



Sheffield Dementia Involvement Group

March 2023

SHINDIG's 'Top Tips'

For living with Dementia



Happy 10th Anniversary

SHINDIG

**Thankyou to all who have contributed over the years
and those who continue to support us.**

Here is to another 10 years.

Background

At our planning meeting in March the group discussed how we could begin celebrating SHINDIG's 10th anniversary year. A cake was the first suggestion followed by other ideas to make the event feel like a party. In terms of a topic we decided to create SHINDIG's top tips for living with Dementia. Our discussions would aim to incorporate the following areas:

New beginnings, strengths and capabilities, diet and nutrition, keeping busy/being still, inside the home/out and about.

In March a group of people from SHINDIG attended a two day conference in Sheffield, entitled '1 in 100 6000'.

The title emerged from the idea that 100 people living with Dementia could have over 6000 years of life experience between them.

This proved to be an inspiring event, it was a conference organised by people living with Dementia. All the speakers had Dementia and the professionals who attended were asked to remain silent during initial discussions. Then invited to speak afterwards. The conference was a valuable learning experience and an excellent opportunity to network with people living with Dementia from around the country and beyond. SHINDIG also managed to recruit six new members.

Key messages from the conference were:

We don't want to be cared for, we want to be cared about.

We need challenge and stimulation not structure.

Art, Poetry, Music should be prescribed as readily as medicine.

SHINDIG's top tips for living with Dementia

1. Keep doing what you were doing.
2. Create memories.
3. Have a hug when you're feeling down.
4. Learn from others and share your knowledge.
5. Avoid getting isolated, find support groups.
6. Deal with new challenges but leave what you can't do.
7. Find a buddy.
8. Don't argue, Change the subject.
9. If someone repeats themselves, react as though it's the first time.
10. Wear a Sunflower lanyard.
11. Address the problem, don't ignore it.
12. Get involved in research.
13. Do everything you can while you still have time.
14. Work as a team, listen to each other.
15. Try not to argue, change the subject.
16. Get involved in the community.
17. Embrace new things.
18. Carry on enjoying the outdoors.
19. Stay strong.
20. Put music on and dance around the house.
21. Go for a walk or a swim.
22. Use signs so you know where things belong.
23. Share the cooking.
24. Teach yourself to slow down and learn to say no.
25. Look after your bowels.

Main Report

New beginnings

Some people say being diagnosed is not 'the end' it's a beginning, do you agree?

A person with a diagnosis described his own observations and acknowledged the importance of peer support and getting involved in community groups.

"The start of the journey to the end, family members see this for their loved ones. Loved ones learn from others and share their knowledge with people just experiencing diagnosis. The fortunate ones find support groups (like SHINDIG) which enable them to age well and slow down the decline".

A further person who was diagnosed several years ago shared his experiences and how he has taken control by learning how to help himself.

"When I was diagnosed there was no suggestions that you could help yourself. It was more of a death sentence. But happily, there is a lot you can do for yourself. Certain aspects of lifestyle are very powerful. Like fasting. I have recently found out about Ramadan style fasting and the benefits it has for the brain and healing".

Most carers did not recognise 'a beginning' following diagnosis. People reflected on the need to deal with what was happening in the moment. Rather than focussing on the past or future.

"It's not an end though you need to just get on and deal with new challenges"
"what else can you do?"

One carer stated that her husband had lived 'well' with Dementia. She was asked to elaborate.

"You have to get out there and keep doing what you were doing".

Another person commented on how her family had altered the way they spent time with their mum as her Dementia progressed.

"We took the opportunity to do new things, we went for long walks creating memories with her".

What advice would you give someone who has just been diagnosed with Dementia?

“Avoid becoming isolated”.

“My husband was 63 so we decided to do everything we could while we still had time”.

Both people with a diagnosis and carers stressed the value of social/support groups.

“My husband died but I still attend a cafe, I know what it’s like I can help other people”.

“It’s the Bees Knees, everybody talks about everything. That’s where I found out about the Blue Badge and things like that. It’s word of mouth”.

One person spoke about the difficulty of receiving his diagnosis amid the pandemic. He listed subsequent losses and a need to adapt. Sharing how having a friend living with a diagnosis has proved highly beneficial.

“It’s been a peculiar experience for me. I had prostate Cancer just when Covid badly affected hospitals and then I had ten UTIs (Urinary Tract Infections) in a row. They decided I had FTD (Frontal Temporal Dementia). I had to stop driving. My wife drives now. A lot of the time I feel perfectly normal and adequate. I realise life has changed. I had my job, but I don’t have the energy or the will to do the things I did. I have learnt a lot from my friend. I never went on buses before. It terrified me. He took me. Last time I said but we’re right out at Crystal Peaks and he said, I don’t care I’ll come and go with you. Having a buddy helps”.

One carer shared how she adapted the way she interacted with her husband as his Dementia progressed.

“My husband would love a hug when he was feeling down that physical contact made such a difference. I found that if he repeated himself, it was best to act as if it was the first time. Or change the subject, don’t argue”.

Strengths and capabilities

A number of people acknowledged a need to take the time to adjust and recognise the changes taking place.

“When you talk about doing new things, coming to terms with the changes that are happening is important. Making sense of it, working things out more. It’s a new transition, letting go of the old and absorbing them into the new. It’s been quite a journey”.

As has been mentioned in previous meetings it is not unusual for friendships to suffer following a diagnosis.

“Friends find it difficult. Lots of levels of adjustment”.

