

DEMENTIA-FRIENDLY YORKSHIRE

FIRST STEPS ON THE JOURNEY

January 2014



JRF

JOSEPH
ROWNTREE
FOUNDATION

CONTENTS

Foreword	3
Making train travel simpler	4
Protection from doorstep crime	5
The local supermarket	6
Raising awareness in a multi-cultural city	7
Starting with the local community	8
Dementia-friendly libraries	9
Opening up the local church	10
Welcoming visitors and tourists	11
Memory cafes and safe havens	12
A whole-town partnership	13
Healthy living and intergenerational connections	14
A dementia-friendly hospital	15
Working in schools	16
The traditional department store	17
The creative arts	18
Sports and leisure facilities	19
Rethinking hospital wards	20
Changing attitudes and services in healthcare	21
Improving legal services	22
Supporting South Asian women	23
Acknowledgments	24



FOREWORD

This collection of case studies brings together 20 simple examples of grassroots dementia-friendly work that is transforming communities across Yorkshire – from Northallerton, York, Hull & East Yorkshire, Rothwell and Leeds to Bradford, Shipley, Keighley, Doncaster, Sheffield and beyond.

These projects are taking place in churches, mosques and gurdwaras, in shops, legal services and cafes, and in public services such as transport, museums, hospitals, trading standards, schools, libraries, and sports centres. We found that local ‘champions’ – extraordinary people in ordinary jobs who have seized the initiative and are leading change – are behind most of this work. Many have already achieved wider impact across their own organisations or sectors at regional, or even national, levels.

As the lead on JRF’s major programme of work, *Dementia without Walls*, I am delighted that the idea of the dementia-friendly community is taking off around the UK. We know that people with dementia and their carers often feel unable to join in with, or make any contribution to, their local community. Faced with a lack of support or understanding, many give up things they love

to do out of anxiety, fear or lack of confidence and slowly withdraw behind their own four walls. What a huge and unnecessary loss – for them, for their families, for their communities and for society as a whole!

Five years ago the concept of the dementia-friendly community was almost unheard of. Things started to move more quickly when the Prime Minister launched his Challenge in March 2012, and there are now over 50 communities across the UK on the way to becoming dementia-friendly.

I hope we can all draw inspiration from these case studies, and each play our role in making our own community or organisation a welcoming and supportive place for people with dementia.

Philly Hare
Philly.Hare@jrf.org.uk
Programme Manager,
Dementia without Walls
Joseph Rowntree Foundation



“Very small steps make a huge difference.”

MAKING TRAIN TRAVEL SIMPLER

Fiona Andrews
Police Officer
British Transport Police, York

“Very small steps make a huge difference,” says PC Fiona Andrews, who has been busy making York Station dementia-friendly.

It was York’s Dementia Without Walls initiative that first got Fiona thinking about dementia. The more she learnt, the more public transport arose as a real obstacle to quality of life. “Older people may not have used the train for 40 years,” Fiona explains. “Everything’s changed. People have lost their confidence.”

Fiona was determined to find out just how accessible York Station was. She arranged for people with dementia and their carers to review signage and facilities. She organised day trips, with free travel from the train companies.

“Arranging to go somewhere takes nothing,” she says. “Fear of the unknown is the block, so let’s just get moving. It doesn’t matter if it gets cocked up, we can sort it out and make it better each time.”

Becoming dementia-friendly wasn’t hard for a station already aiming to make travel simple for so many

different visitors. The main change was in how staff think. “It’s about keeping dementia at the back of your mind all the time,” says Fiona. For her, being dementia-friendly means people feeling confident that station staff will understand and help, both professionally and personally.

And it’s not just about encouraging travel. “York Station is a community within a community,” Fiona says. She wants people to see the station as a safe place just to come and have coffee.

To those wanting to make their own organisations dementia-friendly, Fiona says, “It’s not difficult. I work part-time, have no budget, no influence, can’t make policy or assign staff. But people want to do it. You’ll be supported more than you think.”

Now she’s seeking dementia champions for every North East station, and looking to make the whole transport region dementia-friendly.

Want to know more?

Email Fiona: Fiona.Andrews@btp.pnn.police.uk



“People with dementia can educate us as well.”

PROTECTION FROM DOORSTEP CRIME

Ruth Andrews

Head of Investigations and Safeguarding
North Yorkshire County Council Trading Standards

“Doorstep crime gangs increasingly target people with dementia,” warns Ruth Andrews. “It’s big business and well organised.”

Gangs specialise in, say, roofing or gardening but share information, grooming victims carefully. The stakes are high; offenders can take tens, even hundreds, of thousands of pounds from victims.

“Trading Standards wants to help people stay in their own home safely and confidently. That’s not just about the crime, it’s about seeing the whole person,” explains Ruth.

That’s why her 13-strong team has changed their emphasis from prosecution to safeguarding and protection. They’ve put victims in touch with befriending services, arranged family reconciliations, helped get locks changed and had surveyors safety-check homes.

