

# ON THE JOURNEY TO BECOMING A DEMENTIA FRIENDLY ORGANISATION – SHARING THE LEARNING FOR EMPLOYERS AND ORGANISATIONS

## What's the issue?

An increasing number of people will be affected by dementia in their lives, either directly or as a carer when a relative, friend or neighbour is diagnosed. We know that coping with the first symptoms of dementia, or supporting someone who has it, is often stressful and can affect people at work.

A lack of understanding or confidence can prevent organisations and employers from responding positively to people affected by dementia. Organisations that are dementia friendly recognise and address the impact of dementia on staff and their families.

## Ways forward

- An organisation-wide approach signals that dementia awareness is important for everyone.
- Using a community development approach can help build capacity and lead to more flexibility of approach, greater staff engagement, and a sense of ownership from the bottom up.
- Corporate endorsement and top-down leadership is important in enabling staff participation, giving profile to the work and sustaining the commitment.
- A wide range of mechanisms can be used to raise awareness and provide information about dementia to staff.
- Effective involvement of people with dementia and carers can help challenge attitudes and assumptions.
- Providing multiple and varied opportunities for staff involvement can reveal individual interests, skills and passions.

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SEPTEMBER 2015

# BACKGROUND

JRF's Dementia without Walls Programme started in June 2012, with a vision of the UK as a good place for those of us who have dementia to live, and live well. In 2013 the Joseph Rowntree Foundation and Joseph Rowntree Housing Trust committed to becoming a more dementia friendly organisation and employer. This paper shares the lessons that have been learnt.

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## Dementia and JRF/JRHT

The Joseph Rowntree Foundation (JRF) works for social change in the UK by researching the root causes of social problems and developing solutions. Joseph Rowntree Housing Trust (JRHT) provides housing, care homes, retirement and supported housing. Together they use evidence and practical experience of developing housing and care services to influence policy, practice and public debate. The two organisations jointly employ around 770 staff.

JRF's Dementia without Walls Programme focused on:

- supporting the collective engagement and actions of people with dementia;
- inspiring local communities, organisations and businesses to become more aware and understanding of dementia, and more inclusive;
- challenging attitudes, language, misunderstandings and behaviours.

The programme has been timely and influential. JRF has helped to develop strong local, regional, national and European networks to share learning and ideas, and to influence change. The development of the collective voice of people with dementia is still very new, but has exceeded expectations in growth and influence. JRF's work on dementia friendly communities is known internationally, and debate and challenge has been stimulated across the field.

The learning shared in this paper draws on an independent evaluation of JRF/HT's work to become a dementia friendly organisation. The evaluation was carried out from September 2013 to May 2015.

## Why is being dementia friendly important for organisations?

The number of people with dementia in the UK is forecast to increase to more than a million by 2025. There are more than 40,000 people under the age of 65 living with dementia in the UK. Currently, 18 per cent of people under the age of 65 diagnosed with dementia continue to work after receiving their diagnosis. There are an estimated 670,000 people in the UK acting as primary, unpaid carers for people with dementia (Alzheimer's Society, 2014).

These statistics suggest that in any organisation there will be individuals who are directly affected by dementia – either developing symptoms and a diagnosis themselves or supporting a family member or friend living with dementia. This is often stressful and can affect people at work.

Becoming a dementia friendly organisation will have direct benefits for staff affected immediately by dementia, but also makes good business sense. The Alzheimer's Society guide *Creating a dementia-friendly workplace* (Alzheimer's Society, 2015), outlines a clear business case for organisations:

- it's the right thing to do;
- it will help you to retain staff;

- you will become an employer of choice;
- you will provide a more inclusive service;
- it will future-proof your organisation;
- it will contribute to increased productivity;
- you will be fulfilling your legal responsibilities.

Organisations that are dementia friendly seek to support people affected by dementia in a range of ways, enabling them to continue to remain in employment and manage working life for as long as possible.

Some of the possible features of a dementia friendly organisation include:

- provision of information and awareness-raising activities targeting all staff;
- provision of appropriate training to enable staff to respond empathically and positively to people with dementia;
- a positive and proactive approach to supporting service users/residents/customers who are affected by dementia;
- commitment to the active and supported involvement of people with dementia;
- commitment to making the physical environment as dementia friendly as possible;
- being supportive to staff who are caring for someone with dementia in their personal lives;
- being supportive to colleagues who might be affected by dementia themselves.

## What JRF/JRHT did

### The commitment

As part of the Dementia without Walls programme, JRF and JRHT committed to become more dementia friendly organisations, both as providers of services and as employers. They have been working towards this goal since the summer of 2013. JRF and JRHT recognises that their residents and employees include people who are affected by dementia, and that the organisations can learn from their experiences of how best to support anyone affected by it. Over the past two years, JRF and JRHT have sought to test and evaluate the impact of actions to support residents and staff affected by dementia, either directly or as carers.

