

Dementia and Everyday Life

#3: *Working Together*



Improving
Dementia Care
ESRC·NIHR



You can find out more about living with dementia by contacting:

The Alzheimer Society on the National Dementia Helpline:
0300 222 11 22

Or by going to the website: <https://www.alzheimers.org.uk/>

Age UK on 0800 055 6112

Or by going to the website: <https://www.ageuk.org.uk/>

The NHS has produced a Dementia Guide that is available on its website:

<https://www.nhs.uk/conditions/dementia/about/>

About the authors

This booklet has been created by Domenique Brouwers in collaboration with researchers and participants in the ESRC/NIHR Neighbourhoods: Our People, Our Places study.

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To reference this booklet

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About this booklet

This booklet is one outcome from a research project investigating how neighbourhoods can support people living with dementia. Called 'Neighbourhoods: Our People, Our Places', the research has taken place across Greater Manchester (England), the Forth Valley (Scotland), and Ostergötland (Sweden). The research has investigated how people living with dementia and their care partners experience their local neighbourhoods. This includes understanding how neighbourhoods might support or restrict opportunities for informal and semi-formal support; and exploring how neighbourhoods have potential for enabling people living with dementia to live independently in their local communities. This booklet depicts some of the stories told to the research team by people living with dementia in Greater Manchester.

We have aspired to take a collaborative approach, working alongside people living with dementia and their care partners. People living with dementia have been involved at various stages of the research development, including input into the research methods and information materials. A number of people living with dementia worked with us as research participants and advisors throughout the study.

We are finding ways to tell the stories from the research in creative ways. Many of our collaborators, particularly those living with dementia, wanted a way of telling their stories in an illustrative form that is less reliant on text to share information and key messages.

Working together

This story brings together examples shared by a number of our participants.

The story is about a married couple, Tim and Sally. Sally was diagnosed with Alzheimer's Disease 6 years ago when she was 67. She is now 73 and Tim is 75. They live together in a small, semi-detached house which they moved into 25 years ago when their children left home. The house is in a nearby location to the one that they raised their family in, and Sally has lived in close proximity to this area all of her life. Tim moved to the area in his late teens for work. Sally and Tim have been married for over 50 years, initially meeting in their early 20s, and have three children together.

Tim and Sally both retired in their 60's; not long afterwards, Sally was diagnosed with Alzheimer's. After diagnosis they became involved with some local dementia support groups that they say are a 'lifeline' and that it is really fantastic to have made some friends who understand their experiences and what they are going through. They also maintain other friendships, including occasionally meeting up with people they used to work with, and keeping in touch with couples they have known since they were newly married and raising their families together.

Most days Tim gets up first and wakes Sally by bringing her a cup of tea in bed. Sally finds it difficult to remember what day it is and what plans they have for the day. They have a calendar in the kitchen which has all the activities and events they have planned written onto it and which Tim keeps up to date.

After her cup of tea Sally gets up and prepares for the day ahead. It can be quite difficult choosing clothes to wear and putting them on and Sally can sometimes feel overwhelmed by the choice, and or gets muddled with how to dress herself. Quite often in the morning Tim will begin doing some of the household chores. He has taken on most of the domestic responsibilities since Sally's diagnosis This is something that

has changed a lot in their relationship, they previously had quite traditional gender roles; Sally was the main person to manage the home and had always done the laundry, shopping and cooking, although they had shared the cleaning tasks and both enjoyed gardening.

Tim and Sally usually have breakfast together and talk about their plans for the day. After breakfast there are often more chores to do until mid-morning when Tim will sit down and read the newspaper. Sometimes Sally feels frustrated at not being able to do as much around the house as she once did. She has raised a family, run a household and had a career as a busy administrator at the local hospital. She wants to be able to be more involved in the house and will try to help and do chores alongside Tim.

Sally and Tim have always been sociable people and try to regularly meet with friends. Going out for lunch is something they enjoy, especially as Sally can feel very tired and does not enjoy going out as much in the evenings. Café's, restaurants and pubs tend to get busier and louder in the evenings and this can make it difficult for Sally to take part in conversations, when too many sounds can be overwhelming or disorientating.

Sally finds it difficult to retain information and can quickly forget the plans for the day, and Tim often has to remind her. It is good for them both to stay connected with different friends. Tim appreciates having friends around to help out because he finds that sometimes he feels a little impatient when Sally cannot remember things.

