

Sheffield Dementia Involvement Group



SHINDIG 15

Thursday 1st December 2016

**Sheffield Dementia Action Alliance:
Ideas for Initiatives and how the Alliance
can keep in touch with People with
Dementia & Family Carers**

Introduction

Sheffield Dementia Involvement Group (SHINDIG) is organised jointly between Sheffield Health and Social Care NHS FT and Sheffield Alzheimer's Society. The group was formed to explore and improve the ways people living with dementia are involved in service feedback, evaluation and planning.

The 15th SHINDIG held in December 2016 was attended by 31 people which comprised 17 people with dementia and 14 family carers. Two members of Sheffield Dementia Action Alliance, Anna Machalica and Kath Horner, visited and presented some of the current work the Alliance has been involved with. SHINDIG members then worked in small groups to discuss:

- What priorities should the Alliance look for funding to support?
- How can the Alliance keep in touch with people with dementia and family carers.

A brief summary of the group discussions is reported but for more in depth information of what things people actually said in the groups the reader should read the full report.

SUMMARY

Some people with dementia and some family carers had experienced initiatives that Sheffield Dementia Action Alliance had already been involved in. Key discussion points were:

- There were a range of experiences of bus and taxi drivers, some were helpful and yet others did not seem to understand dementia, more work was needed on this. The orange bus pass holders (which indicate to the driver that the passenger may have additional needs – although not specifically dementia) were largely seen as a good idea, although not everyone knew about them. There was a discussion about whether everyone wanted to 'advertise' that they had dementia.
- The tea dances were good, but it was difficult to get a place and they might be better also offering them more locally than just in the City Centre.

- Not many people had experience of dementia friendly exercise groups – there were mixed views on whether people would want to attend or not.
- Not everyone was aware of safety initiatives such as fire safety checks and the Herbert Protocol (see later in report for details).

Ideas on priorities for future Sheffield Dementia Alliance Initiatives focussed around activities and events in areas such as:

- Ideas included activities based around: music and dance, sport, outdoor activities, technology, arts and crafts, cinema and film and reminiscence type activities such as life story work. There was also interest in activity based on people’s past work interests, and using skills they had.
- People also talked about social events / outings and a ‘hub’ where people might drop in and take part in activities.
- Some family carers felt GP’s needed more understanding about dementia; there was also concern in health and social care services being reduced /withdrawn.
- The need for improved information about services and events was identified by family carers.
- People with dementia identified a range of factors that are important in any activity event to make them feel comfortable and enjoy the event. See the full report for examples of these factors.

Suggestions on how the Sheffield Dementia Action Alliance can keep in touch with people with dementia and their family carers:

- Lots of suggestions were made that included newsletters, attending existing groups such as cafes and SHINDIG, passing information on to dementia support workers to share at groups.
- Some people would like to make contact directly by ‘signing up’ or having a number to call.
- A range of media approaches to sharing information were discussed.

FULL REPORT

People with Dementia & Family Carers (FC)

1: Experience of Current Sheffield Dementia Action Alliance Initiatives

Transport

- Bus and tram drivers are very helpful they tell you where to get off
- Bus drivers not always helpful, bus drivers need to be aware that a person has dementia
- People found the bus drivers variable, some were understanding and others less so
- Transport still an issue – people using the disabled seats and not giving them up, there's a need to remind people how to use them properly (FC)
- Orange pass holder - needs more publicity
- Orange pass holder – ‘Do I want people to know – do I want to advertise that I have dementia?’
- Some people did not know about SDAA or the orange bus pass holder or the tea dances (FC)
- Request for orange bus pass holders to be brought to next SHINDIG (FC)
- Taxi drivers - some have dementia awareness but not all. One pwd prefers Mercury or City

Tea Dances

- Possibly needs another venue? Different places - local as well as city centre
- Time of day is important (varies)
- A good idea but shortage of spaces and difficulty booking on (FC)
- The carpet at the tea dance at the Crucible makes it difficult to dance on

Dementia Friendly Exercise Venue

- Local places more attractive.
- Are they dementia friendly?
- Questionnaires available for feedback.
- Enjoyment from social aspects of exercise.
- Dementia friendly sports staff.
- Special dementia friendly sessions would be helpful.
- Health concerns - falling, dizziness, pace is important.

- What is happening with Activity Sheffield?
- Sports events – no not interested in going to the gym

Safety

- Fire safety - Home visits can be arranged, Leaving the gas flame lit, Using timers is helpful, Using fire guards, Smoke alarms can be adapted to meet your needs eg under pillow alarm (FC)
- ‘The Herbert Protocol’ – a form you fill in with a description of the person you care for – it helps so that police can more easily search for and recognise a person with dementia if they go missing (FC)

2: Things the Sheffield Dementia Action Alliance should prioritise when seeking funding.

