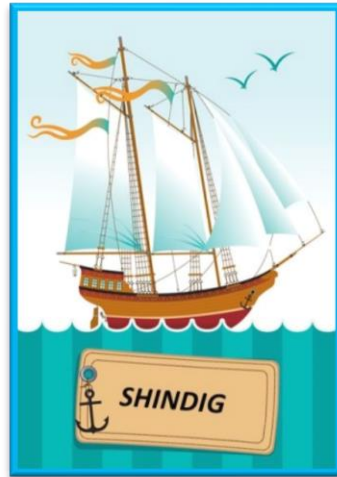


# Sheffield Dementia Involvement Group



**SHINDIG 22**

**Thursday 6<sup>th</sup> September 2018**

**Report:**

**How can People with Dementia  
and Family Carers / Supporters remain  
Active?**

**An Interactive 'Have a Go' SHINDIG**



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## Background

This 'interactive' Sheffield Dementia Involvement Group (SHINDIG) topic was in response to questions from people living with dementia and family carers / supporters about what opportunities were available to keep active.

'Interactive' SHINDIGs take place once a year to provide a more hands on 'have a go' experience.

This SHINDIG was attended by 25 people living with dementia, 21 family carers / supporters and was supported by 16 staff facilitators or visitors. Additionally the SHINDIG was attended by 18 people from organisations in Sheffield with a focus on keeping active, healthy and moving more. These included:

Strength for Life / Sheffield Hallam University	National Centre for Sport and Exercise Medicine
Places for People	Yorkshire Sport
Drink Wise, Age Well	Move More
Sporting Memories	Dance to Health
Sheffield Libraries	Venture Walking Friends (independent group supporting people with dementia to continue walking)
<i>Sheffield International Venues were invited but unable to attend.</i>	<i>Sheffield Health Walks were unable to attend but requested access to Dementia Friends sessions.</i>

Invited people / organisations offered information stalls and or activities that people could participate in.

### Activities included:

A 'Move it or Lose it' activity session delivered by 'Drink Wise Age Well'. Three 15 minute sessions of this activity were offered and gave everyone who wanted to an opportunity to take part regardless of ability.

A dedicated space was put aside where 'Strength for Life' offered people the chance to try out different weight lifting approaches to building body strength. Everyone who took part seemed to enjoy this and the activity was tailored to individual needs.

'Places for People' facilitated Boccia; this is an activity similar to bowls that can take place even in limited space. It was noted how this brought out the fun and competitive side in people.

Sheffield Libraries volunteers organised a 'Sporting Memories' reminiscence group. People were invited to choose photographs that helped them to talk about sporting related memories and activities.

People were encouraged to move around and try different activities / stalls. Each activity or stall was supported by 2 or more SHINDIG facilitators to ensure that activities remained 'dementia friendly' and that people felt comfortable and included throughout.

**Stalls / Visitors Included:**

- *Drink Wise Age Well* information about alcohol.
- *Dance to Health* co-ordinator talking to people about the initiative.
- *Sheffield Libraries* provided information on the wide range of library facilities including the online facilities.
- *Move More* co-ordinator talking about the initiative and the Move More ambassadors.
- *Yorkshire Sport* and *National Centre for Sport and Exercise Medicine* sharing information on their services and initiatives.
- *Places for People* informing people about the GP referral scheme and the Places for People sports centres and dementia specific activities.
- *Venture Walking Friends* informing people about their walking group aimed at supporting people with dementia to keep walking.

Additionally we asked some questions about what people liked to do, what they thought were barriers to taking part and ways they could be more active.

A final whole group brief evaluation was undertaken and staff facilitators and activity visitors were asked to provide feedback in a verbal de-brief session and / or on a written evaluation sheet.

This report details the key findings from the interactive SHINDIG. This is presented initially in a summary bullet point format before the whole report is presented in full.