The overall aim of this work is for them to become organisations that recognise and address the impact of dementia on staff and their families, and residents and their families. The work sought to achieve a number of specific objectives. To:

- involve people with dementia and/or others directly affected by dementia in this process of change;
- engage with staff and influence /challenge perceptions and understanding of the experience of living with dementia;
- support individual staff who are directly affected by dementia themselves, in their families or in their communities;
- have a practical and permanent influence on all the services provided and the way they are provided;

- identify evidence of benefits to the organisation as well as to individual staff;
- demonstrate the value and challenges of such an approach to other organisations across the UK through the evaluation, to influence others and inspire change.

## Community development approach

The programme of work took an incremental, asset-based, community development approach. A community development manager was recruited to JRF's policy and research team in April 2013, with this project as one of her main remits. She has been supported by the Dementia without Walls programme manager and a steering group made up of representatives from different parts of the organisation.

Specific activities to achieve the objectives have evolved and developed over the period of the programme in response to conversations with staff, residents and people with dementia, building on their interests, passions and ideas about how they can make a difference and be the drivers of change. Staff have appreciated this bottom up non-directive approach and a number of benefits have been identified. These include:

- more ownership of the work;
- enabling flexibility of approach;
- helping to engage with staff across all parts of the organisation.

"I think there's been more value on the building up from the bottom... in a way it's got taken up and taken on by the teams and projects themselves...which is good as you need to be building that really."  
JRF staff member.

*"A 'one size fits all' approach wouldn't have worked as we're such a diverse organisation....[it] allowed us to be very flexible and follow our noses."*

JRF staff member.

The work began with a series of Conversations about Dementia roadshows. Between September and November 2013, 17 JRHT and JRF sites were visited and contact made with around 250 staff. The roadshows were a means of setting the foundations for engaging with staff and informing them about the aims and purpose of the work. They also served to help build trust across the organisation, to help staff feel comfortable talking about dementia, enabling them to ask questions and get involved in a way that played to, and supported, their ideas, interests, passions and talents and to identify opportunities for development and easy wins.

Facilitated by the community development manager with the support of an external advisor with expertise in dementia care, the roadshows also ensured staff queries and concerns, be they personal or professional, could be responded to sensitively with expertise. Postcards issued at the events invited people to respond to a set of questions (see Box 1).

### **Box 1: Questions staff were asked at roadshows**

1. What do we (JRF/JRHT) do well for people with dementia?
2. What could we do better?
3. Do you have informal care experience? If so, for who?
4. How could we help staff who have an informal care role outside of work?
5. What would I want JRF/JRHT to do if I got dementia?

Of those members of staff who came to the roadshows 81 per cent (204) responded to at least one of the questions. A summary of the responses was published in a leaflet for staff in early 2014. The questions asked at the roadshows broadly reflected three specific dimensions:

- JRF/JRHT's services to support people living with dementia;
- support for JRF/JRHT staff with informal caring responsibilities;
- support for JRF/JRHT staff who continue to work while living with dementia.

As a follow-up to the roadshows an open meeting was held in February 2014. The 25 staff who attended, from a range of sites and teams, identified a number of possible ideas on how to help make JRF/JRHT more dementia friendly. They then worked with colleagues from across the organisation to develop these ideas into projects that could be implemented.

Examples of projects and activities related to each of the three dimensions are given below

## **Dimension 1: JRF/JRHT's services to support people living with dementia**

JRHT provides general needs housing, residential care homes, a continuing care community, extra care sheltered housing and independent living schemes across Yorkshire. Feedback from the roadshows suggested that many staff feel JRHT provides appropriate care and support to tenants and residents affected by dementia, in particular in relation to one-to-one care.

### **Training**

As a care provider, JRHT already provides a range of training on dementia for its care staff, over and above the statutory requirement. Before the initiative, more than 200 care staff had taken part in the Alzheimer's Society Tomorrow is Another Day course which provides a basic level of dementia awareness with experiential learning.

Since the initiative began, various training and information sessions have been provided to enable and equip staff to better support people with dementia.

All care staff now complete 1.5 hours of dementia awareness during their induction. In addition, to help care staff to better understand and empathise with what it is like to live with dementia, the virtual dementia tour (VDT) has been delivered throughout 2015. This training aims to help staff create a positive environment for those with dementia by giving them a virtual experience of attempting to 'walk in their shoes'. 200 staff have now taken part in the VDT and the sessions are being opened up to non-care staff. Feedback from participants indicates that it provided valuable insights and understanding as to what it is like to live with dementia, how people with dementia may feel and why they may act in certain ways. Participants also indicated how the VDT had made them think about how they could better communicate with people with dementia and change their responses to better meet the needs of those they are caring for.

*"Increased understanding of how a person living with dementia may feel. And how confusing, frustrating, scary and tiring it felt..."*

VDT participant

*"Makes you more aware of how a person with dementia might be experiencing their world on a daily basis – it helps to remember this and to help them by changing your responses and modify care."*

VDT participant.

Other bespoke dementia awareness sessions have been delivered to meet staff needs and individual services. Topics covered have included; different types of dementia; nutrition, to help ensure person centred support at meal times; dementia in people with learning difficulties (see the training resource Supporting Derek (Watchman et al., 2010)); life story awareness; and Best Practice in Dementia Care, a nationally recognised course.