“It’s very labour intensive. But it’s hugely rewarding,” says Ruth.

One challenge has been gathering evidence differently. Ruth’s team think constantly about imaginative ways to build a picture. People with dementia can’t always give

written statements so the team captures what they can tell the court on video. This also helps the judge and jury understand the personal impact.

Diaries are useful: people note things at the time that they don’t remember later. Hairdressers and milkmen can provide patterns of legitimate spending. Google Street View pictures reveal offenders’ lies about what work needed doing. The team’s forensics lab is investigating using GPS and phone images to trace unreported victims and map potential hotspots.

It’s been a big change but one the whole team is committed to. “Everyone has seen victims’ distress. We’ve all been shocked by how many older people live alone, off everyone’s radar,” says Ruth.

She’s leading a national Trading Standards doorstep crime project and wants to learn more about the long-term impact on victims.

“Don’t prejudice what people with dementia can and can’t remember,” she advises. “And don’t forget who that person is as an individual. I’ve met some fascinating people. They can educate us as well.”

Want to know more?

Email Ruth: Ruth.Andrews@northyorks.gov.uk
or phone: 01609 534855



“It has to be a slowly-slowly approach.”

THE LOCAL SUPERMARKET

Linda Gomila

Co-operative and Membership Officer
Northern Region, The Co-operative Society

Linda Gomila believes the The co-operative (co-op) is perfectly placed to bring in dementia-friendly shopping. “Co-op staff stay a long time. They know their neighbourhoods and their customers well,” she says. “And most people can walk to the nearest store.”

Linda supported her mother with her dementia. Now, with Cathy Henwood of the Alzheimer’s Society, she’s piloting dementia awareness in three Bradford co-ops.

Touring a store with one person with dementia revealed how confusing supermarkets can be. “Mirrors can be very difficult for people with dementia,” explains Linda. “But supermarkets are full of reflective surfaces.” People may perceive floor patterns as steps and stumble. People can panic if the exit is not signposted in a way that’s clear to them.”

Awareness training for staff showed that dementia-friendly service taps into existing principles of serving the community well. It may mean opening a second till if someone needs time with change or understanding that people sometimes forget to pay. It’s also about relationships with regulars. When one man bought

headache tablets twice on the same day, staff were able to contact his daughter to check everything was OK.

Dementia awareness is bubbling across the co-op’s Northern region. “A lot of tiny fires are burning,” says Linda. “It’s about stoking those fires to get a bit more ignition.”

“But the co-op is a big ship. It has to be a slowly-slowly approach. For businesses, changes mustn’t be onerous.” She’s working on an action plan to help other stores roll out the pilot. A short film has proved invaluable in promoting the message up to senior management and out to others.

Linda would love to get co-op pharmacies on board and to see the co-op make a dementia society its sponsored charity. “They’re the experts,” she says. “Get in touch with your local organisation.”

Want to know more?

Email Linda: Linda.gomila@co-operative.coop
Watch the co-op’s film about working towards being dementia-friendly at: <https://www.youtube.com/watch?v=m19cXnWi59k>



“We put the person at the heart of what we do.”

RAISING AWARENESS IN A MULTI-CULTURAL CITY

Akhlak Rauf

Health and Social Care Projects Officer
City of Bradford Metropolitan District Council

“Many South Asian languages have no word for ‘dementia,’” explains Akhlak Rauf. “So we talk to people about their memories. If someone asks ‘Why am I losing my memories?’, then we introduce the word ‘dementia’ – and what it means.”

The Meri Yaadain Project is spreading awareness of dementia among Bradford’s South Asian communities. Meaning ‘my memories’ in Urdu, the term is understood across several South Asian languages.

“Meri Yaadain puts its fingers in all sorts of pies, nationally, locally, individually,” says Akhlak. “It doesn’t matter who you are, we are here to support you.” That support ranges from roadshows to raise awareness through reminiscence groups to practical advice for individuals. “We tell people: these are your services, this is how you get help.”

The team works hard to combat preconceptions, be they assumptions about what support families will give or about what social workers do.

“We are always thinking about the best way to connect with the person we are talking to,” says Akhlak. Objects are important for older people who don’t speak English or don’t have a reading culture. A souvenir rickshaw can trigger memories of early life in India. A Meri Yaadain mug can highlight dementia symptoms for people who wouldn’t pick up a leaflet. Information in English reaches adult children; grandchildren help access YouTube and other digital media.

The team now supports around 200 families and is regularly contacted for advice by other projects nationwide. “We’ve been successful because we put the person at the heart of what we are trying to do,” says Akhlak. The team always seeks to treat people with respect in a way they will recognise.

“It’s about breaking down barriers. There are common threads through all our lives. It’s not always about communities being different. Everybody has the right to feel safe.”

Want to know more?

Email Akhlak: Akhlak.Rauf@bradford.gov.uk



“Get to know your community first.”

