



CARERS
WELCOME

2016 NFWI Resolution:

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

‘By supporting this resolution you can help us encourage hospitals to make tangible changes to policy and practice so carers can make hospital less frightening and more caring. We need you to help us hold hospitals to account.’ Brett Terry, Alzheimer’s Society, NFWI Annual Meeting

Hospital care is letting people with dementia and their carers down

Today 25% of all hospital beds are occupied by someone with dementia. These patients, however, are typically not admitted to hospital directly because of their dementia. Instead, they are usually admitted in order to be treated for a separate condition, such as a fractured bone or an infection. This means that often they are receiving their treatment in wards that have not been designed with their dementia-related needs in mind. To compound this, hospital staff may

be unaware that the patient they are treating even has dementia.

This oversight can have devastating consequences for patients with dementia.

A recent Alzheimer’s Society report found that:

- Almost 60% of carers report that their loved one with dementia was not treated with dignity and understanding in hospital.
- Ninety-two per cent of carers report that their loved one found the hospital environment frightening.
- On average people with dementia stay in hospital twice as long as other patients.
- According to their carer, 47% of dementia patients that go in to hospital are physically less well when they leave and 54% of less well mentally.
- Thirty-three per cent of people with dementia who are in hospital for an unrelated condition never return to their own home.

What is our campaign calling for?

A stay in hospital shouldn't be catastrophic for people with dementia and their families, but we know it often sadly is. WI members overwhelmingly believe that the NFWI and members across the country need to make the case for change. This campaign is not about carer compulsion; the WI recognises that carers need and deserve respite. This campaign is about ensuring the rights and freedoms of carers and safeguarding the dignity of those with dementia.

At a national level: The NFWI will let the Government and NHS Trusts know that WI members are concerned about hospital care for those with dementia and the rights of their carers. The NFWI will harness the experiences of WI members to produce a unique evidence base to support the aims of this resolution and ensure it impacts on national policy moving forward.

At a regional level: The NFWI will help members influence regional decision-makers and clinical leads at NHS Trusts.

At a local level: The NFWI will educate WI members about their rights as carers so that they can make full and appropriate use of the facilities already available to them that will enable them to care for their loved one. WI members can act as agents of change in their own communities to build a relationship with their local hospitals and encourage them to make changes. We will also train interested WI members in how to be dementia champions in their local communities.



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What is dementia?

Dementia is an 'umbrella' term to describe the symptoms of more than 100 conditions that can impair cognitive processes, such as memory, mood, thought, and behaviour. Alzheimer's disease is the most common cause of dementia, but is by no means the only one and its symptoms are varied, complex, and sometimes difficult to diagnose. One of its overarching consequences is that the person afflicted is often less able to care for him or herself as time goes on. Currently there is no cure.

Dementia is a global health crisis with a new case diagnosed worldwide every four seconds. In the UK alone there are 850,000 people living with dementia and that number is expected to rise to over one million in less than five years. Dementia is the leading cause of death for British women and according to

the Department of Health over 20 million people in the UK have a close friend or relative with the condition.

If dementia-care was a country, it would be the world's 18th largest economy, with costs totalling £600 billion per year. In the UK dementia costs total £26.3 billion annually. The NHS pays £4.3 billion, social care covers £10.3 billion, and unpaid family carers assume the remainder. Of the social care costs, the local authority covers £4.5 billion and the rest is paid by people with dementia and their family for various social care services, such as professional carers and residential care home fees.

The intangible costs to families, loved ones, and people with dementia are immeasurably devastating.

The Role of Carers

Over half a million people in the UK act as a primary unpaid carer for someone, usually a family member, who has dementia; the majority of these carers are women. It is estimated that at one point in their life, one in every three people will care for someone with dementia. These unpaid carers save the NHS and local authority social care services an estimated £11 billion annually. They are the expert sources of knowledge about their loved one with dementia.

What rights do carers have in hospital?

Carers have certain rights as set out in the NHS Constitution. Carers are supposed to be consulted in all decisions regarding the care of their loved one and they are also, where appropriate, to be involved in their loved one's care plan. Services should also be tailored to fit

around not only the patient's needs, but their carers' as well. Many carers and hospital staff, however, are unaware of these rights and duties.

The impact of carers for patients with dementia:

Facilitating better access for carers and consulting them in the hospital-based treatment of their loved one – from admission until discharge – has been proven to ensure a better quality of care for patients with dementia and leads to improved outcomes. Many hospitals, however, treat carers like normal visitors and restrict their access to their loved to normal visiting hours only. This means that carers are often unable to provide the care they would like to in a way that works for them and their loved one. There is currently no obligation for hospitals to ensure that their patients with dementia have access to their carer.

