specialist services, supported living look at end of life facilities so people do not have to go into hospital for IV drips or similar. Invest in specialist projects or look at seeing what health care providers could offer over and above. Telecare can make a huge difference to maintaining somebody independence offering</p>
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8	<p>There are several projects that I know of, of course - Musical Moments specialises in working with people with dementia and works with over 120 care homes and centres in the north west. I also know of several local charities including Carers Trust 4All and MHA Live at Home that provide sessions and groups for people living with dementia. I am also part of the Dementia Friends initiative as a Dementia Friends Champion and Cheshire East Council have a fantastic dementia steering group that work on support in Cheshire East with regular meetings and action plans to improve quality of life in the area. In this group there are several other individuals working on projects to</p>	<p>Obviously I feel that musical projects are most beneficial to people living with dementia, due to my background and research within the subject. Other reminiscence and exercise activities seem to go down really well too. Dementia cafes are also an excellent way to help combat social isolation.</p>	<p>Continue to help change the negative image of dementia, encourage that it is possible to live well with dementia and having further support groups and projects.</p>	<p>As a social enterprise, we send out a social impact survey to our clients. You are more than welcome to read our 2014 results at http://www.musical-moments.co.uk/results-2014-survey/</p>	<p>To make people feel better - to make them see that a dementia diagnosis does not mean it's the end. To continue to help well-being and a happy life to someone who has dementia.</p>	<p>We received a grant earlier this year which enabled us to give away free sessions for care homes that booked 4 sessions or more with us, supporting us as a small business and helping to relieve their activities budget. We would like to continue this but open it to all care homes in the north west, rather than just in Cheshire East. We also have a fantastic and talented (yet small) team that deliver our sessions, who I would like to be able to increase their wages (without increasing our price as we charge a reasonable and affordable price), so a grant towards that would also be really helpful, useful and economical.</p>
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9	<p>As a charity we provide workshops and 1:1 support to those with young onset dementia thereby enabling carers and family to gain respite or continue to work. The workshops we provide are catered to meet the interests and needs of our clients and examples include singing, walking, running, cycling, art, reading, drama, pilates, furniture restoration, katanuing and drama. We dovetail with local provision to try and ensure 5 days respite for carers per week.</p>	<p>We believe that our model would respond well to local and regional differences across the UK and are working on a blueprint in order to achieve this. It is tailor made to meet individual needs.</p>	<p>We have held information sharing events to gain views of what type of support or intervention those with young onset dementia and their carers actually want. Feedback is that whilst they would like respite, they want their loved ones to be involved in meaningful activity. We regularly gain input from those with young onset dementia regarding their interests and then tailor workshops and 1:1 support to meet these needs.</p>	<p>We have evaluated our provision and this has included looking at antipsychotic prescribing, cognitive function, quality of life questionnaires to carers and those with young onset dementia, delays in admission to hospital. From these findings, we would say that our intervention works, and works well.</p>	<p>To provide a care home/residential home set up specifically to meet the needs of those with young onset dementia within the area. At the moment this group are either placed inappropriately or out of area. This increases the stress levels of both the person with young onset dementia as well as their family/carers.</p>	<p>£10k - would increase our workshop provision. £100k - would expand our service into the east of Berkshire. £1m - would set up a care home in Berkshire West for those with young onset dementia.</p>
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10	<p>We have been working on a number of different initiatives and projects... Helping develop wearable GPS tracking technology to give people with dementia freedom to roam, at the same time giving peace of mind to their loved ones. The tracker has been a great success and we are now involved with rolling out the service nationwide. We have been using technology to help unlock creativity in people with dementia, such as photography, online art therapy via video-link or creating short films. Use of technology and the internet has, we have found, been vital in our remote and rural area.</p>		<p>We have been working on making a dementia friendly community work from the perspective of the community rather than the dementia. We have been developing activities and services which work well in the community and just happen to be also dementia friendly. This fosters inclusion rather than creating 'dementia ghettos'.</p>	<p>We have been collecting data for attendance in activities and we are also gathering qualitative data such as recording feedback from activities, recording information on personal feelings of wellbeing and also results of creative activities.</p>	<p>Make everyone aware that a diagnosis of dementia doesn't mean a person's life has ended - it's just a change that we adapt to and make the most of.</p>	<p>Make our built environments dementia friendly using technology and design - work with a company like IKEA to make as much of our designed world dementia friendly at the same time as aesthetically stimulating.</p>