STARTING WITH THE LOCAL COMMUNITY

Daren Parr

Ward Officer, Idle and Thackley
City Of Bradford Metropolitan District Council

As council Ward Officer, Daren Parr is used to pulling together services to meet the community's needs. Now that includes making Idle a better place for people living with dementia.

A first step was asking the community for practical ideas. “We want to build on existing activities, making them more suitable for people with dementia. It's about setting up things that are sustainable without much funding,” says Daren. “We're always looking for opportunities for the community not just to contribute but to take ownership. That means keeping it simple.”

Daren's been working closely with Bradford's Health on the Streets team and the local Alzheimer's Society, as well as community groups and churches. His Ward Councillors have been crucial champions.

Activities so far have included a training day to give people more confidence about dementia and a new Memory Club at the Baptist Church. A regular walk-and-coffee session offers walks in Buck Woods guided

by a local environmental group or simply tea in Thackley cricket pavilion for those who don't feel like walking.

Recruiting volunteers can be hard given how busy people are. But Daren is inspired by how many people will give their time. “Groups have been doing things they have never done before,” he says, “whether it's a volunteer arranging an outing around his interest in canals or helping a neighbour do their shopping.”

The next big step is converting the disused Methodist Chapel into an enterprise centre with a library. It will be a facility for the whole community – which means being dementia-friendly right from the start.

Asked what advice he'd give others wanting to provide dementia-friendly services, Daren doesn't hesitate: “Get to know your community, without a shadow of a doubt. Find out what they need, what's already happening – and what gaps need filling.”

Want to know more?

Email Daren: Daren.Parr@bradford.gov.uk



“Being dementia-friendly is an important part of our mainstream work.”

DEMENTIA-FRIENDLY LIBRARIES

Nigel Prince

Team Leader , Hambleton District
North Yorkshire County Council Libraries

“Isolation is a real problem for all older people. A trip to the library can break up the pattern of an otherwise isolated day,” says Nigel Prince.

Nigel wants the libraries he oversees to be welcoming, supportive and safe places for people with dementia. “It’s a change of scene and a stimulating environment. Knowing that library staff are there to help can also give carers time to relax.”

He’s been working with the local Alzheimer’s Society, training both library staff and volunteers in dementia awareness. Little things – like not finishing people’s sentences – make all the difference.

But it’s also about promoting what the library can offer. “A library is about much more than just books,” says Nigel. ‘Pictures to share’ publications are designed to spark conversations around common interests like gardening. The library’s free online subscription service allows people to use tablets and home computers to dip into magazines on favourite topics. Those who can’t read can borrow Talking Books.

Some people lose the ability to read much more quickly than others. “It’s important not to class everyone with dementia into one big category,” Nigel says. “There are lots of subtleties.”

For those who can’t come to the library, Home Library Service Volunteers take specially selected books to people’s homes. Libraries offer the same service to care homes.

Nigel plans to compile booklists for people with dementia and carers. He’s preparing a dementia-awareness induction sheet for anyone starting work with the library.

There have been no real difficulties in becoming dementia-friendly. “It’s an important part of our mainstream work, widening access to what we provide,” says Nigel.

“Involve your local dementia society,” he recommends. “They have the expertise to help you see what you’re doing from the perspective of people with dementia and their carers.”

Want to know more?

Email Nigel: Nigel.Prince@northyorks.gov.uk



“The challenge is to show what can be done, so people no longer fear dementia.”

OPENING UP THE LOCAL CHURCH

Elizabeth Milwain

Adviser on Dementia Issues, Disability Task Group
Church of England Diocese of Bradford

In the hall behind St Peter’s Church, Shipley, stand tables covered with well-loved teddies, toys and old comics. Daina hands round homemade cupcakes. It’s the fortnightly Dementia Support Group, started by Elizabeth Milwain and Carol McNab who both worship at St Peter’s.

After an academic career in dementia, Elizabeth wanted to do more on the front line. Her first thought was educational sessions for carers about dementia. “But,” she says, “it soon became clear that carers could not come without a parallel activity for the people they care for.”

The solution arose when Elizabeth got talking with Carol, who offered to run reminiscence sessions for the group. So, after tea, the group divides. Those with dementia discuss memories; today’s theme is toys and games. “Everything’s slowed down, everyone gets a turn, everyone’s voice is heard,” says Elizabeth. “There is always lots of laughter and fun.”

In another room, carers – most here with their husband or wife – support each other, practically and emotionally.

“There is a lot of fear around the condition,” says Elizabeth. “The challenge is to show what can be done, so dementia becomes something people are not afraid of. Now we have opened the door people are starting to come forward.”

The work depends on a dedicated volunteer team. “Money is the biggest obstacle,” admits Elizabeth. But, working with the Bishop of Bradford’s office, she’s making progress, learning to make joint funding bids with others. Individual donations mean she hopes to employ a music therapist for some sessions. She’s confident she’s now got the beginnings of a model to share with other church groups.

“You’ve got to be realistic. Dementia can be difficult. But out of the confusion, you will connect. You just need to care about people as they are in that moment,” says Elizabeth.

Want to know more?