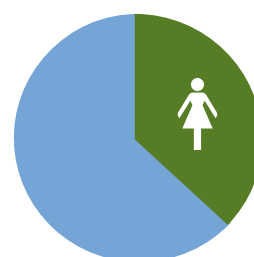
John's Campaign

In 2014 Nicci Gerrard and Julia Jones launched John's Campaign following the harrowing experience of Nicci's father John, who suffered from dementia, in hospital. As Nicci describes:

'My father was a doctor and then a businessman. He was very clever and also enormously competent; he could make things, fix things, solve problems...About 10 years ago he was diagnosed with dementia. It was a slow, but steady decline, with accelerations when he was ill or upset...But he remained largely cheerful...

Then in February [2014] he went into hospital with leg ulcers that weren't responding to antibiotics. He was there for five whole weeks, and for as long as I live I will regret that we didn't understand sooner what this prolonged stay would mean... **He went in strong, mobile, healthy, continent, reasonably**

articulate, cheerful, and able to lead a fulfilled daily life with my mother. He came out skeletal, incontinent, immobile, incoherent, bewildered, quite lost... I am certain that if had not laid in hospital for five weeks, with no one who loved him to take care of him, he would not have descended into such a state of incapacity.' (*The Guardian*, 29 November 2014) John's Campaign is calling for carers of people with dementia to have the same rights as parents of sick children, and be allowed to remain with their loved one in hospital for as long as they feel necessary. Since the launch of the campaign, the then Care and Support Minister wrote to the Chief Executives of all trusts asking them to allow carers to stay on the ward. More than 350 hospitals have now pledged to take action and allow carers greater access. However, it remains unclear what steps they will take or how their progress will be monitored.



36% of WI members
have caring responsibilities.

55% of carers
in the WI don't have confidence that
**NHS and social
care services**

will be able to meet their needs in
the future.



51% of carers
do not think that the NHS is
excellent at caring for those with
mental health issues.

Get involved- things you can do

1 Help us build the evidence base. Policy makers need evidence to support the case for change and incentivise hospitals to alter their practices. If you have experience of caring for someone with dementia who has stayed in hospital in the past 5 years and would be willing to share your experiences as a carer and participate in NFWI research please get in touch with the Public Affairs Department.

2 Knit or craft sensory bands for your local ward! A sensory band is a glove or mitten that has attachments (such as buttons or beads) added on to it that patients with dementia can wear and handle to keep them occupied and calm. Hospital staff say that sensory bands provide a sense of comfort to patients with dementia that they can then take home with them.

Turn over to the next page to see a pattern to get you and your WI crafting! Once you've made the sensory bands, get in touch with your local ward to donate them. Use that opportunity to ask hospital staff or Admiral Nurses how they are welcoming carers on to wards and educate them about the aims of the WI resolution. Make sure you capture photos of your visit to the hospital, and let the Public Affairs team know what your hospital has pledged to do.

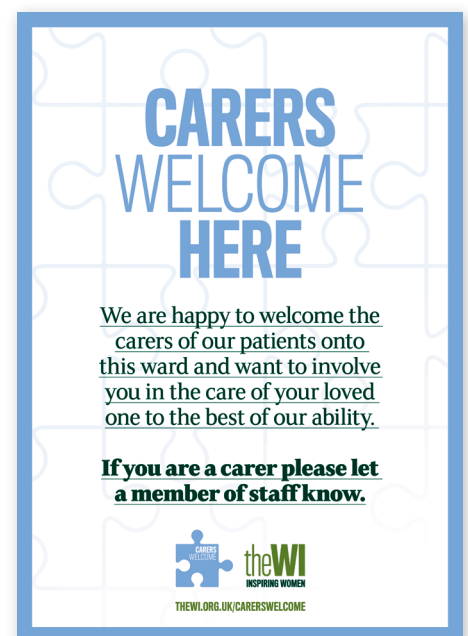
3 Train as a Dementia Friends Champion. Would you like to learn how to champion people with dementia in your community and encourage others to make their homes, communities, and workplaces dementia friendly? Would you like to run training sessions teaching others about dementia and how to

support dementia carers? If so, sign up to attend one of our 'Dementia Friends Champion' training days that will be running throughout 2017. To express an interest in attending, please contact the Public Affairs Department.