## Physical environment

A key element of being a dementia friendly organisation is ensuring that the physical environment is welcoming and meets the needs of people living with dementia.

Specific activities aimed at improving the physical environment have included the development of a disability dementia audit tool to help assess all JRF/JRHT places and spaces.

Around 40 staff completed the University of Stirling's Dementia Services Development Centre (DSDC) dementia friendly design school. Participants purposely included not only contracted specialists such as architects, surveyors and planners as but also JRF/JRHT gardeners, carers, researchers, domestic and maintenance staff. Feedback from participants confirmed that it increased their awareness of dementia friendly design principles, such as the importance of high light levels and good lighting design, the health benefits of exposure to daylight and sunlight and a comfortable acoustic environment.

*"Helped me realise that my work surroundings may need to change to make people living with dementia feel safe."*

Design school participant.

*"Will use top tips and basic principles to help people living in their own homes and communal areas."*

Design school participant.

The refurbishment of one of JRHT's buildings, the Folk Hall, has provided an opportunity to put these dementia friendly design principles into practice (see Box 2).

### **Box 2: case study – Folk Hall**

#### **Background**

The scheduled refurbishment of one of JRHT's property assets, the Folk Hall, has provided the opportunity to consider and implement dementia friendly design principles and incorporate necessary changes at relatively low cost.

The Folk Hall is a large community building, built in 1907, at the centre of New Earswick village outside York. Managed for the community by JRHT, it has a large hall, a reception area, a bar, café and toilet facilities. It also has a number of meeting rooms, offices and a gallery on the first floor. The hall is well used by many community groups, including some dementia-focused activities such as singing for the brain.

JRHT devised plans to remodel and refurbish the Folk Hall both internally and externally to ensure existing health and safety issues were addressed. A key consideration has also been the changes needed to ensure it is a more welcoming place for people living with dementia.

The redevelopment work was led by Jonathan Gibson, Senior Development Manager at JRHT. To help understand the issues and to inform their plans for the redevelopment, he sought feedback and advice both from people with dementia and their carers and also from the University of Stirling DSDC. The initial feedback from a group of people with dementia and their carers (who were invited to audit the Folk Hall during a walk round of the building) highlighted that while they felt warmly towards the building, there were a number of issues which may be problematic. Concerns related to both the exterior of the building (e.g. entrances, signage and gardens) and the interior design, decoration and signage (e.g. use of colour, walls and floors) as well as issues with specific elements including the toilets and café.

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An assessment of the Folk Hall by Ricky Pollock, an architect from the DSDC, provided additional information. Ricky observed that the Folk Hall 'generally struggles to meet even the basic requirements of the Disability Discrimination Act with features such as the inadequate ramps and poor lighting and contrasts'. He highlighted where changes could usefully be made in a number of areas, and recommended that the needs of people with sensory impairments should be a particular focus as these can impact more severely on people with dementia.

### **What's being done?**

As a Grade II listed building, there were constraints attached to the developments that could be undertaken. However, Jonathan was keen to ensure that the refurbishments took into account the needs of people with dementia. The work has been in two phases. Initially a repairs and maintenance contract began to tackle essential immediate work which Jonathan saw as a way to get a few 'quick wins'. 'If we can do things at no cost now, like re-carpeting and decorating using colours that are dementia friendly, these are quick wins. We are doing this work anyway so let's take advantage.' The second phase of the work (to be completed by summer 2016) will focus on remodelling the Folk Hall and will involve more substantial alterations and adaptations.

The intention has been to incorporate as many dementia friendly design features as possible in both stages of the project and the report from the DSDC identified a useful list of design features to consider, including:

- Doors – door handles to contrast with door finishes; use of a consistent bright colour theme for toilet doors; blend in fire doors and staff doors to avoid attracting attention; public doors to contrast with surrounding walls.
- Floors – keep consistent tones throughout public areas; avoid bright contrasting or reflective thresholds; floor finishes to be non-reflective to avoid 'wet' look and glare; contrasting colour with skirting boards and walls essential.
- Internal fittings – use safety glass fronted wall units for people with dementia.
- Decoration – contrasts, colours and tones based on DSDC and RNIB guidance. Ensure any obstructions such as pillars stand out against background.
- Electrical – any switches and sockets to be used by public to have contrasting plates and switches.
- Lighting – double normal IEEE lighting levels required and control effectively/ avoid glare from luminaries and use spotlights sparingly.
- Acoustics – incorporate sound absorbing materials when doing ceiling and wall repairs.
- Toilets – use domestic looking tiling in toilets (and other areas used by people with dementia).

Many of the changes DSDC suggested were at nil or little cost and those completed in phase one included: improved lighting; replaced flooring with a plain, non-slip surface which contrasted with walls, changed paint colours throughout the building to denote the public and private areas; and 'painting out' doors not for public use with the same colour as the surrounding wall colouring. Clear signage in a sans serif text with high levels of contrast have replaced old mixed signage throughout the building.