Email Elizabeth: Elizabeth@brainscapes.co.uk



“Go for it. There’s a lot of support out there.”

WELCOMING VISITORS AND TOURISTS

Sam Farooq
Information Advisor
Visit York

“When my manager suggested dementia-friendly training, I’m embarrassed to say I had to Google what dementia meant,” says Sam Farooq.

That training gave Sam a real insight into what living with dementia involves. But she also realised she was already helping people with dementia day in, day out.

“One lady came in every day with the same question,” she explains. “I wondered why she didn’t remember what I’d told her the day before. Now I think she was probably living with dementia.”

Around 7 million people visit York each year. Whether they live locally or on the other side of the world, many pass through the visitor centre. “We’ll go the extra mile for anybody. It’s what we do,” says Sam. “That made switching to dementia-friendly working easy.”

The big difference is simply having more awareness, taking a little more time. “If someone comes in five times a day asking the same thing, it doesn’t matter,” says Sam. “I’d rather they felt safe and secure.” Sam tells how one lady came into the centre in distress,

having completely forgotten why she was in York. Staff were able to reassure her, find her address in her handbag and arrange a taxi home.

Sam is proud of the centre’s dementia-friendly sticker. It impressed four Canadian visitors so much they came in just to say congratulations. “They gave me a huge hug,” she laughs. “I’d like to see the sticker across the whole city. On buses, in taxis, at the post office and the library, in schools.”

To anyone thinking of making their workplace dementia-friendly, Sam says: “Go for it. Don’t be embarrassed if you feel you know nothing. Go on a course, talk to other people, listen to their stories. There’s a lot of support out there.”

Want to know more?
Email Sam: info@visityork.org



“Don’t expect too much. Start small and build from there.”

MEMORY CAFES AND SAFE HAVENS

Peter Smith

Voluntary organiser
Tea Cosy Memory Café, Rothwell

One hundred people turned out to celebrate the Tea Cosy Memory Café’s second birthday. “There were eight people at the very first one,” recalls organiser, Peter Smith.

The café offers a monthly get-together for people with dementia and their carers. Those with learning difficulties or mental health problems are also welcome. “We don’t label people. That’s why it’s a memory café, not a dementia café. It’s a great mix,” says Peter. “The café is just one big conversation. People who might have been sitting at home, withdrawn, really come out of themselves.”

For Peter, the café is the first brick in building a dementia-friendly Rothwell. There’s been a clear ‘domino effect’. Offshoots include Friendly Fridays, showing DVDs from the Yorkshire Archive Memory Bank, and Music for the Memory sessions. Neighbouring areas are starting their own cafés and thinking about how to be more dementia-friendly.

Dementia-friendly communities don’t necessarily need funding, says Peter. What they must have is awareness. “But you can’t just play at it. It needs a lot of work and

someone who is focused on it. The key is to start small and build from there.” Peter, who’s retired, not only organises the social events, he encourages local businesses to get involved, runs awareness sessions across Leeds, talks to the media. It’s at least a couple of days work each week.

He’s trialling ‘safe havens’ with the local Yorkshire Building Society. “Staff know people in the community,” he explains. “If anyone has a problem, they can go in for a cup of tea, take 10 minutes in a quiet room, no questions asked.”

“It’s about nibbling away at things. Don’t start too big and expect too much,” advises Peter. “Give it time and plenty of patience. Each week, each month, you’ll get more people on board.”

Want to know more?

Email Peter: Peter.Smith011@btinternet.com

“No matter where you pop up, people will be able to help. That’s the test.”



A WHOLE-TOWN PARTNERSHIP

Wayne Goddard

Head of Strategy and Delivery (Vulnerable People)
Doncaster Clinical Commissioning Group

“Most of us still don’t realise how many lives dementia touches and the impact it has,” says Wayne Goddard.

For Doncaster Clinical Commissioning Group (CCG), raising that awareness and helping people live well with dementia are stated priorities. Its aims include increasing diagnosis rates and reducing crisis admissions related to dementia. The CCG is also developing a ‘resilience’ toolkit for carers. “If you don’t support carers, you end up with two patients,” says Wayne.

But the CCG’s not working alone. It’s part of the Doncaster Dementia Strategic Alliance, which wants to get the town recognised as dementia-friendly by 2015. Other members include representatives from the Health and Wellbeing Board, social care, the voluntary sector and the community.

“Local leaders are passionate about the agenda. That alignment between priorities and passion is crucial,” says Wayne. “You won’t do anything unless you get the key players signed up.”

“The Alliance’s Action Plan reaches well beyond health and social care. Local businesses, cinemas, libraries, transport and schools, for example, are all involved. There’s unusual people too like Doncaster Community Arts, who’ve used drama and photography to promote dementia awareness,” says Wayne.

The Action Plan includes expanding existing good work in local shops. The town centre has emerged as a vital social hub for people with dementia. “No matter where you pop up in Doncaster, if you have a need, people will understand and be able to help,” says Wayne. “That will be the test.”

