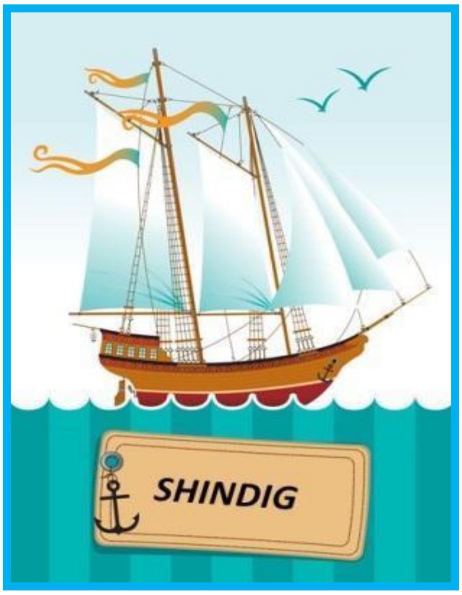

Sheffield Dementia Involvement Group

October 22nd 2020

Reviewing home care provision and training the next generation of home care providers

Alzheimer's Society
United Against Dementia

NHS
Sheffield Health and Social Care
NHS Foundation Trust

SHINDIG is a collaborative project between Sheffield Health and Social Care NHS Foundation Trust and The Alzheimer's Society. Our aim is to provide a forum where people living with Dementia, their family and supporters can have their voice heard around a particular topic. Topics relate to living with Dementia and health and social care services.

This virtual SHINDIG was attended by 12 people living with Dementia and their carers. Of the 30 people invited 11 did not respond, 4 sent apologies and were unable to attend due to illness. One person was due to dial in but didn't and another couple were unable to join due to faulty technology. We were supported by 9 volunteers who facilitated three groups and documented discussions.

The theme for this SHINDIG resulted from us being approached by Paul Higginbottom, Strategic Commissioner with Sheffield City Council. Paul is leading a large piece of work which aims to review and improve the home care provided for people living with Dementia within Sheffield. Emphasis is being placed on training home care providers appropriately and providing services which meet the needs of people with Dementia.

Summary

- Maintaining a good quality of life was seen as very important by people living with Dementia and carers.
- If people were accessing home care they needed familiarity, consistency and to be able to trust the person coming into their home.
- Negative perceptions of home care still exist at times resulting in reluctance to explore this option.
- People living with Dementia want to maintain their independence as much as possible and build a positive rapport with care providers
- Couples living with Dementia did acknowledge that they do at times need a break from each other.
- People want individualised care provision tailored to their needs
- It is often hard for carers to acknowledge they need help and trust someone else to look after their loved one.
- People saw day services as a good source of support and are currently missing face to face contact.
- People living with Dementia feel they should be involved in the training future care providers.
- Carers recommended that training involve shadowing services that are at them ‘top of their game’
- Carers want solutions not too many options and care providers that can provide accurate advice when needed.

Main Report

Do you currently use, or have you ever used the Council's Home Care services?

If you haven't used them could you tell us why not?

None of the people present had or were currently accessing home care. Despite this, rich discussion took place and people were able to share opinion on what home care should and shouldn't involve. Lengthily discussion also took place on what home care staff should learn in preparation for this role.

One couple had in the past had hired a private carer for domestic tasks. Another had explored the idea of home care but the person living with Dementia had eventually declined. During discussion it was clear that people living with Dementia took pride in being able to maintain their identity and independence and stressed the impact of 'needing' care.

"I've been independent all my life and done everything myself, i'm still able to operate reasonably independently"

"There is a change in identity for the person needing care, it takes time to adjust"

It is important to acknowledge that a number of SHINDIG attendees are couples. Many of whom have very strong commitment to their carer role. Some people hinted that they may need help but described how difficult it is to acknowledge this. One carer was unsure where to get help.

"Families go through a process of needing to accept support"

"They should know that is not's easy, it's emotionally hard for me to say that i cannot do this anymore. You need to feel secure before you leave the person you adore, you need to feel they are having the best time possible"

"We are getting to that stage now where help would be useful, but no, i wouldn't know where to go"

In terms of the kind of support people do access, the majority stressed the importance of day services for opportunity to socialise, have fun and make friends. Many are accessing online groups but do miss the face to face contact. People spoke about their experiences of day services like Darnall Dementia Group and how well these worked because of the high ratio off staff to people living with Dementia. One to one support was seen as extremely valuable.

It was recognised that couples at times need to take a break from each other for practical purposes such as getting tasks done but also to maintain well being as a couple. Home care was seen as a possible solution to this.

Two people living with Dementia gave examples of ‘care’ which were felt to be beneficial. One person spoke about the Short Term Intervention Team (STIT) coming to his home following a hospital admission.