Art / Craft Activities

- Art classes / groups; Crafts - knit and natter to sell to raise funds
- One person runs and art group
- Creative activities / art

Music / Dance Activities

- Singing / choirs
- Singing is good
- Music – one or two people – plays guitar / organ like listening to music
- Local teas dances – might bring people out that don’t come into town

Cinema / Film Events

- Cinema - dementia friendly - Showroom Cinema - choose films
- Films – ‘I like to go to the pictures’ ‘I like war films’ ‘Depends what it is’
- Cinema smaller venue better when not overcrowded (FC)
- Cinema in a room rather than in a cinema and dementia friendly (FC)
- Important to have intervals for toilet breaks and consider mobility issues (FC)
- Issues at crucible for people in wheelchairs – more difficult to accommodate lots of people in wheelchairs sitting together (Visitor)

Technology Activities

- TV technology, computers, user friendliness
- Events, clubs Age UK
- Games / entertainment

- Access / tuition
- Sharing skills groups

Sport / Outdoor Activities

- Outdoor bowls / indoor (crown) bowls
- Taster sessions
- Exercise - Gym partnership dementia friendly would be good - although not everyone liked exercise / the gym
- An exercise group for older people would be good - maybe exercise / activity groups not in gym environment (FC)
- One person with dementia used to enjoy swimming but has not been for a long time - made more difficult as their spouse was not able to swim
- Gardening - some people like gardening / being outdoors
- Growing things
- Community gardens a garden that people can do something in, talk about the plants 'might be a good idea'
- Walking
- Walking with dogs so this helps get people out and about (FC)
- Being outdoors

Reminiscence Type Activities

- Coming together - reminiscing - life history group 'make a book' 'our stories'
- Some people in the group are already creating their life story - 'Brilliant idea' to have support to put a book of memories together - photographs, helping with writing memories down
- 'Relaxation for me' (to be writing life story with Jane and students)
- 'Everybody's reminiscing now'

Skills / vocational activities

- Joinery / building / designing
- A person with dementia gave the example of local fund raising he had undertaken - looking at ways to use the skills people have to contribute to raising funds etc

Social Meeting Place / Events

- A 'Hub' sharing skills, making things, with each other - with others
- Social event - eating out - going to the pub

- Ideas of large day activities where everyone comes together from time to time- example given of memory walk – amazed at the amount of people all there to support dementia – was emotional
- Transport to organise trips / days out (FC)
- Social group to go where you can join – like a ‘youth club’ for older people with dementia, garden and outdoor space and contact with other people (FC)

Carer Support Services

- Activity centres - providing activities which individuals are able to do. Example of a place where the person with dementia can go and do things they enjoy eg games, whilst their carer goes shopping for example, a current service in Hillsborough is closing and will be missed (FC)
- Long term services - changes with a day and respite Centre closing - funding freed up will be offered to other organisation to bid for the offer services (Visitor / FC)
- Expanding knowledge / information between resources and communities (FC)
- Safe trades – for example being able to have people to help who can be trusted and aware of dementia (FC)
- Working with GPs / surgeries about priority appointments so you don’t have to wait so long in the GP surgery – although this is varied (FC)
- Work with GPs and reception staff to understand that carers and a priority and it’s important they keep well and to know what their situation is (FC)
- They (GPs) need to understand that we are together and I have to go in with my husband (with dementia) (FC)
- Admiral nurses – we don’t have them in Sheffield, especially for people with specific conditions (FC)

Information Services

- Information – being able to find out what’s on, what’s available (FC)
- Memory clinic doesn’t give a pack of information out anymore and there’s a lack of information (FC)
- Note: It feels like things take a long time (FC)

3: Things that people with dementia value in any group / activity / event

- Coming together in a group
- Facing what's happening 'not doom and gloom'
- Sharing – difficult to get people together with similar types of dementia – confidentiality
- Sharing takes a bit of the weight off you
- What's Important?
- That people are kind
- That people listen
- Transport
- Refreshments / free lunch
- Venue – a place to meet – 'like here'
- Discussion about dementia
- 'I want this discussion' 'You've got to come out'
- Emotional support
- How important is short term memory?
- Thinking about the impact on others – wife
- You've got to be able to laugh – 'main thing'

4: How Sheffield Dementia Action Alliance can keep people informed?

- Information, Via GP / cafes
- Meeting groups already taking place eg cafes, SHINDIG (FC)
- Through workers / staff (FC)
- Reporting back to the dementia support workers through the cafes (FC)
- Dementia friends meetings locally (FC)
- Circulated through cafes
- In the Star (newspaper)
- Notice board in the library
- Radio Sheffield
- Service where we could receive information directly
- Internet
- Newsletters, keep in touch various ways at meetings etc (FC)
- A number – we could contact you – 'we would be genuinely interested'

- Email - be a member of SDAA get newsletter
- Can we register with the SDAA? (FC)
- Can some services act as an advocates - to gather the views of people with dementia and feed back to SDAA? (Visitor)
- Can they feedback on progress and how things are developing? (FC)

Comments or feedback on this report are welcomed by:

jane.mckeown@shsc.nhs.uk 0114 2263950

or

jo.wallace@alzheimers.org.uk 0114 276 8414