Resources are the biggest challenge. “You’ve got to fight your corner when money is tight,” says Wayne. “Demand is up and resources are down. One way to deal with that gap is by being innovative. Partnership is the key. If you have that, it’s amazing what you can do.”

Want to know more?

Email Wayne: Wayne.Goddard@doncasterccg.nhs.uk



“Helping people interact is a big part of what we do.”

HEALTHY LIVING AND INTERGENERATIONAL CONNECTIONS

Safa Ahmed

Networker Co-ordinator/Deputy Manager
Health Action Local Engagement healthy living project,
Shipley

The Health Action Local Engagement (HALE) healthy living project links hundreds of activities in the Shipley Constituency. “Our mission is to improve health where need is greatest,” explains Safa Ahmed. “For us, it’s really important that our work enhances wellbeing for people with dementia.”

Regular wellbeing cafés allow people to get out and make new friends. “Helping people interact is a big part of what we do,” Safa says. “We connect people so that they build a network around them, until they don’t need HALE anymore.”

HALE’s befriending project reaches out to older, isolated people. “We’re developing the training for our volunteers,” says Safa. “We want to create volunteers who are very comfortable befriending people with dementia.”

But HALE works with people of all ages, bringing generations together. Joint drama workshops and ‘mocktail’ parties for local students and people with

dementia have proved enjoyable social occasions and helped change perceptions on both sides.

Getting the practicalities right matters too. “We don’t ring too far ahead to remind people of appointments,” says Safa. “If we send a taxi, we take into account that, for some people, a car’s black carpet can feel like stepping into a black hole.”

A ‘Living Well with Dementia’ pack is currently under trial. The simple design helps people keep track of medicines, appointments and resources all in one place. “People with dementia see so many people, it can feel overwhelming,” explains Safa.

HALE’s supported over 400 people with dementia. But, says Safa, “there’s always something to learn. We can’t get it right all the time. We can only improve by learning from the community, other agencies and our user groups.”

Connection is at the heart of everything. “Speak to each other,” Safa urges. “It really helps. So much is lost from not communicating.”

Want to know more?

Email HALE: Info@haleproject.org.uk



“It’s not one size fits all.”

A DEMENTIA-FRIENDLY HOSPITAL

Fiona Throp

Senior Nurse for Older People
Airedale General Hospital, Keighley

With an average patient age of 82, Airedale Hospital’s been developing its dementia-friendly action plan since 2010. The hospital uses the Butterfly Scheme, designed to help patients with dementia get appropriate care, whatever their clinical need.

“It’s not about making decisions for people but asking ‘how can we help you?’” explains Fiona Throp. “Could we do your pre-op assessment at home? Would you like to be met at the hospital door? Should a relative stay with you during anaesthesia?”

Links with GPs’ IT systems mean A&E staff can check straightaway if someone is living with dementia. “We want to identify people as early as possible so we can get them to the right place,” Fiona says. “There’s a ‘Butterfly Room’ with appropriate tools for assessing pain and calming artwork and music to round off the clinical edges.”

If patients choose, the ‘butterfly’ follows them through their hospital stay. “The principles underpin everything we do,” says Fiona. All clinical staff have mandatory training, however brief their contact with someone with dementia might be. “Staff are so busy. Dementia training should be really practical,” Fiona advises.

“Invest in awareness. There’s no point improving the environment without a culture of care.”

The hospital is refurbishing four wards. Distinctive colours and matt flooring help people find their way around. Patients can select a picture to mark their own bed. Revamped day care areas allow more stimulating social activities. For those at the end of their life, a dedicated room offers them and their relatives privacy, togetherness and calm.

“We’re on the cusp of a lot of hard work paying off,” says Fiona. What’s the key thing to remember? “It’s not one size fits all. If we do the same things for all people with dementia, we’ve got it wrong. We have to adapt, to treat the individual.”

Want to know more?

Email Fiona: Fiona.Throp@anhst.nhs.uk



“You surprise yourself with what you can achieve.”

WORKING IN SCHOOLS

Jayne Gledhill

Voluntary Project Manager
'Tuning into Dementia' film

Jayne Gledhill thought she had a great idea to help people with dementia. “But, talking to people with dementia, I realised it wouldn't work,” she confesses. “I hadn't truly understood what living with dementia means.”

Jayne wanted to share what she'd learnt with others, especially young people. Her new idea was a film bringing together students from York's Joseph Rowntree School and some residents with dementia from Hartrigg Oaks, the retirement village neighbouring the school. “Raising young people's awareness would give York a population that has grown up understanding dementia,” she explains. Her proposal won funding from GeniUS!York.

Young and old got to know each other through art workshops. “The students enjoyed these visits the most,” says Jayne, “and wanted to come back.”

Jayne briefed arts company Inspired Youth to produce a nine-minute film called *Tune into dementia*. The students imagine how their own daily lives might be with dementia and talk about what they've learnt.

Clever use of cutting and colour evokes the confusion dementia can bring.