## Brief Summary Report

- People with dementia and family carers / supporters participated enthusiastically in the different activities and stalls.
- There were positive comments about the event being friendly, fun and worthwhile.
- A few people found the event too crowded and some did not feel they had enough time to get around all the activities and stalls.
- People with dementia and family carers / supporters were largely unaware of the organisations and activities on offer in Sheffield related to keeping active.
- People with dementia and family carers / supporters largely felt that advertising of many activities online or through email excluded them from knowing about initiatives and taking part.
- It was felt that flyers and colourful posters advertising opportunities would be a better way of communicating with older people more generally. It would be good if these were displayed at bus stops and at places and groups that older people attended.
- It was felt that organisations and people involved in keeping people active should make more efforts to attend face to face groups and / or places that older people frequented.
- Some of the common activities that people with dementia and family carers would like to participate more in included: walking; swimming; badminton; activity groups with a social element.
- Barriers to accessing such activities included: transport; not knowing that activities existed; having to rely on other people to take them there; lack of personal motivation; location; not being able to walk far.
- There was a range of understanding about dementia from the visiting people and organisations. Some were particularly understanding of dementia and how it affects individuals. Some were less aware of how to include someone with dementia and sometimes using jargon or out dated language that reflects a less positive perception of people living with dementia.
- There was a particular interest from activity visitors / organisations to have more networking events, particularly in local communities so that everyone had a better understanding the services provided by one another.
- There was a desire from organisations and people involved in keeping people active in participating in more events similar to this SHINDIG.

## Full Report

People with dementia and family carers attending SHINDIG took full advantage of the activities and stalls and participated enthusiastically. People attending were asked a number of questions about keeping active, the questions and answers are reported below.

### **Are you aware of the organisations and activities available in Sheffield around keeping active?**

When asked if people were aware of the organisations and activities available in Sheffield the overwhelming response was:

- NO.

A few exceptions included:

- *'I've heard of a couple – especially the Drink Wise Age Well.'*
- *'Yes I did know about Graves Swimming Pool but not about any of the others.'*

This also reflects the considerable challenges that the SHINDIG organisers had when arranging this event in knowing:

a: Which organisations offered what

b: How all the different initiatives in Sheffield connected (or not)

c: Who were the key contacts

d: How people could access the activities

This raises the question that if workers with some knowledge of City wide initiatives and access to email, online resources and network contacts were struggling to find out what was on offer where and by whom – what implications does this have for older people living with dementia who may not all have access to the internet?

### **How can organisations related to keeping more active better communicate with older people and people living with dementia?**

We asked people at SHINDIG how organisations could better communicate with older people and people living with dementia, the responses given were:

- *Not with computers – we can't be bothered with them, we are 'kept out' because it's all online. I'm not happy using a computer, I don't like mobile phone either – come to groups like this – meet people.*
- *Person with dementia: I still use a computer – it would be useful to use email. Some things are useful some are not – you have to accept that.*
- *We don't have an email address – we have an address!*
- *Organisations should come to more groups like SHINDIG to advertise. It would be good if they attended groups like this – it's more hands on that way.*
- *Leaflets – I prefer leaflets as I can't always get online – then I can read it when I want to.*

- *What would interest me is if I saw a bright coloured poster. Posters at Bus Stops and places older people might go for example groups like SHINDIG.*
- *It's got to be more widely advertised.*

### **What activities would you like to do more of to keep active?**

We asked people what activities that they would like to do more of, answers included:

- *Would love to do swimming – mixed changing rooms – which is good as we need them. I got some more information today at SHINDIG. Carer: Is there anyone that does swimming groups?*
- *Partner with dementia finds it difficult as he has lost his coordination, but walking is good and he enjoys that – although is quite slow. Person with dementia: enjoys walking, especially going downhill. They should organise set days where they say where they are going to. The social part is the best bit.*
- *Carer: I used to go walking – don't know what happened to it.*
- *Yes – even simple things like walking – it's important to keep going – it's so easy to stop and then it's difficult to get going again.*
- *Carer: I like ten pin bowling – it's relaxing.*
- *Person with dementia: Yes we need something to keep us young – jog us on.*
- *Carer: In our area Tai Chi, chair aerobics – something to help us balance. No Zumba – not shouting all about.*
- *Person with dementia: Trouble is finding the time. Keeping busy is the key – having a community – for example church, Alzheimer's Society.*
- *Badminton.*
- *Dance to Health.*
- *Walking Football.*
- *Activity groups across the City – mixed groups – games and handicrafts, table games, cards – around 20 people.*
- *Gardening.*
- *Keeping handy.*
- *Dancing – foxtrot, quick step.*

The social aspects of any activity were seen as important as the activity itself.

