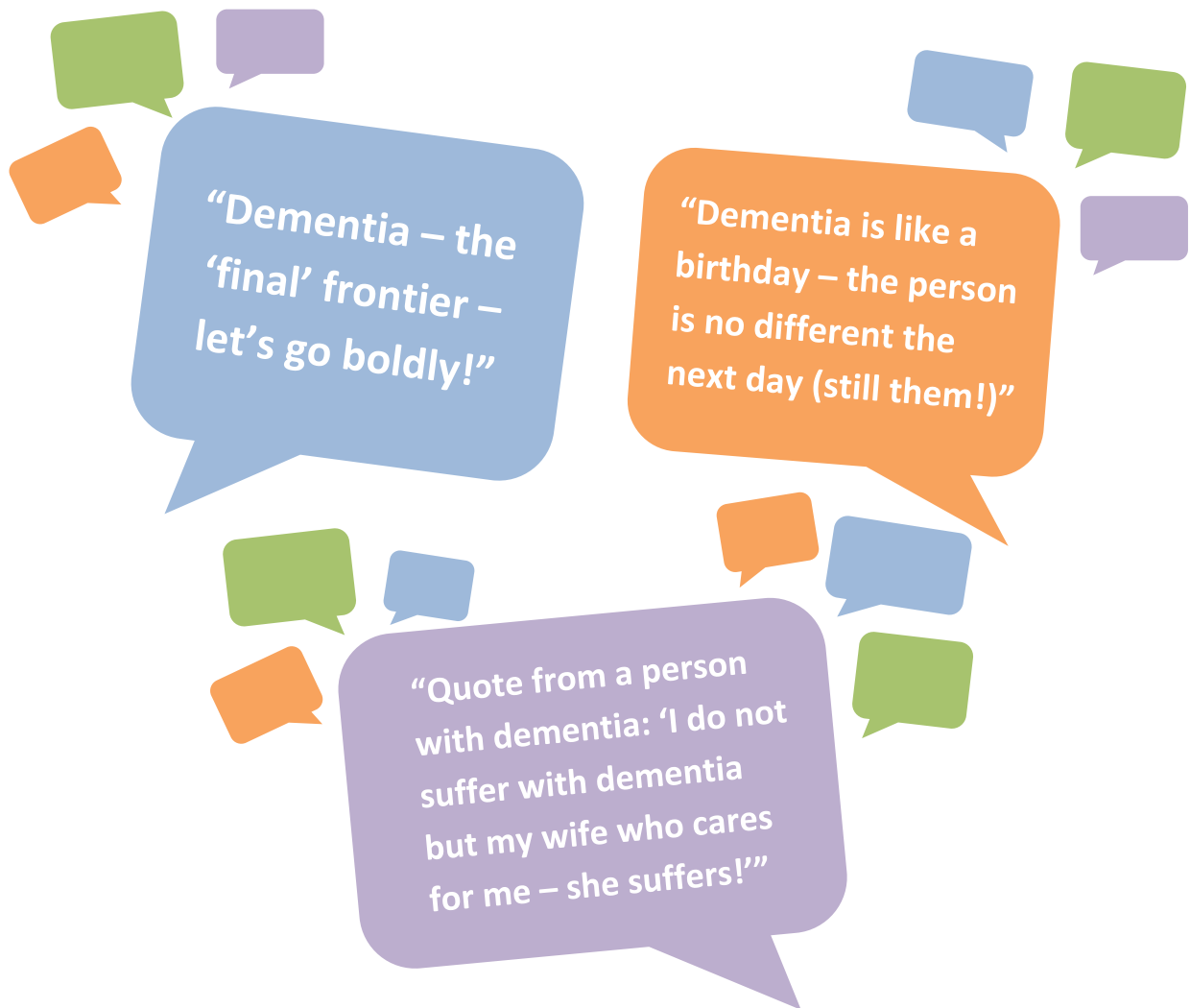


# Dementia Friendly East Lothian



## Learning Event

Wednesday 19<sup>th</sup> November  
North Berwick Community Centre

## **Introduction and Background**

Dementia Friendly East Lothian exists to make East Lothian a great place for people affected by dementia to live, visit and work in.

It does this by raising awareness and understanding of dementia and how it impacts on the lives of people with the disease, their family, friends and carers; providing a forum for discussion on how people across the community can support people living with dementia; and empowering communities to do things which improve the lives of people with dementia, including influencing decision-making and service delivery.