Working with teachers, Jayne's drafted a lesson plan to go with the film, providing a ready-made resource for Personal, Social and Health Education (PSHE) lessons in York's nine secondary schools. With the film on YouTube, Jayne's looking at ways of sharing the lesson plan too. “There's no reason for this to be York's secret,” she says.

Jayne's never done anything like this before. “I thought it was going to be easy,” she laughs. “But it's proved a challenge.” Time's the main problem; she's balancing demanding voluntary work with life as a working mother.

“It's the people who have made it work for me. It's been a true community project, involving young and old, schools, City of York Council and the Joseph Rowntree Foundation. Enjoy the challenge!” she says. “You surprise yourself with what you can achieve.”

Want to know more?

Email Jayne: jaynegledhill@btinternet.com

Watch the *Tune into dementia* film at:

<http://www.youtube.com/watch?v=LSAzAeBvh-E&feature=youtu.be>



THE TRADITIONAL DEPARTMENT STORE

Linsey Wood

Operations Manager
Fenwick Department Store, York

When her store director asked her to attend a dementia awareness day, Linsey Wood wasn't sure what to expect. But the course reassured her that the store already had much good practice in place.

"Being dementia-friendly comes down to great customer service," Linsey says. "We're always talking to customers about what they want. After all, we have to understand our customers' needs to run a successful business." As a traditional department store, Fenwick has a lot of older customers. Many are regulars, on first-name terms with staff. "We take the time to help our customers. We don't want anyone to feel alienated."

With around 250 staff, the main difficulty is getting everyone together for dementia-awareness training. The managers have been first; they, in turn, are training staff on the shopfloor. Feedback has been very good. "Lots of staff have a personal link with someone living with dementia," says Linsey. "They've found the training quite touching."

She's considering how to build dementia awareness into induction training. The next stage will be involving

staff from the concessions stores. "That will take a lot more planning," Linsey admits. "The fashion floor is full of concessions."

"We also need to spread the word to customers, to make sure people know we're dementia-friendly," she says. "Some people might be anxious about coming into the store. We want them to be confident that they can come here."

Linsey hopes the store's example will inspire both other Fenwick branches and other shops in York to adopt dementia-friendly service.

"A lot of people are scared of dementia and want to shut it away," Linsey says. "Don't be scared of talking to people with dementia – they're just like everybody else. Understanding how people with dementia feel is the biting point. Treat everybody as you would like to be treated yourself."

Want to know more?

Email Linsey: linseywood@fenwick.co.uk



“People with dementia can engage with things that are modern and changing.”

THE CREATIVE ARTS

Emily Abbott

Director

here:now dementia, York

“I can’t bear the lack of ambition for people with dementia,” says Emily Abbott. “It’s a human need to explore new things.”

As a hospital patient, Emily was struck by how music calmed another patient’s distress. This led her to think deeply about how art can help people with dementia. “The arts are a brilliant medium for changing how people feel about themselves,” she says. “And art should be for everyone!”

After working on York’s first Alzheimer’s Society ‘Singing for the Brain’ sessions, Emily approached York Museums Trust to explore more arts-based activities for people with dementia. She now directs here:now dementia, developing ways of living well with dementia.

Projects have included a weekly group at the National Railway Museum and film-making using iPads with artist Claire Ford. “The iPad project is a lovely reminder that people with dementia can engage with things that are modern and changing,” says Emily. “Routine and structure are important but that doesn’t mean you must avoid anything new.”

Emily runs art workshops and has persuaded lifelong residents to visit York’s galleries for the first time. “Staying at home makes people bored, distressed and agitated. That’s avoidable,” says Emily. To prove it, she’s setting up a cycling project with York’s Get Cycling. But, she admits, “Transport is a big problem. Getting to what’s there is a nightmare for lots of people.”

She’s preparing recommendations for York Castle Museum after ‘dementia-testing’ it with people with dementia. “I try to work collaboratively with people with dementia, to consult with them. Just ask people what they want. It’s not a secret!” She’s also in the early stages of creating a user-led involvement group.

“Being dementia-friendly is about seeing what people can do,” says Emily. “People with dementia still have potential. We’ve got to move away from focusing on loss.”

Want to know more?

Email Emily: Emily.Abbott@herenow.org.uk



“Why can’t people with dementia be as active as anyone else?”

SPORTS AND LEISURE FACILITIES

Catriona Sudlow

Older People’s Physical Activity Officer
Sport and Active Leisure, City of York Council

“Why can’t people with dementia be as active as anyone else?” asks Catriona Sudlow. “They’ve just as much right to keep doing things they’ve done all their lives.”

York’s Sport and Active Leisure runs the first course in the country helping sports and leisure facilities become dementia-friendly. “That means creating an inclusive environment where people with dementia continue to feel comfortable doing the sports they love,” she says.

“There’s little or no cost to what we ask clubs to do. Most of it is just good customer service. Lots of centres are already very inclusive. It’s about understanding the signs and symptoms that go with dementia, so people can do their activities knowing someone will help no matter what the situation.” For coaches working with people with dementia, Catriona’s advice is simple. “Be flexible. Don’t treat everyone the same. Everyone’s an individual.”