Sally and Tim attend a number of dementia support groups where they have made some really good friends with other people who are also experiencing the same everyday challenges of living with dementia that they have. Often during these dementia support gatherings time is given for peer support, where carers spend some time apart from those living with dementia. Sally and Tim are members of a range of different groups: some provide fun activities; others are more about talking; they have even begun going on holidays with friends from the dementia support organisations. They have found the peer support from the dementia support sessions incredibly supportive to be a part of.

On the way home from the groups they might stop in at the supermarket to do a bit of shopping. Sally used to do all the shopping, and it is a task that Tim has now taken over because Sally can find the lighting and noise in the supermarket difficult, and there are too many things to choose from on the shelves. Sally struggles to read what everything is and can find money difficult to manage. Sometimes Sally finds it is easier to wait for Tim in the café of the supermarket. They go to a 'dementia-friendly' supermarket which offers some opportunities to make shopping easier for people living with dementia, such as having 'slower tills' where people who need more time can go to and also having more supportive staff on hand around the supermarket. In the café the staff are friendly too and will have a chat with customers especially if they are not too busy.

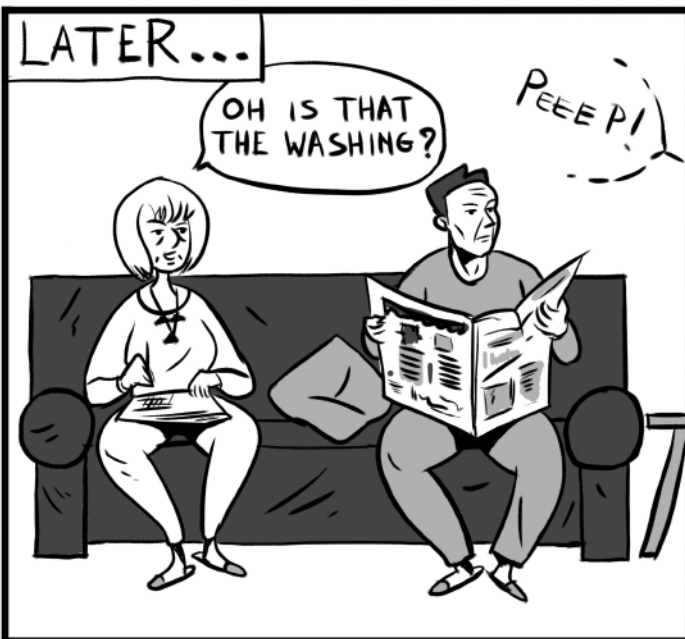
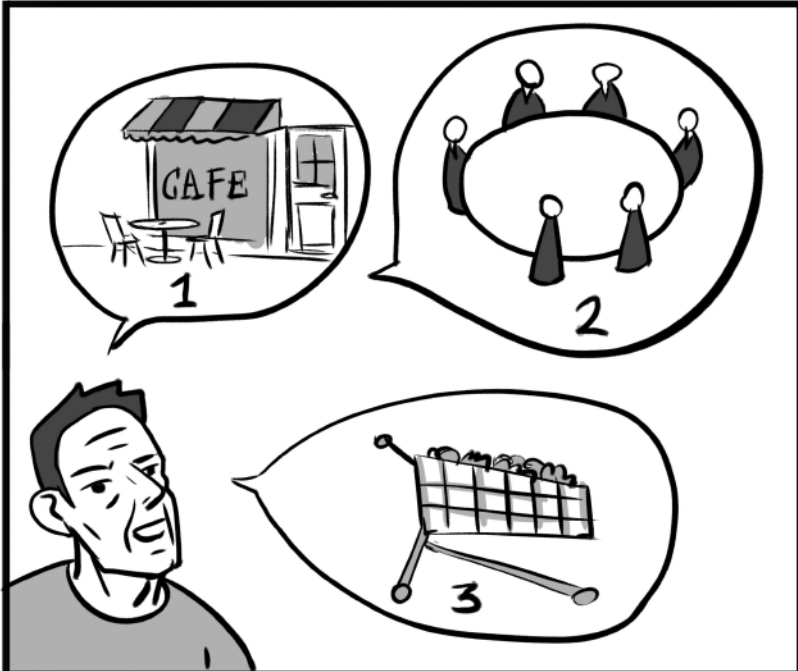
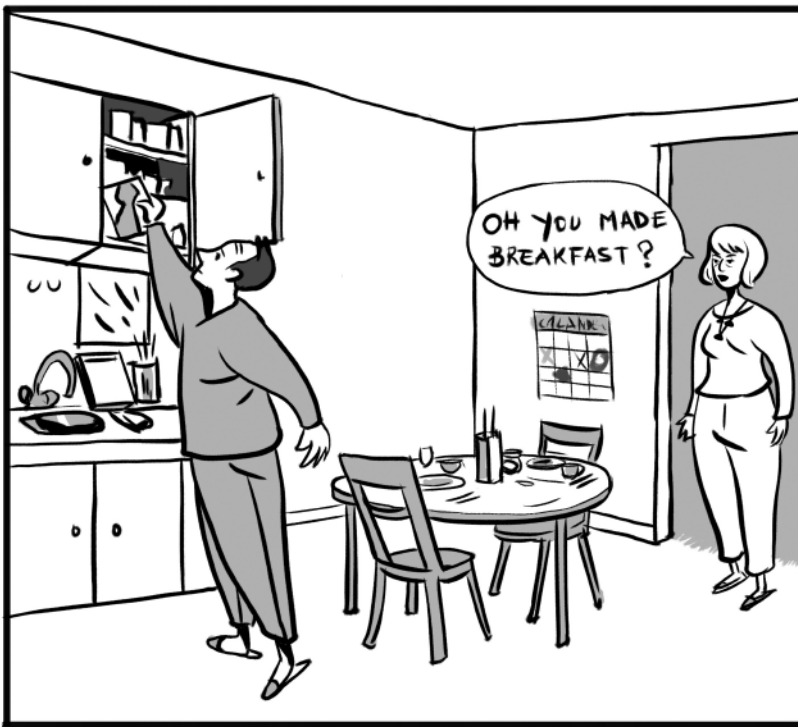
Sometimes at the supermarket Tim will buy flowers for Sally; Tim wants Sally to know how important she is to him, and for her not to worry too much about having dementia. Tim feels that they are a team and Sally still loves to receive flowers from him.