In early Summer of 2014 DFEL applied to the Scottish Community Development Centre for support through the Supporting Communities Programme. This programme was established to provide support for community groups, organisations and networks across Scotland to strengthen their activity, become more sustainable and more influential.

Members of the collaborative identified a clear need for support to develop a vision for a Dementia Friendly East Lothian, to broaden their activities and to develop a structure which is fit for purpose and allows dementia friendly work to grow and be sustained long into the future.

As a first stage in this process it was decided to organise a learning event to bring together a wide range of people with an interest in dementia to share stories of their experiences and explore the challenges and opportunities which currently exist for people living with dementia across East Lothian.

The event took place on Wednesday 19<sup>th</sup> November 2014 in North Berwick Community Centre attended by 32 people from a wide range of groups, agencies, backgrounds and areas.

This report attempts to capture the richness of the stories presented on the day as well as distilling the key learning and insights from the discussions. It also identifies key priority areas and makes recommendations for how these should be progressed over the coming months.

## Format of the Event

The event provided an opportunity to share dementia friendly ideas and the work they're doing, to find out what people across East Lothian are doing and to shape the future of dementia friendly activity across East Lothian.

The event started with lunch with plenty of time to network. Ann Pascoe who runs Dementia Friendly Communities and is a Trustee of the Life Changes Trust delivered an introductory presentation. After this we split into groups to hear real 'stories' of people's experiences of dementia and used these to develop our hopes and plans for dementia friendly communities across East Lothian.

### Programme

12.00pm	Arrival, welcome, networking lunch
1.00pm	Welcome to the event (David from SCDC/Sue from DFEL)
1.05pm	Introductory speaker – Ann Pascoe (Life Changes Trust) speaking about how they've developed their dementia friendly communities in Highland.
1.20pm	Story Group Session 1 – in each story session we will get a chance to hear about people's direct experiences of dementia and will then discuss what this means to us as individuals, community members, volunteers or service providers.
2.20pm	Break and networking
2.40pm	Story Group Session 2 – participants will have the opportunity to join a different story group, the format will be the same as the first session.
3.40pm	So what? Now what? This final session will draw on the learning and insights generated in the story groups to develop key priorities for action in dementia friendly activity across East Lothian. This session will be facilitated by David from Scottish Community Development Centre.
4.15pm	Closing remarks and participatory evaluation session (no evaluation forms here!)

## Introductory Presentation

Ann Pascoe is Founder and Director of [Dementia Friendly Communities](#) and a Trustee with the [Life Changes Trust](#). She is based in Helmsdale and covers the Highland area. She also cares for her husband Andrew who has dementia. Dementia Friendly Communities provides help and advice about dementia and support people in largely rural communities. Ann set up Dementia Friendly Communities as a volunteer with a vision and a mission to change the lives of people living with dementia. Dementia Friendly Communities works as a collaborative, fuelled by passion to make a difference and influence and engage people in taking action round dementia. They have set up a number of Task Groups to take forward the issues that matter to people living with dementia. These groups involve people with dementia and paid and unpaid carers working together to find effective solutions. For example, they wanted to bring the local care home into the heart of their community and set up a 'friends' scheme to do this. Local people also voluntarily help in in the care home gardens.

Dementia Friendly Communities supports carers giving a bit of help and support at an early stage to avoid the crises no one wants to happen. Ann explained how people can be scared to let go of controlling the care and support for their loved ones and so they may not seek support until a crisis happens. The DFC Collaborative has demonstrated that supporting people in the first 24 hours after a crisis like a fall was often enough to get people through and avoid problems escalating.

Dementia Friendly Communities' work is led by people with dementia, but not just people who have a diagnosis of dementia. Everyone creates the vision and the task groups work to make the visions a reality.

Ann explained that rural communities are different to urban ones with different problems and challenges. They want to make their communities inclusive and welcoming of everyone, rather than create dementia ghettos in the community.

Ann encouraged us to share our ideas and find out what works for our communities. She urged us not to see dementia as about charity, it's about everyone and has to be sustainable. The Life Changes Trust is a valuable source of support and advice, not just finance but mention and encouragement too. Ann is here to hear our stories, support and encourage our work and share her learning.

