## National Federation of Women's Institutes

Campaign legacy pack





### **Carers Welcome**

# What did the Carers Welcome campaign call for?

The WI's Carers Welcome campaign arose out of an NFWI mandate passed at the 2016 Annual Meeting:

#### Appropriate care in hospitals for people with dementia

"We call upon HM Government and the NHS to provide facilities to enable carers to stay with people with Alzheimer's disease and dementia that have been admitted into hospital". Norley WI, Cheshire Federation

The resolution signalled members' concerns about the quality of hospital dementia care and the urgent need to improve it. Shortly before it was passed, research published by Alzheimer's Society showed that almost 60% of carers report that their loved one with

dementia was not treated with dignity and respect while in hospital. And 92% of carers said their loved one found the hospital environment frightening. Our Carers Welcome campaign called for action to change this.



# What has the WI achieved on this issue?

### Members used their craft skills to support people living with dementia.

As part of the campaign, we invited WI members to knit or craft sensory bands (also known as twiddle muffs) to donate to their local hospital wards or care homes. Sensory bands are designed to bring comfort to those with dementia by triggering senses through the use of different textures, embellishments and colours. Across the country, hundreds of members took part creating sensory bands as well as a variety of tactile items including quilts, aprons, lap mats and comfort teddies. Thanks to the combined efforts of WI members, thousands of resources have now been created that will continue to benefit people with dementia. Turn to page 3 to see how federations and WIs got involved!

### 2. Members raised the profile of the issue of carer access.

Using our 'Carers Welcome' poster, members approached local hospital wards and encouraged them to offer better access to carers. Family carers sometimes don't realise they are allowed on wards outside of normal visiting hours so the poster was also designed to let them know they are welcome. In addition, members joined our letter writing action. This called on acute and mental health hospital providers in England and Wales to outline the steps they are taking to enable carers of people with dementia to stay with their loved ones while they are on the ward.

# The NFWI produced an educational resource for family carers in partnership with the Care Quality Commission (CQC).

Recognising the importance of engaging carers in the care and treatment of their loved ones while in hospital, this booklet was designed to raise awareness of the rights of family carers and what they should expect from a good hospital. The resource is available to download from My WI and the WI website and was sent out to all 6,300 WIs to help spread the message.





Sixpenny Handley's WI's craft club made 40 sensory bands for two local specialist nursing homes



Members of Cottingham WI presenting 75 sensory bands to staff at the Hull Royal Infirmary

# How members got involved in the sensory band challenge



Fidget quilt made by Jeanette Green, Great Missenden Evening WI



Sensory band crafted by a member of Wanstead WI



Members of Wadsley WI with some of the 200 sensory bands they made



Members of Teignmouth WI with their fidget aprons



Halton WI's sensory band presentation



Members of Felpham Evening WI handing over 24 sensory bands and 30 mats to St Richard's Hospital

### What has the WI achieved on this issue?

### **Members became Dementia Friends Champions and** Dementia Friends.

By taking part in one of these programmes run by Alzheimer's Society, members took the campaign as an opportunity to find out what they can personally do to help, whether that be by visiting someone they know who is living with the condition or helping others to understand what it's like to live with dementia.

### **Members forged local** partnerships to improve support for carers.

For example, Lincolnshire North and Lincolnshire South Federations joined forces to target four NHS Trusts in their region and introduce the campaign to them. Federation representatives met with Jennie Negus, the Deputy Chief Nurse with a lead for patient and carer experience across all of United Lincolnshire Hospitals and services. Jennie outlined some practical ways WI members could help in the hospitals and was eager to strike a partnership.

Huntingdon and Peterborough Federation worked alongside Dementia Action Alliance, Alzheimer's Society, the Chair of the Carer's Trust, and an Admiral Nurse to develop comfort packs for carers. Around 300 packs were made for two local hospitals containing all the essential items for an unexpected overnight stay in hospital with a loved one. The initiative has been hugely

appreciated by hospital staff who say the packs offer carers that extra bit of support at what can be a difficult time. The federation continues to work closely with its local hospital trust and has been able to offer support in other ways, such as by knitting hats for new-born babies and adding green to some blankets so that staff can easily identify those at risk of falls.