“Initially I was reluctant as I like to look after myself but it was good encouragement to be shown how to walk up and down the kitchen”

“I’ve not had care as such but I had help from the GP practise. They referred me to Ponds Forge where I had a personal trainer once a week until ‘lockdown’”.

Can tell us about a good experience of Home Care, why it was good and how it made you feel?

Of paramount importance to all present was, trust. It was felt that time would be needed prior to any home care provision for the carer and person living with Dementia to get to know each other. Continuity was also seen as vital, as were the personal qualities of the carer.

“Having the same person all the time and the opportunity to build a rapport. With paid carers it’s a different person every time and it’s confusing”.

People living with Dementia were prompted to identify which qualities would make a good carer.

“Friendliness, Patience, People need to care”

“I need their kindness”

“I need them to listen”

It was also recognised that care provision should be tailored to meet individual need.

“Proper assessment needs to take place to find out what that person needs”

Can you tell us about a poor experience of Home Care, why it was poor and how it made you feel?

There was a shared negative perception of home care which could have contributed to the reluctance of both the carers and people living with Dementia present, to access it. The idea of having multiple people coming in and out of the home put most people off even exploring home care. People felt that carers would be task orientated and rushed in their approach.

"Friends say the carers don't stay long they give them and cup of tea and sandwich then they're off"

"Wouldn't want someone who is disinterested and just comes to do the 'jobs'"

The attitude of the person coming into the home was also very important. One carer spoke of feeling patronised and commented how a staff member didn't even introduce herself.

An overriding theme was that carers wanted solutions not too many options. References were made to being given too much information.

Being given 'wodges' of paper work to read was unhelpful and it felt like 'more work'

People living with Dementia shared concerns about being given a carer they couldn't bond with. Or someone too young, that they couldn't relate to. One person feared having a person of the opposite sex being sent to manage personal care.

What do you think are the most important factors in how care is delivered to you at home? If you were training Home Care workers what would be your top three priorities?

Of key importance was communication, knowing how to communicate effectively and having knowledge of how Dementia may affect the individual. People living with Dementia spoke about the need to be treated with care, dignity and respect.

"You don't want someone who will just come in and take over, for example not telling you 'sit down at the table' but asking 'are you ready to eat yet'

"Seeing the person with Dementia as an individual with things to contribute"

One couple spoke about sensory impairment and the need for care providers to have a good awareness of how this can affect communication. The person living with Dementia spoke about being deaf as a:

"Double Whammy"

Being unable to hear had on several occasions lead to him being labelled as confused.

Carers spoke about the need for staff to value their job in order to engage well with the person living with Dementia.

"Giving a personal service, making that person feel special. Not that they are just another person on the list being visited"

"Don't look on it as just a job"

What seemed important to both people living with Dementia and carers was quality of life. If home care could enhance this then it was seen as valuable. People didn't want to be passive recipients of care. They wanted to have a positive relationship with the person coming into their home. They wanted support to do the things that mattered to them. Socialising, having fun and remaining engaged with the community. People living with Dementia need to maintain their identity and continue to contribute to society.

If you were to develop a tool kit for home care workers to improve the way in which dementia care services were delivered to people in receipt of home care. What would be the most important tools?

Strong opinions were shared on the issue of training. A range of ideas were listed Including the development of a set of web pages to help people understand about Dementia and what might help people with Dementia. Some felt that care providers should have an awareness of the different types of Dementia. Several people spoke about the need to be able to see things from the perspective of the person living with Dementia. One carer spoke positively about training she had attended at the Zest Centre which involved role play. It was deemed important that the care providers were able to offer advice and sign post people when necessary. Despite numerous efforts made to inform people of what help is available, there still remains some confusion on this matter.

"What you need is a phone number in case you are desperate and their knowledge and expertise"

People listed existing resources that could be used to educate care providers.

- The Alzheimer's Society Website
- Sheffield Dementia Directory Webpage
- Older Adult Community Mental Health Team Dementia pack
- This Is Me document

Two people living with Dementia commented on the importance of learning from them as they are experts by experience. Carers suggested staff spend time shadowing others already experienced in providing high quality Dementia care.

"You can't rush training like you can't rush care. You can't do it in a ten minute video they need to spend time with people/services who are at the top of their game"

Recommendations

- Emphasis needs to be placed on quality of life
- Home care needs to be individualised
- People want be-Frienders not carers
- People living with Dementia want to maintain independence as much as possible
- The perception of ‘home care’needs to change
- Collaborative care planning with the person living with Dementia, family and care providers is necessary
- Time needs to be provided to build rapport and trust
- Home care staff need to be inspired and encouraged to learn and develop so that they value and remain in their roles
- Both face to face and online training could help educate future care providers

Conclusion

This SHINDIG provided people with Dementia and their family carers the opportunity to share their opinions of home care and ideas on how to train the next generation of home care providers. The findings will be shared with all relevant SHINDIG stake holders including Sheffield City Council commissioners.

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