## **Story Dialogue Sessions**

Story dialogue is a technique which uses people's real life experiences – their stories – to generate discussion, insights and learning on a particular topic. These insights and learning points can help to identify actions which will address the issues and problems raised and further the good work that has been described in the stories. At the learning event we had 5 different stories of dementia from very different perspectives. These stories triggered off discussion in 4 story groups (there were 2 stories covered in one of the groups) and are summarised here.

### **Session 1**

#### ***Sue's Story - 'Living not existing'***

Sue was the primary carer for both her parents who had different dementias for over 10 years, she also had grandparents with dementia. Having supported them from before diagnosis to end of life care, Sue didn't want anyone to go through the bad experiences her family had had and worried about what happened to people who didn't have someone to look out for them – dementia can make people very vulnerable. Sue started talking to people about dementia and through Sandra at the Community Centre made contacts with other interested people in making North Berwick Dementia Friendly. Sue then met Maureen who wanted her community in Tranent to be Dementia Friendly too. Soon people across East Lothian were talking about dementia and how to make their community Dementia Friendly. Sue found lots of people across East Lothian want to help make life better for people with dementia and now goes round talking to different communities about what they would like to happen where they live. It's really important that people with dementia have a voice and ability to influence the things that matter to them. People with dementia want things to do, places to go and people to see. So many people across East Lothian want to help to make a difference. Sue wants to know how she can make a difference and do her bit to change the world.

#### ***Charlotte's story***

Charlotte works for Alzheimer's Scotland and her story is from more of a professional perspective, as no-one in her family has Dementia. Charlotte worked in a care home from when she was 16 years old, when she was still at school. She studied radiography at university which is when her fascination with dementia grew. Charlotte then worked as a domiciliary carer whilst at university and then went into management in an independent care company in Edinburgh because she couldn't get a full time radiography job. That job

led Charlotte to her current post as a training and community development worker with Alzheimer's Scotland. Although Charlotte doesn't have personal experience of dementia it's lovely to be able to use her experience and knowledge to help people who are directly affected. Her current job allows her to improve education and training around dementia. Her main frustrations lie around not being able to do as much as she wants due to time and capacity. Her post is also only currently funded until March 2015 which prevents the development of a sustainable training strategy. Charlotte spoke about continually wanting to do more and how this motivates and drives what she does.

Sue and Charlotte's stories led to a conversation about the importance of talking about dementia with families, friends and in communities. Suggesting someone might have dementia can be really hard for family members, friends, and professionals, but talking about it can reduce the stigma, secrecy and isolation that build up around dementia. This helps build links and understanding. By involving more people, we can use the different skills and help of people who are paid or unpaid, professional or part of the community.

### ***Maureen's Story***

Maureen's parents live 200 miles from her and her father has dementia and has had a diagnosis for 2 years. Her brother lives near to her parents but he often works away from home. Maureen's mother often looks after her grandchildren alongside caring for her husband. Maureen spoke about how dementia was often hidden in families; her own parents keep it to themselves and do not want to let others know. Maureen spoke about the guilt she feels about living so far away and how difficult it is to leave her family to come home. Maureen works for an independent agency which delivers care services. She is part of the Dementia Friendly group in Tranent and together with the Community Council they have submitted an application to the 'Life Changes Trust' for funding to create a reminiscence story.

Maureen's story led to a conversation about awareness of and attitudes towards dementia. It was felt to be important to do inter-generational work to ensure that young people are involved and informed at an early age. This would help to counter-act the feelings of fear and guilt that can easily affect people in a caring role. There was also agreement that attitudes to care need to change and that care in the community needs to be looked at more positively. It is an undervalued service, but critical to help people live independently, and more funding is needed for preventative care.

## **Session 2**

### ***Carol's Story***

Carol is a Registered Nurse and has worked in Geriatric wards, Hospitals and Nursing Homes over many years. She found herself asking why a lot of people are in nursing homes for a long period of time when with support in the community they could be in their own home.