“My friends left and then came back very slowly”.

The following statement highlights that although people may be willing to share their experiences once a diagnosis has been given. Some may still feel unable to raise their concerns if observing ‘signs and symptoms’ in others.

“I think his sister has it now. She repeats herself. She forgot who her son was. She gets lost. But the word dementia is never mentioned”. She could be waiting to see the Memory Service for six months”.

Do you still do what you’ve always enjoyed doing or do you try new things?

“I’m starting swimming”.

“I have taken up ballet dancing. During lockdown I searched the internet and YouTube for various exercise classes. I found “Lazy Dancer Tips”. She’s a proper ballet dancer. There are balance exercises for core muscles. Which is good because you use your brain a lot to control core muscles. Also, it calms down my neck muscles and my arms. I have OA (Osteo Arthritis) in the neck and now I’m more mobile than most. In lockdown I found that there were ways I could help myself, a whole lot of lifestyle changes”.

Several people spoke about the challenges they faced as a couple. Recognising strategies, they have developed.

“We are working more as a team, we are listening to each other better, I am learning how to be more patient”.

“I’m not clear on my diagnosis, things were moving around, not the right way. I’m pissed off with it, I’m starting to get back into doing things. Being here has

made it clear that there is a problem, getting older means you must 'get in and get on'. Swimming is my thing; we've always done it. I feel alive still when I'm swimming".

People agreed it was important to maintain independence where possible and continue with activities that were familiar like walking, gardening, and swimming. Others enjoy new challenges like attending meetings and contributing to research studies.

Diet and nutrition

One person suggested taking more of an interest in diet and avoiding alcohol as it can affect both mood and cognition.

"Fruit and vegetables and fibre are good for your gut. Sweet potatoes and parsnips are resistant starches that create bulk which is good for constipation".

"A top tip is look after your bowels".

It was acknowledged that appetite and food preferences can change as Dementia progresses.

A discussion took place about forgetting to eat and drink and how this can lead to numerous health problems. Carers commented on the need to prompt people to eat but also the need to maintain a person's independence.

At the last SHINDIG planning group in March people living with a diagnosis met with Sheffield Hallam University design student Libby Shepard. They offered advice on her design for a vessel aimed to encourage dietary intake. Libby has since invited the group to her end of year exhibition and feels their advice really help to move her project in the right direction.

Keeping busy/Being still

One person reflected on the building where we hold our SHINDIG meetings. The Quaker Meeting House.

"The Quakers have the ability to sit still and be quiet. They speak only when they have something to say". People discussed the value of being still and taking the time to observe your surroundings.

A carer shared how she has adapted her own pace.

“I realised my husband had got slower and slower. I had to teach myself to go slow”.

The following statement could suggest the need for the person living with Dementia to adopt a work/productive role.

“He would often start chiselling away at our door frames and the windows, he used to be a joiner. He would say to me, don’t tell me to stop, I know what I’m doing”.

All groups commented on a need to slow down and be realistic, while still enjoying activities that made them feel happy.

“I adapt by saying ‘no’, leave what you can’t do because it’s too demanding and too draining. I spend a lot of time in the garden”.

“Gardening is important to me too. I did a Doctorate in linguistics and lived in a house that was shared with 3 other graduates. I was a University Professor in Finland and when I came back the vine, I planted was there full of grapes”.

Being out in nature was important to many people.

“We try to do walks. We are lifelong birdwatchers. I saw 2 mistle thrushes in Norfolk Park dancing about. It can be a beautiful walk when you see things like that”.

One couple described though how they had embraced new things like travel and attending meetings. Others spoke about the benefits of being physically active.

“I am determined to keep fit and active and carry on enjoying outdoors. Staying strong is the biggest help for any health condition”.

One carer laughed sharing:

“I put music on and dance around the house and even in the garden. My neighbour enjoys it”.

Inside the home

Again, people spoke of adapting and working as a team. Not stopping altogether when things became difficult but finding tasks that are manageable.

“With the new house. I find it very good. All the cupboards. I know exactly where everything is. My job is washing pots. It’s very organised. My wife knows where all the stuff is in the garage and the garden. I know where things are in the house by the way it is laid out”.

“I stopped him using the cooker. He used to do all the cooking. I’d let him do the vegetables”.

“We share the cooking. We have an old type of gas cooker. I can set the cooker to come on and off at a fixed time which is a bonus for me. If we had to change it, I couldn’t do it”.

Out and about

During the introduction to the afternoon a person living with a diagnosis stood up to show everyone his sunflower lanyard. Informing the group how useful he finds it and advising people where they could get their own.

The Sunflower lanyard indicates that a person has an invisible disability and may need assistance.

One group reflected on the difficulties of the financial crisis which led to a conversation on managing your money and the benefit of using cards instead of cash.

Following on from last SHINDIG one person commented that she had tried to access a card with a limited budget at her local post office but had been refused. It has since been confirmed that this service is available at the central post office in the city centre.

One carer whose wife has advanced Dementia offered practical advice when going out.

“Incontinence can be so embarrassing; you have to plan and be sure you know where the disabled toilets are”.

Conclusion

This SHINDIG offered people living with Dementia and carers/supporters the opportunity to share their top tips for living with Dementia.

As with all events our conversations touched on numerous topics and advice and information was provided on the following:

How to manage a nuisance 'gardener'

Where to find walking groups

Groups available for carers

The Dementia Advise Service (DAS)

For further information please contact

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To see past reports please see our website www.shsc.nhs.uk/shindig