Following these phase one changes, a group of people with dementia and their carers revisited the Folk Hall to give their views. Generally, their feedback indicated that the changes were helpful and that the building felt brighter and more light and airy. They also came up with a list of recommendations to be considered in future plans, including:

- improved signage (externally and internally);
- accessible toilets (e.g. improve lighting levels, red emergency pull-cord to be used to make it easier to see);
- toilets (e.g. paint the men's and women's doors different colours, add gender symbols, replace noisy hand drier with paper towels).

The refurbishment of the Folk Hall should mean the building is more attractive and accessible for a wide range of people. As Ricky states, 'The building should not look in any way 'special' or 'different' but should have an attractive and welcoming appearance...which will actually benefit everybody ...and not just those users with dementia'.

Reflecting on Ricky's report, Jonathan says, 'The attention to detail from Ricky and the University of Stirling is quite remarkable in the sense that they picked up things I would never have thought of... things like signposting ...and use of colours. The University of Stirling dementia design guides<sup>1</sup> are useful... but what I learnt was that we can put things in place that won't cost anything in terms of designing buildings that are dementia friendly for the future.'

Jonathan confirms that dementia is now a standard item on the agenda for his work. He has been involved in the development of a dementia disability audit tool, a checklist of things to look out for to make a building more dementia friendly, which will be used for all of JRHT's public buildings.

Another example of changes to the physical environment includes the redevelopment of a section of the Homestead Park, a public park in York owned and managed by JRHT (see Box 3).

### **Box 3: case study – dementia friendly garden**

Bob Williams is team leader for JRHT's landscape maintenance team. His role involves managing the outside spaces on JRHT sites and his team regularly comes into contact with JRHT residents.

JRF/JRHT's work to become dementia friendly got the landscape maintenance staff thinking how this could apply to their work. When an area of the Homestead Park was to be redesigned, consideration was given as to how to make this more dementia friendly.

After an initial site survey and analysis, the task was to identify what a dementia friendly garden looked like. Drawing on the skills and expertise within Bob's team, they set about the task of identifying other examples of dementia friendly gardens.

#### **Design principles**

Design work for the garden has been guided by a number of principles e.g. textures, circulation round the site, movement, surfaces, seating, accessibility, routes, visual and sensory considerations. Each member of the team was tasked with looking at a specific design element using the design principles, e.g. types of paving, types of seating, surfacing, built elements.



The case studies of other dementia friendly gardens informed their thinking, as did feedback from people with dementia and their carers, with JRF's community development manager and external consultants advising on practical factors. Design team members accompanied people with dementia around the park so they could give their views and pick out certain design features. As Bob states:

*"We essentially needed to address the aspirations of the user group and design something that works for them. It's never a designer's role to impose design on a group of people or environment, it's very much a collaborative project....We're looking to create a space for everybody but take into account the needs of people with dementia and their carers – a place which is comfortable, safe and stimulating for people with dementia."*

One of the challenges with the work has been funding as some of the ideas being considered are costly. Sustainability of the design is another challenge, with some elements in a public park possibly prone to vandalism.

Following the consultation with people with dementia and the research into dementia friendly design, there are now three options for the development of the Homestead Park:

- a five senses garden in one area of the park;
- a community garden in an enclosed space within the park;
- a dementia friendly park (entire park).

To help progress this work, JRF/JRHT are supporting the development of a Friends of Homestead Park Group, made up of local people with dementia and their carers. This group, which aims to be a consultative group to inform decision-making relating to the uses of the park, has met informally on a regular basis over a number of months. Members have spent time with skilled gardeners and visited other park groups to seek inspiration and get ideas. The group wants to be involved in the design process as well as actively involved in tasks within the garden.

Dementia awareness has influenced Bob's thinking and planning for other projects he is leading and JRHT gardeners are working in different ways and taking on board the learning in other work.

*"The stuff I have learnt and picked up has influenced my thinking about other projects and about other things we plan to do. We are hoping there will be ripple effect. The garden will be a standalone example of how things could be delivered."*

The new skills of JRF/JRHT staff in dementia design, and their growing awareness of its importance, is proving invaluable in many areas of the organisation's work. All specialist contractors, such as architects, landscape architects, and engineers are also required to follow these principles. JRF's London office in Vauxhall has also been audited by people living with dementia, and dementia-friendly design principles have also been fed into the planning of the major refurbishment of the public realm around Vauxhall itself.

### Impact of the work on JRF/JRHT's services

A survey of all staff (n = 158) was carried out in March 2015 near the end of Phase 1. More than two-thirds of respondents (68 per cent) felt that JRF/JRHT was supportive to service users and residents who are affected by dementia, with an additional 23 per cent (36) feeling the organisation demonstrates this to some extent. The vast majority of survey respondents (85 per cent/134) stated that their ability to support people who have or are affected by dementia had increased since the work began. 39 per cent (62) said it had increased 'a lot' and 46 per cent (72) said it had increased 'a little'. Over three-quarters of staff (78 per cent) who responded to the survey felt that JRF/JRHT is

committed to providing appropriate training on dementia for staff, with an additional 18 per cent (28) feeling the organisation demonstrates this to some extent. Almost half the staff surveyed (46 per cent, n = 158) felt JRF/JRHT demonstrated a commitment to dementia friendly design, with an additional 35 per cent (55) feeling they demonstrated this to some extent.