Starting in the mid 90's she began work towards establishing day care support for people with dementia. She worked with the local Community Development Officer and the Community Council, got a start-up grant, and visited other Day Centres. She then recruited volunteers - 14 people from various groups but with similar experiences – and ran training workshops focusing on seeing beyond the illness, life stories and reminiscence, and music therapy. Important learning for Carol was that you can do things with little or no money - you can do it if you really want to. At the start there was nothing in North Berwick and now there is a Day Centre which has been there for 10 years. The Day Centre has developed into a community hub, not just a separate place for people with dementia and their carers. A mix of people meet there and it is important for it to be at the heart of things with a real focus on re-engaging people with the history of their community. The Centre strives to have person-centred approach by finding out what the person wants to do or to try. Although what the Centre can offer is fairly limited they have ambitions and want to continue to evolve their service e.g. around sporting memories – all with the long-term aim of keeping people as independent for as long as possible.

Carol's story led to a conversation about the factors that are needed to make vision into reality. These include starting small, retaining enthusiasm, passion and motivation and most importantly sheer persistence to see things through to fruition.

### ***Helen's Story***

Helen was working with care in the community. She visited a couple at home and was struck by how quiet the house was. The gentleman of the house was always in bed, and never spoke. Helen decided to sing to the gentleman as she went about the room. Initially there was no response but within approximately 6 weeks she had found a connection with him and he was responding to stimulation through music, touch and movement. His wife felt responsible for his wellbeing and was too worried to leave him alone to go out for a short time. With encouragement she eventually went to the shops. Through support Helen could see the difference she had made to the couple and wondered how she could take this forward and decided to train as an activity co-ordinator/therapist and now works within one of the care homes in North Berwick. Helen feels that everyone responds to music, there is always at least one song that we can remember an association when we hear it. She thinks

that it is important to capture musical memories now. We should be making these associations to music from childhood and throughout adulthood.

The group shared experience of how music transforms life for people living with dementia, but that we also need to communicate through other mediums too. For example, touch (hugging, holding hands, and non-verbal behaviour) is really important, as are open welcoming facial expressions, and tone of voice. There was further discussion about the value of taking a creative and varied approach to communicating with people with dementia, e.g. through physical activity, talking mats, life books and photographic picture books. Communicating with people with dementia, especially at the later stages, means being in that person's life and in their moment. We need to be in their reality and see the world through their eyes.



## Insights and Recommendations

Each story group generated a large number of insights based on what participants learned from the stories. The insights are listed as bullet points in Appendix 3 but have been summarised in this section along with some associated recommendations.

### Awareness and Understanding

We were reminded constantly throughout the session to 'see the person, not the illness' and that making our communities dementia-friendly is in many ways, just being people-friendly. The core messages about awareness-raising and developing understanding are to emphasise that people with dementia are all individuals with different needs, we should not put them in a box marked 'dementia'. We need to help carers and others understand where the person with dementia is coming from and education is important to do this. Everyone needs to understand what life is like with dementia – from the earliest years onwards. A recurring theme throughout the session was the need to keep people with dementia and carers at the centre of any initiatives that are developed. They will provide the drive and the focus to keep change sustainable. We need to keep listening to people with dementia and their carers and remember that everyone will have a different perspective. Carers' perceptions of the situation will be different from the person with dementia and professional perceptions. Carers' feelings of guilt need to be recognised and focus on how we can support carers to ask for help.

So what can we do? There is still a massive task facing us in relation to raising awareness of the reality of dementia. However, never under-estimate the power of bringing people together to learn about each other and build relationships and friendships. Inter-generational work in the community, including in schools can make a significant contribution to building awareness and understanding of dementia and across the generations. It is important to recognise that such inter-generational work is based on key principles (including participatory, asset-based and well-planned) and is planned, delivered and evaluated accordingly. (Oral) history projects can be a fantastic way of exploring people's lived experiences and making connections with people's lives today. By building understanding and relationships, based on the real voices and experiences of people living with dementia can help to challenge the stigma of dementia. It is the development of human relationships and understanding that breaks down the stigma of dementia and the damage that anxiety, fear and social isolation bring.

It is important to maximise the use of existing community assets to drive forward dementia-friendly communities and a key part of this is sharing information and resources, and building productive links between those involved and those affected. Experience of Dementia Friendly work in East Lothian has demonstrated a wealth of interest and support across the age groups in helping to make life better for people with dementia. People want

to help - schools, libraries, day centres, care homes, independent care providers, shops, churches and the Brownies are all actively engaged in learning about dementia and supporting people with dementia in many different ways. These community assets and networks help to spread the word about dementia into the farthest reaches of the community.