### In 2018, the NFWI launched a research report into dementia care in hospitals.

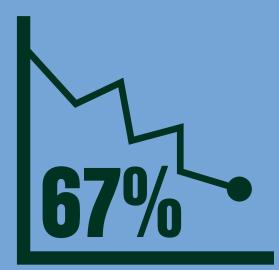
Drawing on the experiences of 221 family carers of people with dementia, our research found that despite pockets of good practice across England and Wales, the quality of dementia care in many hospitals is falling considerably short of accepted standards. With our findings featured by many news outlets including the Daily Telegraph, Daily Express and iNews, the research has undoubtedly helped raise public awareness of the issue and put pressure on hospitals to alter their practices. Following the publication of our report, members have called on their MPs or AMs to take action by raising the findings of our report with their acute hospital provider or Local Health Board. For a summary of our key findings, see page 5. To download the full report visit: https://www.thewi.org.uk/ campaigns/current-campaigns-andinitiatives/carers-welcome

"Flexible visits for dementia carers – plea. Hospitals should make it easier for carers of dementia patients to stay with their loved one outside visiting hours, the WI has said". The Daily Telegraph

"Readers back call from Women's Institute for dementia patients visiting hours to be more open".

Sunderland Echo

# KEY FINDINGS OF THE NFWI'S 2018 RESEARCH REPORT



OF CARERS SAID THEIR LOVED ONE'S ALZHEIMER'S DISEASE OR DEMENTIA BECAME WORSE AS A RESULT OF THEIR STAY IN HOSPITAL 41%

OF CARERS SAID THAT 'ALL OR MOST OF THE TIME' HOSPITAL STAFF DID NOT MEET THEIR LOVED ONE'S CARE NEEDS IN RELATION TO THEIR DEMENTIA

42%

of carers said their loved one was not treated with dignity and respect while in hospital

**37%** 

OF CARERS BELIEVED THAT STAFF DID NOT LISTEN TO AND, WHERE APPROPRIATE, ACT ON THE INFORMATION THEY PROVIDED ABOUT THEIR LOVED ONE



said that hospital staff recognised and valued their role as a carer

66%

of respondents were able to recall a time when the nursing or healthcare needs of their loved one were not met 42%

OF CARERS SAID THAT HOSPITAL STAFF DID NOT SUPPORT THEM AS A CARER

# How you and your WI can take the campaign forward

### Up until 3 May 2019

# Take part in the National Assembly for Wales' Cross-Party Group on dementia inquiry into hospital care.

The Cross-Party Group on dementia would like to hear specifically from people in Wales about their experiences of hospital care for people with dementia. The findings will be used to assess the effectiveness of the recommendations made in the Welsh Government's Dementia Action Plan for Wales (2018-2022). The inquiry will be examining issues such as hospital staff understanding of dementia and experiences of admission and discharge from hospital. If you'd like to contribute to the inquiry which closes in June 2019, please share your feedback with the NFWI-Wales office who will be putting together a response based on members' experiences. Please email: walesoffice@ nfwi-wales.org.uk. Make sure you send in any information by 3 May so that it can be included in our submission.



### **Ongoing**

### Volunteer with Alzheimer's Society by:

#### Becoming a Dementia Friend.

• If you'd like to learn about what it's like to live with dementia and how you can help to create dementia friendly communities, why not become a Dementia Friend? You can watch an online video produced by Alzheimer's Society or attend a face-to-face Dementia Friends information session which usually last an hour.



#### Becoming a Champion.

 As a Champion you'd be trained and supported to run Dementia Friends information sessions locally to help people understand the condition and how they can make a difference.

Anyone can register to take part in these initiatives - you don't need prior knowledge of dementia or any specific experience. To find out more visit https://www.dementiafriends.org.uk/

### Ask staff in your local ward to display our Carers Welcome poster.

NFWI research showed that only a minority of family carers are able to visit their loved one outside of normal visiting hours or have unrestricted access to the ward in which their loved one is staying.

It's possible that in some instances this could be because carers simply aren't told about the policies in place. In 2016, when the Carers Welcome campaign was launched, the NFWI produced a poster for members to display in their local wards, with the permission of hospital staff. It lets everyone know that carers are welcome. Building on the success of this initiative to date, we're asking more WI members to take part. Please contact the Public Affairs Department for copies of the poster.

### Mark Carers Rights Day in November.

Carers Rights Day is about helping carers to find out about their rights and the support they are entitled to. If you are based in England, why not hold an event as a federation and invite a speaker from the National Institute for Health and Care Excellence (NICE) or the CQC to come and talk to members? If you're looking for a speaker in Wales, you could get in touch with Health Inspectorate Wales or Carers Wales.

Alternatively, you might like to host a Dementia Friends Information Session for members of your WI. These sessions are run by Alzheimer's Society volunteers across England and Wales and require 10 or more people to attend. For more information, visit: https://www.dementiafriends.org.uk/WEBRequestInfoSession



### **Contact us**

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