Sport and Active Leisure is busy rolling out the work across York. Bowls, tennis, golf and cricket top the list. With these sports popular with older people, some players are likely to be living with dementia. Clubs like

New Earswick Bowling Club are already responding to what these members need.

Catriona is planning a database of dementia-friendly clubs in York. Future work includes going into care settings, using physical activity sessions to help residents stay active as long as possible. She’d like to reach people with dementia who are socially isolated, but that’s more of a challenge. “We have to try lots of different things,” she says. “If we reach just one extra person, that’s one person we haven’t reached before.”

“I’ve found something I’m passionate about,” Catriona says. “One day it could be me living with dementia. I like to think someone would be there to help me then, so why not start the ball rolling now?”

Want to know more?

Email Catriona: Catriona.Sudlow@york.gov.uk



“Environment plays a key part for people with dementia.”

RETHINKING HOSPITAL WARDS

Liz Sweeting

Specialist Mental Health Nurse
The York Hospital, York

In the bright sitting area in Ward 37, a patient enjoys having her hand massaged by a Red Cross volunteer. Others wander freely within the ward's light, open space. Colour coding helps people find their way around. A spring flower – daffodil, tulip, snowdrop – identifies each side bedroom. Raised lettering and symbols mark toilets and showers clearly.

“Coming to hospital can be overwhelming for everybody. For people with dementia, the environment plays a key part,” says specialist nurse, Liz Sweeting. “Colour, lighting and signage can all create a flowing space, one which is stimulating but still calm.”

Ward 37 is a mixed medical and mental health ward, freshly redesigned for patients with dementia. But Liz and her team don't restrict their work to one ward. They are always available to anyone with concerns about dementia, visiting any ward to provide advice and support.

“Being dementia-friendly is not just for one nurse, one team, one ward, it's everybody's business,” says Liz. She's running awareness sessions for 300 non-clinical

staff – porters, kitchen staff, cleaners and security personnel.

New approaches don't stop at refurbishment. Staff are introducing iPads to supplement more traditional activities such as jigsaws and dominoes. “We're using tech in a setting you wouldn't traditionally think of. Simple arts apps are an amazing way to engage with people creatively, even those with quite advanced dementia,” Liz explains. The hospital is planning to identify resources for an Activities Co-ordinator.

Liz takes her work beyond the hospital too. She liaises with GPs, care homes and the Alzheimer's Society, looking to connect acute care with community care in the widest sense. “It's about raising awareness for everybody, including the public. Working with other people locally and nationally, is the key to becoming dementia-friendly,” Liz says.

Want to know more?

Email Liz: Elizabeth.Sweeting@york.nhs.uk



“If you want to know what to improve, listen to the public.”

CHANGING ATTITUDES AND SERVICES IN HEALTHCARE

Dr Dan Harman
Dementia Clinical Lead
Hull & East Yorkshire NHS Trust

“We want our dementia services to thrive, not just survive,” says Dan Harman. “Acute Trusts should be partners with community and social services, providing timely support for people with dementia.”

Dan chairs the Trust’s Dementia Program Board. It coordinates practice and shares ideas between health, social care and voluntary organisations.

Initiatives range from quick wins, like relaxing visiting hours, to major infrastructure projects. “We plan to refurbish two wards at Hull Royal Infirmary,” says Dan. “Raising the money is the hospital’s next big charitable campaign. We also want to expand digital reminiscence on wards and volunteer ‘dining companions’, helping patients eat well.” The community’s involved too: Hull FC’s one example, running sports memory cafés to reach out to older men in particular.

“Being dementia-friendly means thinking about delivering care differently to meet people’s needs,” Dan says. “Surveying carers showed they wanted more information following discharge, for example. Now we’re producing a straightforward leaflet about services.”

Dan is keen to back practical change with evidence. He’s creating a ‘dementia dashboard’ measuring indicators like length of stay and readmissions. A database tracks the number of patients with dementia and where each is in the Infirmary at any one time.

All hospital staff now have an hour’s awareness training, with longer sessions for those working with older people. The Trust’s Intranet has a regularly updated section on dementia.

“Changing attitudes is a big challenge. Many staff don’t realise that dementia is a life-limiting illness,” says Dan. A joint research project with Hull University is looking at spirituality and end-of-life care. “It’s something we rarely ask about.”

“If you want to know how to improve, listen to the public. There’s so much valuable information in complaints letters, for example,” Dan says. “Just think of the numbers dementia affects. We need to offer services very differently.”

Want to know more?
Email Dan: Daniel.Harman@hey.nhs.uk



“Being dementia-friendly shouldn’t be something we just do at work.”

IMPROVING LEGAL SERVICES

Dawn Moore

Solicitor

Harrowells Solicitors, York

“Solicitors have a long tradition of working in a sympathetic and practical way with people with dementia,” says Dawn Moore, Harrowells’ Dementia Champion. The firm’s Dementia Working Group is embedding that deep-seated experience across its six branches.