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11	<p>working with people living with dementia in the community and throughout the care homes of South Yorkshire and beyond. They use highly trained professional musicians using a variety of musical instruments and styles to help stimulate some amazing responses through the power of music song and dance.</p> <p>1. Monthly sessions in Alzheimer's Memory Cafes in order to help reduce isolation and the stigma attached to the disease as well as encouraging early diagnosis by encouraging people with dementia to attend with their carers. Because of the impact of music on people with dementia it is the most successful way of doing this therefore people are being drawn in to the cafes where they can be signposted</p>	<p>Having worked for 16 years in the field of dementia we have expanded our services across the UK into London Cardiff, Bury St Edmunds, Ipswich and Coventry. But with limited funding we have to turn down so many referrals on a weekly basis. It is only the lack adequate funding that prevents us from expanding further. This therefore is a highly successful model, that has achieved some amazing results, which could be rolled out into the local and regional areas of the country.</p>	<p>with dementia it is crucial to encourage early diagnosis in order that they still have the cognitive function to be able to contribute their expertise and experiences, however their carers would be able to assist in this. This is why we work in partnership with the Alzheimer's Society in their Memory Cafes encouraging people with dementia in the community and their carers to attend not only to give them much needed peer support but being involved in their shares experiences helps to shape the scheme for the future. See below a letter of support from the Alzheimer's Society: Please find below information to support an application to fund concerts at our memory cafes. Alzheimer's</p>	<p>been subject to regular and ongoing evaluation which takes the form of reports received from every session from the musicians, the volunteers and the carers on behalf of the people with dementia. Therefore we have extensive data going back 16 years on the successful impact of music on people with dementia. Lost Chord has recently completed a research project in partnership with Sheffield University in their new research unit 'Music and Wellbeing' The launch of the research was held at Firth Hall as part of the university's Arts and Humanities Festival. Presentations were given from David Robinson lead Music Therapist from Nordolf Robins, the Chief Executive of Lost Chord, Helena Muller and Professor Lord Robert Winston of</p>	<p>Lost Chord is a national member of the Dementia Action Alliance and as a result of a recent campaign to reduce the use of antipsychotic drugs in the care of people with dementia, the use of these drugs has successful been reduced across the country.. Ideally I would like to see the savings made of this reduction of drug use being used to roll out the use of music to help transform the lives of the struggling and help curb aggressive violent behaviour without the use of potentially fatal drugs.</p>	<p>Lost Chord Aspires to affect the lives of every person living with dementia across the UK, therefore I would use the money to make sure the scheme was in operation throughout the UK and available to all residential homes and Day Centres.</p>
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12	<p>approach called Welcome Values. Twelve members of staff from across the organisation spend time observing an individual on four separate occasions and in different settings. The idea is to experience and feel what they do. At the observation stage it is not about intervening or changing things, just feeling as a human being. In feedback and analysis sessions we then identify often small things that could make a big difference for that person. Then look at whether this can be generalised across the organisation. This approach reaches the parts where checklists and kitemarks cannot reach. Our staff have been trained in Empowered Communication. Often we ask people with dementia questions</p>	<p>Dementia is very personal and affects people in many different ways. Large scale projects tend to become very standardised and general. We feel that project interventions should be very specific, local and personal.</p>	<p>The Welcome Values approach described above, is an opportunity to step into the lives of people with dementia and experience it. Often it creates a bond with a person, so that in lucid moments they can explain what their experiences and needs are.</p>	<p>Not sure. We find it hard to get deep qualitative information as people with dementia cannot always respond in meaningful ways. We would be interested in a global review of what is out there already.</p>	<p>We bought Woody, a British Bulldog for our dementia day centre. We have been quite astonished at the effect of just having him around. People become animated, caring and they connect more with each other. Pets are a very powerful thing for people with dementia.</p>	<p>10K We would create 'Biblets' about the lives of each of the people we support for use by them and their families. A biblelet is a widget where you can embed film, pictures, words, music about anything. Currently used for marketing books, but we see this as being really useful as people begin to lose track of their lives. £100K. At our dementia day centre we have the space to create a small day nursery. The effects of mixing young people with older people and those with dementia can be extraordinary. We would like to create a space which has a degree of integration. £1 million. We already have the drawings. We want to turn our run down day centre into the world's best place to be if you have dementia.</p>
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13	<p>There are some very good housing with care schemes (extra care housing) and housing providers that support people living with dementia, some specialist schemes and some for older people with a range of needs. The Housing Learning and Improvement Network is not involved in their development or management but works to promote good practice in a number of different ways through our website and networks. If you would like examples of specific providers and schemes I can provide them. See our dedicated dementia webpages at www.housinglin.org.uk/dementia</p>	<p>Housing with care schemes are all very different and that is largely due to local and regional differences in policies, population profile and players.</p>	<p>The Housing LIN is represented on the steering group of the Housing and Dementia Research Consortium (HDRC) which is running focus groups to see whether the consortium's research priorities are shared by those living with dementia.</p>	<p>There is insufficient evidence of the effectiveness of housing with care for people with dementia although Dawn Brooker's Enriched Opportunities Programme research in Extra Care Charitable Trust housing with care schemes illustrates the effectiveness of that particular approach. http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Practice/Workforce/?parent=5154&child=5357</p>	<p>I would ensure that all staff, including housing staff who have or are likely to have any contact with people with dementia have awareness-raising and training appropriate to their likely level of contact with people who have dementia, as a first step to organisations becoming dementia-friendly. http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Practice/Workforce/?parent=5154&child=9203</p>	<p>I think I would probably invest in the workforce - training, adequate staffing levels and pay levels that recognise their skills. Another area, very specific to our own field of interest would be research into the pros and cons of different accommodation and care models for people living with dementia and their carers</p>
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