## **Dimension 2: Supporting staff with informal caring responsibilities**

The roadshows and related work have served to reduce stigma and increase awareness by encouraging staff to talk more openly about dementia at both a personal and professional level. The roadshows also revealed that a large proportion of JRF/JRHT staff who attended (44 per cent /89) have informal caring responsibilities for someone with dementia, with 9 people stating they were informal carers for more than one person.

Staff have also indicated that informal carers (as well as other staff) need better access to information, advice and support about dementia and a number of steps have been taken to provide this.

Dementia information boxes containing leaflets and literature about dementia were distributed to most JRF/JRHT workplaces to provide access to free information for staff to share with friends and family.

A collection of dementia-related books has been developed at the JRF Homestead staff library, based on links with the Reading Well Books on Prescription scheme.

Four information sessions on lasting power of attorney (LPA) have been delivered for staff, with free support from local solicitors Harrowells. These sessions inform staff about the importance of setting up LPAs and wills, especially where an individual or relative has dementia. These have been very well attended and valued, both for personal and professional reasons, and there are plans to offer the sessions to residents in JRHT's care services.

Human resources staff have produced a revised carers policy statement which signposts relevant policies, and have supported a number of carers through the time off work policy.

JRHT has an Admiral nurse (specialist dementia nurse) who provides staff with dementia related information and advice. This support service to staff has been promoted via postcards attached to staff payslips, stressing how she can support people in their personal as well as professional roles. 45 enquiries from staff to the Admiral nurse were recorded in a six month period from Nov 2014 to May 2015. The majority of enquiries (87 per cent) were made in person, with the remainder being by phone (9 per cent) or email (4 per cent). Almost half the enquiries (48 per cent) related to a relative, 45 per cent related to a resident in JRHT accommodation, and 5 per cent related to a friend. Many related to care management of residents for staff dealing with issues such as distressed behaviour. For staff seeking support about their own relatives, the Admiral nurse was able to provide reassurance, a listening ear and practical advice about issues such as care and hospital admissions.

By the end of Phase 1, around a third (36 per cent) of survey respondents (n = 158) felt JRF/JRHT was supportive to staff who are caring for someone with dementia in their personal lives, with an additional 32 per cent (51) feeling the organisation demonstrates this to some extent.

## **Dimension 3: Supporting staff who are working while living with dementia**

Being able to work while living with dementia is important for many reasons (a sense of self-worth, meaningful activity and contribution, income, pension accrual, etc), and with the right support and adjustments, is possible in many cases. While information on the number of JRF/JRHT staff with dementia is not known, human resources staff are currently supporting at least one employee who is probably in the early stages of dementia.

A small number of staff who attended the roadshows (5 per cent /10) reported concerns about revealing symptoms or a diagnosis of dementia to JRF/JRHT. For some this was because of the fear

that JRF/JRHT would not provide the necessary support, while others were concerned about the reactions of colleagues or about losing their job.

Staff gave the following suggestions as to what JRF/HT could do to better support staff living with dementia:

- create a 'culture of openness', where people feel able to talk openly about their needs without worrying about the consequences;
- recognise the desire of people with dementia to be treated with respect and be valued as individuals;
- make reasonable adjustments to enable staff to continue working, e.g. buddying, reviewing responsibilities and reduced hours or flexible working.

In addition, JRF/JRHT human resources staff have been involved in an Alzheimer's Society task group, producing a national practical guide for employers on dementia, which was launched in May 2015.

By the end of Phase 1, just over a quarter (27 per cent/43) of survey respondents felt JRF/JRHT was supportive to colleagues who are affected by dementia themselves, with an additional 22 per cent (35) feeling the organisation demonstrates this to some extent. Around a third (36 per cent/57) of survey respondents (n = 158) felt JRF/JRHT is supportive to staff who are caring for someone with dementia in their personal lives with an additional 32 per cent (51) feeling the organisation demonstrates this to some extent.

## Cross-cutting themes

In addition to these three dimensions, there are three cross-cutting themes related to the work:

- raising awareness of staff;
- involving people with dementia;
- sharing learning and influencing.

### Box 4: case study – Dementia Friends

Raising awareness of staff about dementia has been a core focus of JRF/JRHT's work to become a dementia friendly organisation. One key method that has been used to reach large numbers of staff has been the delivery of Dementia Friends information sessions.

#### Who are Dementia Friends?

Dementia Friends is a national initiative led by the Alzheimer's Society that aims to increase understanding about dementia and inspire action to support people with dementia to live well. A Dementia Friend learns a little bit more about what it is like to live with dementia and then commits to a personal action e.g. being patient or sharing information about the programme.