**Recommendations:**

- *Produce key 'messages' about dementia in attractive and accessible formats which can be disseminated widely and used with a wide range of target audiences. This may involve production of new information or widening out access to existing information through signposting, web portals, etc.*
- *Explore means by which inter-generational work can be developed using a community development approach (as outlined below).*
- *Ensure that a community development approach is taken to dementia friendly work in East Lothian. Crucially this will mean that all activity is community-led and will have a focus on improving the quality of community life through building the strength of communities to address the needs of people affected by dementia across East Lothian.*

*Training – generating understanding and reducing stigma/fear about dementia*

It was agreed that training on dementia is an important tool in creating dementia friendly communities and services. There was agreement that there needed to be more investment in dementia training and that the resource for this should be sustainable. Training helps people understand and feel confident to act effectively around dementia. Training can help people in a range of different roles from paid professional staff in care services to shop keepers, carers and local businesses. Participants were unsure where funding for training would come from after the current Change Funded post ends in March 2015.

**Recommendations:**

- *Discuss DFEL's draft dementia training strategy with the Health and Social Care Partnership and press for this to be effectively resourced.*
- *Ensure that the dementia training strategy builds on current work and supports the Dementia Friendly Community approach.*
- *Ensure that the East Lothian dementia training strategy reflects the Scottish Government's dementia training strategy (Promoting Excellent) and extend thinking about this to ensure it embraces the whole life and dementia journey of people with dementia.*
- *Explore options for widening out training in and with communities, and involvement of people with dementia in this.*

### Care services

Person centred care that is suitable for the different stages of living with dementia is critical. Dementia Friendly Communities are all about supporting members of our community to live meaningful and engaged lives throughout their dementia journey, whatever the accommodation setting. Dementia Friendly Communities is all about how our communities can support people with dementia to continue to do the things they want to do despite having dementia. Assets based approaches to the provision of care mean that the person with dementia is seen as someone with capabilities and resources, including family, friends and local community support. The provision of services has to be developed on this basis - person-centred approach to care which promotes people's independence. This means that care providers need to have different conversations with people with dementia and families and carers as early as possible. This also relates to the need to talk more about dementia, to remove the stigma and fear which stops people planning ahead and seeking help and support at an early stage.

### **Recommendations:**

- *Develop case studies/examples which help service providers and decision makers understand the role that community resources and organisations can play in providing effective care at all stages of dementia, supporting people with dementia to live meaningful independent lives in the community for as long as they wish to do so*
- *Talk with service planners and decision makers about this*
- *Support opportunities for care providers to come together cross-sector to share learning and ideas*
- *Continue to raise profile of dementia in local service planning structures (e.g. local area partnerships)*
- *Increase opportunities for people with dementia to have more say and influence on the decisions that matter to them*

### Building Relationships

People connect and build relationships in diverse ways from informal conversations in community settings, cafés, shops, community centres, libraries, on the street, etc. to more formal links and connections between organisations. The recurring view throughout the conversations was that we need to keep talking about dementia (to everyone!) and that the more we talk about it openly and positively the more we will break down barriers and stigma. We also need to forge links between professionals and the community as professionals need to talk with communities, not just amongst themselves. The other important aspect is about people involved in service provision talking to each other and sharing ideas and information about what they do e.g. between care homes and day

centres. There is a lot we can do if we work together e.g. Care Homes and the East Lothian Ranger service. Other ideas included 'twinning' dementia-friendly towns in order that productive and useful links can be made not just across East Lothian but also wider. We need to make sure that the voices and experience of people living with dementia are at the heart of this. They have to lead the conversation, otherwise it's just professional people talking to each other which is what they are doing already!

**Recommendations:**

- *Continue to develop opportunities for service providers (all sectors) and communities, people with dementia, carers and families to meet, share stories, develop learning and generate action around dementia – explore options around suitable methods e.g. annual event, regular forums/meetings, online chat, etc. – i.e. our collaborative.*
- *A forum to be established for people living with dementia to influence decisions that matter to them.*
- *Explore means for sharing/developing professional practice on dementia – possible focus for a task group or sub group of DFEL.*
- *Explore opportunities for wider sharing of practice and learning – through 'twinning' of dementia-friendly towns or other initiatives. Life Changes Trust will do this.*

*Resourcing and Sustainability*

There is a substantial amount of resource within the community to support and take forward dementia-friendly work. Schools, libraries, churches, volunteers from day centres, community groups and individuals all give freely of their time. It is important that this commitment is recognised, valued and supported. In this context we need to be able to collaborate better and more effectively e.g. through developing better networking, and continuing to develop the dementia-friendly collaborative. However, we also need more investment in services and so need to identify any opportunities to attract funding through public sector, private sector or independent sector. There are parallels that can possibly be drawn with initiatives such as 'Support from the Start' and it may be worth exploring if we could do something similar in relation to dementia.