Sometimes after days when they have a number of activities on, Tim is too tired to cook and they might treat themselves to a take-away meal and they will sit down on the sofa together and watch some TV. Sally still enjoys a number of TV shows, although she struggles if the storyline is too complex to follow.

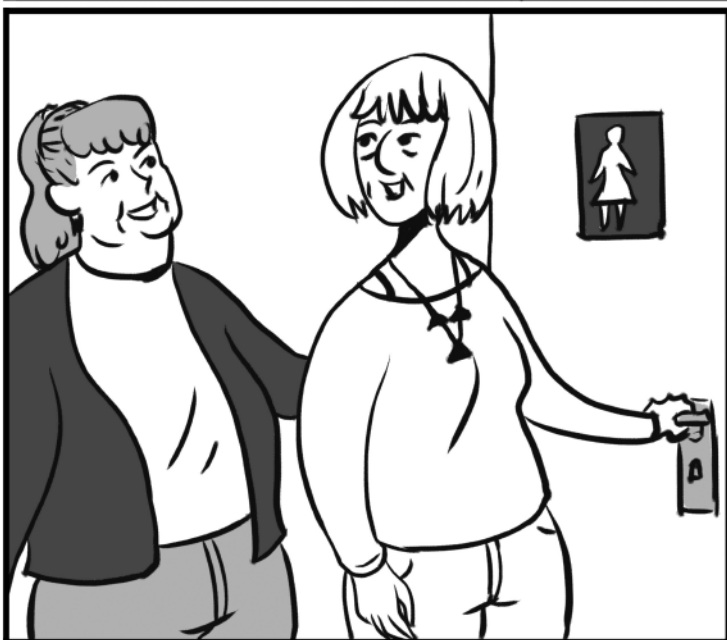
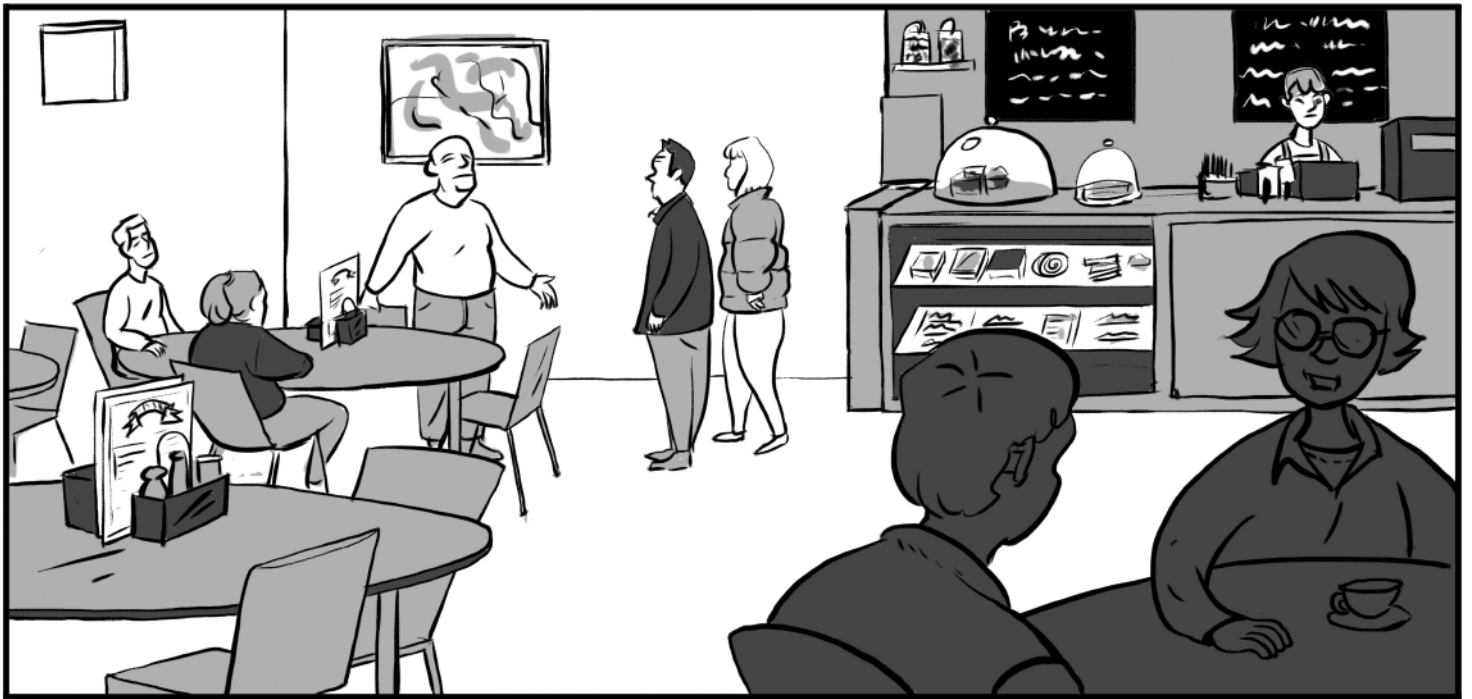
It has been important for Tim and Sally to stay connected to friends as well as to their family. They have also made a number of new friends through joining dementia support groups. As Tim has taken on additional roles at home, Sally sometimes feels frustrated at not being able to do things and it is important that they have been able to talk about these kinds of changes in their life. Tim and Sally do not know what the future holds, but they hope that Sally will be able to continue living at home with the help of the different networks of individuals and organisations in their lives.