The sessions last an hour and are activity based, providing helpful tips and small ideas to help people support those they know with dementia and their carers. The session explores attitudes to dementia, aims to increase understanding about dementia and inspire action to support people with dementia to live well.

Natalie Gordon, a policy and research intern at JRF, has trained as a Dementia Friends champion and since September 2014 has delivered 30 Dementia Friends sessions to over 230 staff across JRF/JRHT, as well as to the trustees.

Sessions have been offered to all staff, apart from those in care services who receive higher level training on dementia. JRF/JRHT staff have been encouraged by managers and directors to take part and there has been an expectation that all staff will attend.

Natalie sees the sessions as a starting point for learning about dementia: 'I hope it will help create a cultural environment where staff feel comfortable discussing dementia at work and know how to receive support. I hope that understanding about dementia increases and that people with dementia are supported to live well more widely, which could be through little actions that can make a big difference.'

### **Need for Dementia Friends**

Around a third (34 per cent) of staff who have attended the sessions stated that they come into contact with people with dementia either daily or frequently. This confirms the need for staff to feel supported and aware of the needs of people living with dementia. Natalie states that, even though many staff are already working well with people with dementia and showing an awareness of their needs, there is a need for further training: 'Staff are responding positively to support people with dementia to live well. However customer-facing staff need to feel confident in how they are responding, have a high level of awareness about signposting procedures and what to do if they have concerns that a resident or customer has dementia. Specific training for staff is key to increasing staff confidence and skills in these areas.'

To help with this, Natalie has been reviewing the dementia related training needs of staff in different jobs and has put forward proposals for meeting these.

A number of staff also indicated that they are personally affected by dementia: 'In every single session I've heard from people affected by dementia, both personally and professionally. Experiences are diverse and extensive. It has highlighted just how prevalent an issue it is, how important it is that staff are supported, and that staff who work with people with dementia know how to respond effectively.'

Benefits of attending the sessions reported by staff have included improved understanding and awareness of the signs and symptoms of dementia and of how to better meet the needs of people with living with it. They also reported the need to be more patient and understanding with people with dementia and to share learning with others.

Natalie identified a number of factors that helped to make the sessions successful:

- a culture where it is recognised and accepted as an important issue by staff across the organisation, including having leadership and support from key senior staff members;
- the support of staff across different sites and departments to assist with organising the sessions and ensuring maximum attendance; this has meant tailoring the session to the appropriate time of day for some staff e.g. first thing in the morning for direct labour operatives or tagging onto department meetings;
- the contributions from staff members, both personal and professional.

### **Next steps...**

In an effort to maintain levels of awareness and increase access to information about dementia, a quarterly Dementia Friends newsletter now goes to all staff that are Dementia Friends

providing more information about JRF/JRHT's work on dementia and related resources. All new staff also receive Dementia Friends awareness as part of their induction.

JRF now has 230 Dementia Friends who are committed to a range of actions aimed at improving the lives of people affected by dementia.

## Raising awareness of staff

There has been a range of activities aimed at raising awareness of staff. In addition to the initial roadshows and information boxes, there have been myth-busting poster campaigns during dementia awareness weeks, and the delivery of dementia friends 4 sessions ([www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)) (see Box 4). A number of staff have also contributed articles to the staff newsletter and the intranet.

In terms of the impact of this work, the vast majority of staff (94 per cent/147) who responded to the survey at the end of Phase 1 stated that their understanding and knowledge about dementia had increased since the work began. 53 per cent (82) said it had increased 'a lot' and 42 per cent (65) said it had increased 'a little'.

## Involving people with dementia

Involving people with dementia and others directly affected by dementia in the process of change has been key to the initiative. People with dementia and carers have been actively involved in several projects across JRF & JRHT including:

- providing their perspectives on how to improve the Folk Hall during a refurbishment programme;
- involvement in writing the brief for, and in the selection and training of, a film production company commissioned by JRF to make a series of films about life with dementia;
- visiting the Homestead Park to give their views;
- auditing the Pavilion, JRF's meeting facilities in York;
- advising JRF's York Committee on its community grant-giving to dementia focused projects.

Involving people with a range of needs and abilities has helped show it is possible to engage those at different stages of dementia, so long as consideration is given to how they can best contribute and what support mechanisms need to be in place (e.g. physically walking round the Folk Hall as well as asking questions). These have also provided more informal opportunities for staff to mix with people with dementia, which has served to increase awareness and challenge attitudes. The value of involving people with dementia as a means of changing people's attitudes and shifting organisational culture should not be underestimated:

*"When you spend time with people with dementia and see them being involved in these sorts of consultations and work...that's the quickest way to change people's perceptions about dementia...it demonstrates to you that it's possible...seeing people doing something you wouldn't expect them to – it's powerful."*

External consultant, dementia specialist.