### **What are the challenges or things that make it difficult to keeping active?**

We asked people the challenges and barriers they encountered in terms of keeping active, answers included:

- *Lack of personal motivation.*
- *Location.*
- *Not able to walk far.*
- *'I can't drive'.*
- *Transport – no good if I can't get to a place.*

- *'Having to rely on other people.'*
- *'I can only go out when my partner does.'*
- *Volunteers – more needed to support people to get to activities.*
- *With or without carers.*

### **What small ways can you think of that you could do to Move More?**

Before the event the organisers had found it difficult to understand what the Move More initiative was and how it was organised. This was clarified in a 1:1 meeting with a key Move More ambassador. We felt that the Move More messages did not always focus clearly enough on the smaller but important ways that older people and people with disabilities could improve their activity. We asked SHINDIG members to identify some ways they might personally keep more active and these included:

- *Get an SIV membership.*
- *Stand up – sit down – to get the heart going.*
- *Make the most of the hills in Sheffield – but at a steady pace!*
- *Go to chair aerobics classes.*
- *Make a dash for the bus.*
- *Don't drive – walk instead.*
- *Park at the opposite end of the car park at the shop.*
- *Try different taster classes for exercise.*
- *Walk my little dogs (Charlie and Scamp).*
- *Get up and move whilst the TV adverts are on.*
- *Get off the bus a stop earlier.*

There is scope for building on this work so that older people themselves have more of a voice within the Move More initiative and help make it meaningful to a broader range of Sheffield citizens.

### **Feedback and Reflections from the event**

We asked for feedback on the event from people living with dementia, their family carers / supporters and from SHINDIG facilitators and visitors. Here are their summarised responses:

#### ***From SHINDIG Members***

Feedback from the group found that:

- People had overwhelmingly enjoyed the event and valued trying out different activities.
- People had found the SHINDIG useful and they had learned about what was available in Sheffield.



- People were a little more mixed in terms of whether there had been enough time to get around all of the activities. Some felt that more time was needed.

### ***Activity Organisation Visitors***

Feedback found that activity organisation visitors:

- Appeared to largely enjoy the event in terms of networking with people living with dementia and finding out what activities they enjoyed or would like to do.
- Valued meeting with other activity organisations to better understand what they offered. They would have liked more time at the start of the event to network with other activity organisations.
- Commented on the friendly and positive environment created at the event.
- Found the noise due to the amount of people at the event a little distracting sometimes making conversation difficult, whilst appreciating the noise was related to people having a good time.
- Would like to put on more activities for people with dementia to participate in.
- Hoped people with dementia would take up some of the activities they had tried out at the SHINDIG.
- Wanted more events such as this possibly in specific postcode areas.

### ***SHINDIG Facilitator / visitors***

Feedback found that SHINDIG facilitators and visitors:

- Were impressed with the range of activities on offer and the enthusiastic manner in which people with dementia took part.
- Found the event useful to better understand what was available in Sheffield relating to activity for people living with dementia.
- Were pleased to support an event where people with dementia were sharing their views with activity providers.
- Felt that the interaction, the variety of activities and the ability for people to 'have a go' worked really well.
- Thought that the event could have been improved by better signposting of activities, more time and a larger space.
- Requested that following the event more information could be made available about activity opportunities and resources.
- Hoped that people with dementia attending would follow upon some of the activity opportunities.
- Thought it important that activity organisers looked to become more 'dementia friendly' and take up Dementia Friends or dementia awareness sessions.