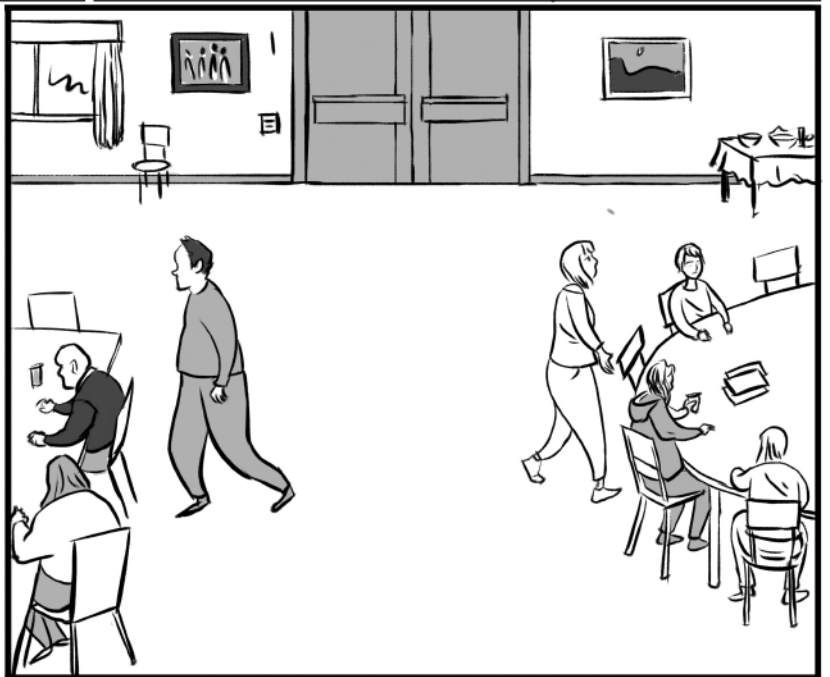






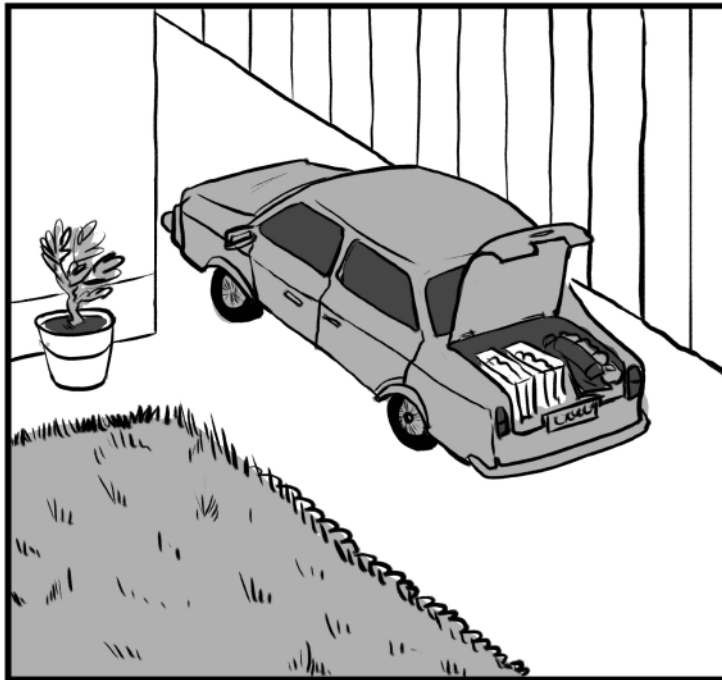












Dementia Support Day to Day

People with dementia can feel vulnerable as their condition progresses and they increasingly rely on other people to do things for them and with them. It is important that people who have dementia feel reassured and supported, while retaining some level of independence. Local places can play a role in this.

There is currently no known cure for the condition and although some symptoms are common to many people with dementia, each person's experience of living with dementia, and how they cope with it will be different. These ideas and suggestions will not suit everybody, and they are small in scale and scope. But they have been suggested to us by people who are living with dementia or supporting others with the condition as ways in which they try to keep as independent as possible.

Staying in: If you are less able to get out and about it is still possible to enjoy connections to others through visitors to your home, chatting on the door step or over the garden fence. Sometimes enjoying



the sounds of the neighbourhood, or the feel of sunshine through the window can be equally important. Visitors to their homes were a vital connection to the neighbourhood. Even a neighbour popping by, a chat over the garden fence or a conversation with a delivery person all have a part to play. Being able to see and hear the goings on can help. Sitting in the front garden or near a window are small ways in which people can feel more connected to others.

Try to stay connected: Neighbourhoods are about people as well as places. Local relationships can provide important everyday support as well as assistance in times of need. Neighbours can be a useful point of call, from taking out rubbish to keeping an eye on someone.