JRF's approach to involvement of people with dementia has been seen as valuable by external stakeholders:

*"The sense that I get is that it's been done seriously, that they've approached it with conviction and it hasn't been a tick box exercise. It feels to me that they've really meant it and have invested a lot of time and money in this...and I think that may be quite unusual – it's the sort of thing that easily becomes a token exercise...it has felt genuine and not a token effort."*

External consultant, dementia specialist.

Feedback from people with dementia and their carers who have been involved in the work has also been very positive.

*"I'm so grateful for that [involvement with JRF] ...allowing you guys to get some real, real insight into what it's all about...for real people...because that is important. ...it's helped an awful lot...you giving me the opportunity to give you what I know about it and how it feels...it takes me back to that stage when I was in work...and was useful."*

Peter Jones, person living with dementia

*"We get a lot of support and understanding...and patience...that's really important for people with dementia. To feel involved...that you're no longer sidelined...because it's very easy ...to take a person with dementia and their carer and family and sideline everybody ...and we still live a normal life. The main word we like to use is respect ...everyone we have dealt with [at JRF] has treated us with the upmost respect... It's important for me but it's more important for me that I know Peter feels valued and he feels he's giving something back while ever he can....Whatever we've done... we've been listened to, we've been looked after...and that's really important...it's meant that we're still part of society, we're still cared about and that we still have a lot to give and it's recognised that we'll give it. Whatever they ask of us , it's never something that they know we can't do, it's never something that will make us look foolish...and we're always, always valued...They've [JRF] been a joy to work with...we'd never say no."*

Avril Jones, wife of Peter Jones (above)

Peter and Avril also reported how JRF had made involvement easy for them from the start, e.g. arranging practicalities such as taxis to collect them.

Some key factors to consider when enabling the effective involvement of people with dementia have

#### **Box 5: Tips for involving people with dementia**

- Think it through, plan carefully and be committed to the process.
- Build relationships and allow time for conversations with people with dementia.
- Ensure time for informal socialising for people to get to know each other.
- Provide nice food and refreshments.
- Ensure feedback is given to people following their involvement.
- Consider how people with dementia get from A to B and provide transport if needed.
- Consider how you may need to time or pace things differently.
- Be prepared for the financial cost of involvement work (e.g. transport, refreshments).
- Understand what details make a difference for each individual, e.g. meeting in familiar spaces, ensuring familiar faces are around to greet people, writing personal thank you letters.
- See every person as an individual.

also been identified through this work (see Box 5).

In the staff survey, 62 per cent (n = 158) of staff felt JRF/HT is committed to involving people with dementia, with an additional 31 per cent (49) feeling the organisation demonstrates this to some extent.

## Sharing learning and influencing

JRF/JRHT hopes to demonstrate the value and challenges of the approach to other organisations, to influence them and to inspire change. A number of external links with other agencies and programmes of work have helped and supported the work and provide potential opportunities for influencing. These include:

- links developed with University of Stirling's DSDC;
- short film made for Dementia without Walls – Making Our Places and Spaces Dementia Friendly (available at <https://vimeo.com/111215799>)
- influencing other projects in the Dementia without Walls programme;
- learning about involvement of people with dementia through Dementia Engagement and Empowerment Project (DEEP) (<http://dementivoices.org.uk>; Williamson, 2012);
- JRF/JRHT is part of a human resources directors group in York, a forum to share learning;
- JRF/JRHT staff have presented at various high-level conferences including the 2014 UK Dementia Congress, CIH in Scotland, and
- Genio in Dublin;
- human resources staff have played an active part in the national dementia friendly employers' forum (part of the Prime Minister's champions task group) and contributed to a practical guide for employers;
- York Dementia Action Alliance and Dementia Friendly Hartlepool.

## Outcomes and impact

In terms of the outcomes and impact of the work, there have been some clear changes. These include the improvements to the physical environment (e.g. Folk Hall, audit tool) and increased staff awareness and knowledge through the initial roadshows and provision of specific training and awareness raising activities.

The involvement of people with dementia and carers has been effective in that it has served to challenge attitudes and assumptions and led to practical learning to aid good involvement. Links with other agencies and programmes of work have supported the work and provided potential influencing opportunities. The views of external consultants further highlight the value of the work externally:

*"The work of the JRF is really highly respected in the dementia scene...I don't think they'd have that level of respect if they hadn't shone the light on themselves as an organisation and spent money and time on that."*  
External consultant.

In terms of levels of staff awareness of and involvement in the work, the staff survey (n=158) at the end of Phase 1 revealed that the vast majority (99 per cent) had some level of awareness of the dementia friendly work, with almost three quarters (73 per cent /113) reporting they had been very aware of the work. 84 per cent (132) of staff had been involved in the work to some extent. The majority of staff (96 per cent/71) saw the dementia friendly work as relevant to their job role, with 51 per cent (80) feeling it was of great relevance.

While 12 per cent (18) of respondents felt that JRF/HT had a long way to go to become a dementia friendly organisation, 82 per cent (127) felt that JRF/JRHT was making good progress towards becoming a dementia friendly organisation, and 6 per cent (9) indicated they felt JRF/JRHT were 'nearly there'.