**Recommendations:**

- *Explore structure options for DFEL and continue to develop the activities of the collaborative.*
- *Develop 'funding opportunities' package/guidance for work on dementia.*
- *Analyse 'Support from the Start' model and identify possible parallel developments for working on dementia.*

### Shared Values and Principles

It was very clear from the discussions and shared experiences of participants that dementia-friendly work is based on shared values and principles. It should be: community-led; inclusive; participatory; empowering; person-centred; and collaborative.

### **Recommendations**

- *All dementia-friendly work should be underpinned by these principles.*
- *All participants in DFEL activity should be made aware of these underpinning principles and how these influence both what DFEL does and how it operates.*



## Summary and Next Steps

We were heartened by the turnout at the event and the enthusiasm and energy that participants brought to the discussions. There is obviously a very clear commitment amongst those involved (and others) to take forward work and activity which will make East Lothian a better place to live for people with dementia and their carers/families. There are a number of clear themes which emerged from the discussions and sets of recommendations relating to each of these but there is a need to build on the work the work of the DFEL core 'folk' so far.

- A focus for the DFEL collaborative has been on how to take forward these ideas and recommendations – how to make the vision a reality – and there are a few imminent developments which should help this to happen.
- Preliminary work on funding applications has been undertaken. These will be aimed at taking forward and rolling out dementia-friendly activity in East Lothian.
- Appropriate structures for DFEL will be explored over the next 2 or 3 months which will allow us to develop the work of the group further. These may include some or all of the following ideas: loose network, formal collaborative, social enterprise, federal structure, etc.
- The DFEL collaborative will continue to circulate information about dementia-friendly activity that is taking place and will keep on connecting people up and bringing them into discussions.
- This report will be disseminated widely to key partners across East Lothian – there will also be a number of dissemination events with a view to raising awareness and increasing support for dementia-friendly work across the area.
- All the participants were keen to stress how important it is that people with dementia remain and are seen to be valued members of the community. Our discussions and actions will focus on how we develop more inclusive communities and not just solely focusing on people affected by dementia.

In summary, as mentioned by one of the participants at the learning event:

**“Dementia – the ‘final’ frontier –  
let’s go boldly!”**

## Appendix 1 – Evaluation and Feedback

### Dementia Friendly Learning Event – Evaluation and Feedback

15 participants completed evaluation forms and other participants left comments on the feedback wall at the end of the event.

	Satisfaction Ratings	5.Excellent	4.Good	3.Adequate	2.Weak
1.	Information received in advance	4	7	2	0
2.	Booking process	4	7	1	0
3.	Prior Knowledge/confidence/skills	1	6	5	0
4.	Venue-suitability/comfort/accessibility	4	10	0	0
5.	Ability to take part	11	3	0	0
6.	Facilitator-Knowledge/confident/clear	9	5	0	0
7.	Content relevant to your needs	8	5	0	1
8.	Topics covered in sufficient detail	6	5	3	0
9.	Event learning outcomes met	6	6	3	0
10.	Story Dialogue Session	7	7	0	0
11.	Knowledge/Confidence/Skills gained	5	5	4	0
12.	Ability to implement learning	4	4	5	0

#### How do you plan to use what you have learned?

- *To feed into exhibition, planning and programming of events*
- *By planning with other committee members*
- *Find groups to work with collaboratively*
- *Take forward ideas and share such with other groups*
- *Network with other people*
- *Take forward information and ideas in my role*
- *I plan to take forward all the information and take to my care home*
- *To arrange visits for our residents forum and from the range of services to email Maureen Allen who will send me details of resources.*
- *Ongoing work.*

#### When do you think you will use what you have learned

- 0-3 months (x8)
- 6-12 months
- 12 months plus
- When appropriate

#### What improvements could be made to this event?

- *Smaller groups (x 2)*
- *Prior knowledge and/or experience of dementia was assumed – I want to be dementia friendly but do not how and this event didn't help.*
- *Quite hard to hear some participants*