“We aim to get clients with dementia from A to B in the easiest way,” Dawn explains. “We think about where best to meet people, make sure they see someone they know. We try to avoid long letters full of legalese, talking people through things at an easy pace instead. We might describe what we are trying to achieve without written words. Pictures or simple diagrams are often useful when explaining what assets are going where when discussing a will, for example.”

“If you’re in the early stages of dementia, seeing the solicitor can feel like the first step to losing control,” adds partner, Hudda Morgan. “We stress that it’s about your decision, your choice to empower someone to act on your behalf.”

“As solicitors, client service is paramount,” says Dawn. “We are here to serve the client’s instructions. The only challenge is sometimes making this clear to families.”

The group looks at the ‘choreography of contact’ from the moment a client makes that first call or steps through the front door. Being a dementia-friendly employer is also high on the agenda. “Staff information sessions are a good starting point,” says Dawn. “And many ideas come from staff. In most organisations, someone has personal experience of dementia. Draw on that expertise, don’t just consider professional issues.”

The aim is to enable any employee to spot someone needing help and offer appropriate support – whether in the office or in the community. “Dementia is a part of life, and it always has been,” Dawn says. “Being dementia-friendly shouldn’t be something we just do at work.”

Want to know more?

Email Dawn: dawn.moore@harrowells.co.uk



“Most older South Asian women won’t have an understanding of dementia.”

SUPPORTING SOUTH ASIAN WOMEN

Farzana Camran

Project Coordinator
Roshni South Asian Women’s Resource Centre,
Sheffield

In a Sheffield café, a group of women are discussing dementia. Some have tea and cake; others are fasting today for religious reasons. It’s the second such meeting set up by Roshni, which supports South Asian women of all ages in the city. “We want to raise awareness of dementia,” says Farzana Camran. “This dementia café is a pilot. We’ve deliberately made it simple, homely and hospitable.”

“This generation of women has given so much for others, they’ve aged very quickly,” Farzana explains. “Now they have many complex needs – living in poverty and poor health, lonely after children leave home, perhaps widowed or divorced, facing language and cultural barriers. We’ve started the café to bridge the gap between clients and services.”

There are plenty of questions. Can arthritis lead to dementia? What’s the difference between depression and dementia? Are headaches a symptom? Rose from the Alzheimer’s Society is here to respond, with Farzana and her colleague Salma translating.

“In this community, most older people won’t have an understanding of dementia,” Farzana says. “We’re gently introducing the concept.”

Raising awareness matters to Roshni. Staff have had dementia awareness training. Farzana is giving a presentation on dementia at Roshni’s AGM. As part of the Sheffield Dementia Action Alliance, Roshni networks with other organisations. They are also reaching out to local Yemeni and Somali people.

“With so many funding cuts, the biggest challenge is resources. We’re very squeezed financially, short of staff and time. And building trust takes a lot of time,” says Farzana. “I would love to have more staff so we could carry out intensive one-to-one support and home visits and reach out to the city’s most deprived areas.”

“Being dementia-friendly comes down to kindness. You must respond to each individual,” she says. “You don’t know what pain and worries may lie behind that smiling face.”

Want to know more?

Email Farzana: Safeandsecure@roshnishffield.org.uk

ACKNOWLEDGMENTS

Special thanks to:

Sharon Telfer, writer, and Eloise Ross, photographer, for collecting these case studies.

Simon Wallace, Project Manager, Yorkshire and Humber Dementia Action Alliance; Cathy Henwood, Dementia Friendly Communities Coordinator, Alzheimer's Society Bradford Area; and Jill Quinn and Netty Newell from Dementia Forward, for their help in accessing the wide range of case studies.

All of the subjects of the case studies who gave up precious time to tell their stories.

The many Yorkshire people living with dementia – people like Trevor, Marlene, Daphne, Jenny, James, Dennis, David, Maureen, Hella and Peter – who, with their partners and carers, have been at the start and the heart of these initiatives.

JRF's programme *Dementia without Walls* started in 2012. Our long-term aim is that the UK is a good place for those of us who have dementia to live, and live well. To achieve this, we believe we need to challenge attitudes, understanding and behaviours around dementia that reinforce stigma, isolation and exclusion.

We need to inspire local communities, organisations and businesses to become more aware and understanding of dementia, and more inclusive. We need to support the collective engagement of people with dementia so their voice is heard more clearly in this debate and they have more confidence and capacity to influence attitudes, policies and practice.

For further information please visit: www.jrf.org.uk/dementia

FOR FURTHER INFORMATION

This summary is part of JRF's research and development programme. The views are those of the authors and not necessarily those of JRF.

Read more summaries at www.jrf.org.uk
Other formats available
ISBN: 9781909586055

Joseph Rowntree Foundation
The Homestead
40 Water End
York YO30 6WP
Tel: 01904 615905

email: publications@jrf.org.uk
www.jrf.org.uk
Ref: 2940