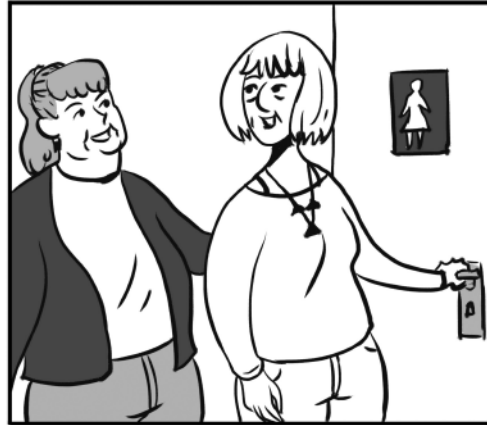
Local businesses and services can help maintain a sense of being connected. Sometimes it can help to carry a card to let others know that you have dementia. There is information about these found here:

https://www.alzheimers.org.uk/info/20113/publications_about_living_with_dementia/774/helpcards

Neighbourhood routines: Try to keep up habits and routines to help stay connected locally. These might be regular dog-walk, visiting the same cafés, regularly attending a dementia support groups, or even a short walk along a familiar route. These help you to become recognized locally and to create a sense of belonging. Visiting local shops regularly such as to the Bakers or Newsagents can foster friendly local relationships. Attending local dementia groups can be an important way to stay connected, to create new routines and to meet new people. Local businesses can customers feel welcome, providing assistance with money, help making purchases, or just by being patient or letting someone sit for a while on their premises.

Little acts of kindness:

Kindness helps people to maintain independence, feel connected, be cared for and give something back. Acts of kindness are often carried out without comment and enable people to continue to live independently. People living with dementia can



reciprocate support and play their own role in supporting the social life of local places. Try to continue to contribute to your own neighbourhoods, visit local shops, keep an eye out in your street, and continue to care for other family members, friends, or pets in whatever ways you can.

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