- *Acoustics – a bit difficult to hear (x2)*
- *Perhaps only 1 group in the hall but otherwise a very good event*

**Do you have any suggestions or ideas for future events?**

- *A dementia training session*
- *None - going on a similar thread*
- *Turn group into a collaborative and use task groups*
- *Keep the momentum going – link the idea of dementia friendly – similar model to Support from the Start*
- *A Question and Answer with the story teller, in order to gain more information on that topic.*
- *Let's have a really 'can do' approach and take forward all the wonderful ideas to the next step*
- *Hold annual story dialogue event (smaller groups)*

**Any other comments**

- Great hosts, lunch and lovely people
- Great opportunity to network x 3
- Great, thanks
- Share Stories
- Loved every minute, great networking and thanks for lunch!
- Need to become a constituted network or collaborative as soon as possible.
- Attract joint funding to take forward some key initiatives across the county

**One thing I can do to take forward dementia-friendly work in East Lothian?**

- Already doing – going to give a talk about wildlife to Fidra House residents
- Transport
- Provide an 'at a glance' list of book titles on dementia which are currently available in East Lothian libraries – currently looking at ways to involve Dunbar library.
- Tiny steps to take this forward

**What could be improved?**

- Ideas for how I can be part of a dementia-friendly community?

**What did you particularly like?**

- Stories –real-life
- Story dialogue concept – very useful for all to feel they can contribute rather than only a few talking
- Story dialogue – a powerful technique to share stories & experiences

**How was it for you?**

- A good use of my time 😊



## Appendix 2 – Insights (what people said)

### *Information/Awareness*

- Sharing information and tackling stigma – increase opportunities to raise awareness and talk about dementia
- Break down barriers and stigma
- Sharing of information - blog
- Sharing information – building links
- We need to communicate with families and members of the public to introduce them to the kind of care available – before they need it!

### *Training*

- Further training for staff in hospitals who will have to care for the dementia patients on different hospital wards – current lack of investment in staff.
- Put together training or source training for everyone + anyone to take up – especially people who work front of house (café, receptions, hairdressers, etc)
- Local shops, etc. to be involved in planning/training, etc.
- Make dementia-training compulsory for everyone who will come into contact with people living with dementia.
- Teaching carers coping techniques – community assistance and understanding.

### *Connections and Links*

- Conversations and connections.
- Maintaining and promoting relationships.
- Dementia-friendly towns link together (twinning).
- Referrals from CPNs of family members/carers who would benefit from support (i.e., to carers groups, etc.)
- Talk about dementia to everyone! Keep talking!
- Knowledge is power.
- Forging links between 'us' and the community.
- Lots we can do if we work together e.g. care-home and ELC Ranger service.
- Professionals need to talk with communities – not just amongst themselves.
- Activity co-ordinator forum – so advice and information can be passed between care-homes and day centres, etc. and so activities can be shared that are varied and person specific

### *Care Services*

- Ensure there is a structured personal centred approach to care
- Be inclusive – develop social interaction
- Social contact – being with others

- Young and old learning about music together
- Reaching people who are isolated and would benefit from support
- Promote independence
- Where are the GPs?
- Familiar surroundings
- Person-centred approach
- Some individuals with dementia will have different needs to remain independent
- General groups mixing – not separate ‘dementia groups’
- Fear of diagnosis and ending up in a care home
- ‘All about me’ being filled in - so available for when people go into hospital, care-home and care-settings
- Time constraints for carers
- Lack of routine in care

### *Funding*

- Reduction in service
- Set up collaborative
- Develop dementia-friendly services, exhibitions and reminiscence sessions
- Activity co-ordinators forum
- Council commission service
- Payment for carers
- To increase independence and wellbeing, we need increase in services.

### *Sustainability*

- ‘Permission’ to just do it – give it a go
- Sustainability networking
- Emergent process – things fall into place
- Sustainability is essential
- ‘Support from the start’ – parallel development for dementia?
- Sustainability through community determination
- If you don’t ask, you don’t get! Ask for free services from private sector.
- Frustrations with the NHS/care provisions
- Importance of maximising use of existing community assets to drive forward dementia friendly communities