## Conclusions and key learning for other organisations seeking to become dementia friendly

The following is a summary of the key learning from the work for other organisations and employers seeking to become more dementia friendly.

### **Increase awareness about dementia and related issues among staff to challenge perceptions and attitudes**

- Use a range of mechanisms and channels to address the needs and interests of different staff groups – not just training.
- Make use of the existing resources and programmes available to raise awareness of dementia (e.g. Dementia Friends, employers guide).
- Make dementia a normal thing to talk about in your organisation.

### **Use an organisation-wide approach and involve all staff**

- Employ community development approaches to achieve more ownership, flexibility of approach and a sense of leadership from the bottom up.
- Engage staff and provide the opportunity for them to contribute in a way that plays to their strengths and interests. This can reveal untapped skills and passions.
- Anticipate and address possible barriers to staff involvement and provide staff with the necessary support to get involved.
- Cultivate staff as ‘dementia champions’ at all levels (from directors to frontline) to maintain momentum for the work.

### **Secure senior management buy-in and support**

- Support good bottom-up staff engagement through directors’ endorsement.
- Build the dementia friendly agenda into business plans and policies – embed the policy in practice and good practices into policies.
- Ensure human resource policies are fit for purpose for people affected by dementia (directly or as carers).
- Link the work to other relevant strategic priorities e.g. diversity and inclusion. What’s good for people with dementia is good for everyone.
- Recognise that the work may expose organisational and cultural blocks but also untapped skills, resources and good practice.



## **Involve people with dementia and their carers**

- This can help to challenge attitudes and assumptions about the capabilities of people with dementia.
- Engage as much as possible and make involvement meaningful. Don't do it 'to' them.
- Make use of the practical learning to aid good involvement e.g. take time, listen.
- Provide staff with support to become confident in involving people with dementia and their carers if necessary.

## **Support staff or services users affected by dementia**

- Support staff, service users or customers who may be directly affected by dementia.
- Show understanding of the needs of staff who are informal carers, and work out how the personal can be supported in a professional context.

## **Ensure the physical environment is welcoming for people with dementia**

- Implement dementia friendly design principles in the places and spaces that staff, services users or customers access. A dementia audit tool may help.
- Be aware that simple practical changes to the physical environment need not be costly and can make a big difference e.g. signage, flooring.

## **Influence service provision**

- Ensure staff are enabled to support and respond appropriately to people with dementia.

## **Share learning and influence others**

- Learn from other organisations and share learning to influence others.
- Allow enough time to achieve impact. This is a long journey.

This paper has described how one organisation has moved forward in its ambition to become more dementia friendly. It has reflected on activities and key lessons learnt along the way which should be helpful to others. Overall, it is hoped that this evaluation will encourage many other organisations and employers to start on their own journey of becoming dementia friendly. This will not always be easy and progress may sometimes be slow – but there is much to be gained.

## **Notes**

- 1 University of Stirling's Dementia Services Development Centre (DSDC), Dementia Design Guides. Available at <http://dementia.stir.ac.uk/design/design-guides>

## **About this paper**

Sarah Frost is an independent evaluator and researcher based in Leeds. This report draws on her formative evaluation of JRF/JRHT's work to become a dementia friendly organisation. The aim of the evaluation was to help JRF/JRHT to learn from the approach and activities they employed to help maximise the impact of the work, and to share the learning from it. The evaluation ran alongside the implementation of the work, from Sept 2013 – May 2015. Methods employed included reviewing existing information sources, interviews with key informants within JRF/JRHT, a staff survey and the development of case studies.





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Alzheimer's Society (2014) *Carers support position statement*. London: Alzheimer's Society. Available at: [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=546](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=546) (accessed on 30 July 2015)

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## Other sources of information

The following are additional good sources of information for organisations seeking to become more dementia friendly;

*Tips for employers who want to be more dementia friendly* (2013). DEEP Guide. Available at: [www.dementiaaction.org.uk/assets/0000/8841/DEEP-Guide-Tips-for-employers.pdf](http://www.dementiaaction.org.uk/assets/0000/8841/DEEP-Guide-Tips-for-employers.pdf)

*Supporting employees who are caring for someone with dementia* (2014). Carers UK. Available at: [www.dementiaaction.org.uk/assets/0000/9168/Supporting\\_employees\\_who\\_are\\_caring\\_for\\_someone\\_with\\_dementia.pdf](http://www.dementiaaction.org.uk/assets/0000/9168/Supporting_employees_who_are_caring_for_someone_with_dementia.pdf)

*Dementia Friendly physical environments checklist*, Dementia Action Alliance. Available at: [www.dementiaaction.org.uk/assets/0000/4334/dementia\\_friendly\\_environments\\_checklist.pdf](http://www.dementiaaction.org.uk/assets/0000/4334/dementia_friendly_environments_checklist.pdf)

*British standard for dementia friendly communities* (2015). Sponsored by the Alzheimer's Society. Available at: [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2790](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2790)

## 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 the JRF.

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Other formats available  
ISSN 0958-3084  
ISBN 978 1 85935 944 0

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