## Key Messages from this SHINDIG

- People with dementia and family carers / supporters want to be more active and are enthusiastic to try new things.
- People with dementia and family carers / supporters (and SHINDIG organisers) find it difficult to understand what is available and how different initiatives connect or don't connect and how to access them.
- Some of the key organisations or initiatives rely on online and email advertising, promotion and access. Many people with dementia and family carers / supporters feel that this excludes them.
- Better ways for organisations or initiatives to get their message to older people could be with fliers, colourful posters at bus stops and other places older people access. Organisations should meet people face to face in local communities and in existing groups perhaps replicating and extending the SHINDIG event.
- A number of challenges are faced by people affected by dementia in remaining active, these include: transport; not knowing that activities existed; relying on other people to take them there; lack of motivation; location; not being able to walk far.
- Sport and activity organisation staff largely enjoyed the opportunity to share their work and to find out the needs of people affected by dementia.
- Sport and activity organisation staff would like more networking meetings between one another so that they could understand what one another offered.
- It is important that people working within the sports and activity sector have an understanding of dementia, how it affects people and how to include them. Becoming a Dementia Friend would be *one* step towards this.
- Move More messages need to broaden to include and promote smaller practical ways that older people can increase their activity.
- There needs to be a better joined up approach to promoting initiatives and opportunities to people with dementia and to workers who support these people.
- This event aimed to bring older people with dementia and their family carers / supporters together with key organisations or initiative around keeping active. It shows what is potentially possible on a larger scale with more resources and a City wide commitment to make it happen.
- Enabling an event like this to be meaningful and inclusive of people living with dementia requires careful planning that is tailored to the needs of people living with dementia. The SHINDIG model provides a means of creating a friendly and positive environment that is well organised and supported by facilitators skilled in working with people living with dementia. The short taster activities were very successful.
- This 'have a go' 'interactive' SHINDIG forms part of a vision for SHINDIG to maximise the engagement of people with dementia beyond discussion and verbal methods alone.

## Recommendations

- Organisations within the sports and activity sector may replicate this SHINDIG event on a larger scale inviting a wider range of organisations and workers in order to further engage with and learn from older people living with dementia and their family carers. Whilst SHINDIG could support this it is beyond its remit, capacity and funding to organise such an event.
- Organisations within the sports and activity sector should explore a wider range of ways to publicise events and opportunities – these might include email, and online but also should offer posters, fliers and provide a telephone number for people who are not computer literate to engage.
- Activity organisations wanting to publicise opportunities to people with dementia are recommended to ensure information is passed onto local organisations that specifically come into contact with people living with dementia; for example, the Alzheimer’s Society, Age UK, the Carer’s Centre, Sheffield Dementia Action Alliance, GP practices, local NHS memory services and local Dementia Cafes.
- Organisations within the sports and activities sector should explore ways to better network and communicate between one another.
- Sheffield needs to better articulate and publicise how all the different sports and activities initiatives and organisations work together.
- Any City Wide work to improve the activity levels of local citizens needs to consider the needs of people living with dementia and their family carers. Work needs to address particular challenges such as access to information, transport to reach venues, having ‘dementia friendly staff’, support for individuals to attend, especially when they have no family close by or are struggling with motivation.
- Organisations within the sport and activity sector may want to consider as a minimum enabling staff and volunteers to become a Dementia Friend. A request can be made through the Dementia Friends website or through Sheffield Dementia Action Alliance or Sheffield Alzheimer’s Society.

Many of these recommendations fall beyond the authority and remit of SHINDIG. In order for the recommendations to have the best chance to be put into action we are sharing this report as widely as possible with relevant organisations within Sheffield. We also propose a follow up meeting with Activity Providers to review the recommendations from this report and plan future actions.

**Feedback, questions or follow up relating to this report can be directed to Jane McKeown or Jo Wallace. Contact details can be found at: <http://goo.gl/P9kJYb>**