4 Encourage your local wards to show that they welcome carers. Many hospital wards do welcome carers at all or extended times, but many carers simply don't know it! A good first and easy step to spread the word is for wards to hang 'Carers Welcome' posters, which lets everyone know that carers are allowed on the ward. Contact the Public Affairs department for a 'Carers Welcome' poster (like you see here) and ask staff in your local wards to display it.

5 Join our John's Campaign CQUIN letter lobby. Introduced in 2009, the Commissioning for Quality and Innovation (CQUIN) payment framework makes a proportion of NHS healthcare provider's income conditional on demonstrating quality improvements in specific areas. John's Campaign (the policy of welcoming carers of those with dementia into wards) is now a local CQUIN for 2016/2017, which means that hospitals that do change practice and allow carers increased access will be financially rewarded for doing so. However, hospitals do not have to take up the CQUIN and it remains unclear what impact it will have in practice.

Join our NFWI CQUIN letter lobby by writing to your local mental health or acute hospital and asking them whether or not they are implementing the CQUIN. Contact the Public Affairs department for a template letter that you can adapt.



Have a go at: Creating a Sensory Band

There's no right or wrong way to make a sensory band. The aim of each one is to create something that will keep hands busy 'remembering.'

Many people with dementia often find comfort in having something for their hands to do, especially those staying in an unfamiliar environment, such as a hospital. Sensory bands can also provide constancy for patients and help calm them.

Since these interactive textiles are meant to stimulate memory, it is important that you trigger the senses by using different textures and embellishments as much as possible. You can create your own original sensory band or you can use the pattern below as an example.

Things to consider

- Think about the kind of texture you want to create with the fabric and pull together different thicknesses of wool and cotton.
- Colour is very important! Bright, cheerful colours are great, but consider contrasting colours as well. Mixing in a really bold colour amongst a muted pallet of colours will draw the eye.
- Don't neglect the inside of the band; attach buttons, hooks, pom poms, or beads to both sides.
- Consider alternating your stitches, mixing up knit and purl stitches can provide some really interesting patterns and textures.
- Make grooves for fingers to run up and down or create holes to insert ribbon or lace; this provides texture for inside and out!
- You can also add a scent to your band. A small fabric parcel attached with a popper so that it can be changed/washed is a good idea; you can insert lavender or scented rice if you wish.



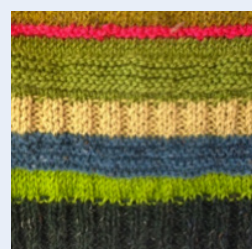
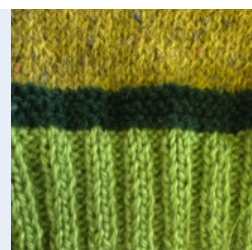
Sensory Band Guidelines

You will need:

- Size 6 or 8 knitting needles
- Selection of wools from DK, cotton and super fine
- Selection of ribbons, buttons, name tags, length of pom pom trim, felt and poppers

- Cast on 70 stitches
- Knit 16 row of rib in a DK wool (K2, P2)
- Row 17 change colour and K for the next 6 rows
- Row 23 change colour and knit 16 rows in stocking stitch (Knit one row, Purl one row)
- Row 39 change colour knit 3 rows (Note you could insert eyelets here if you wish to insert ribbons)
- Row 42 purl
- Row 43 knit
- Row 44 purl
- Row 45 knit

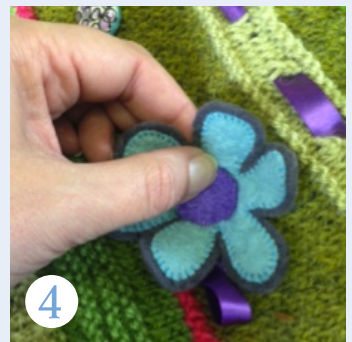
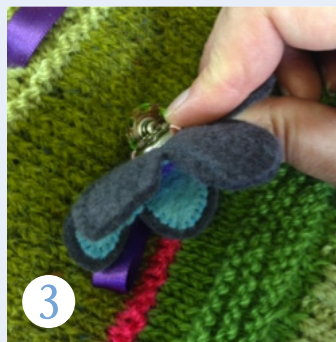
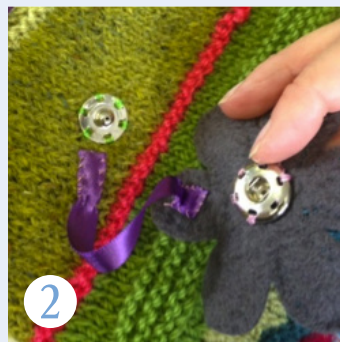
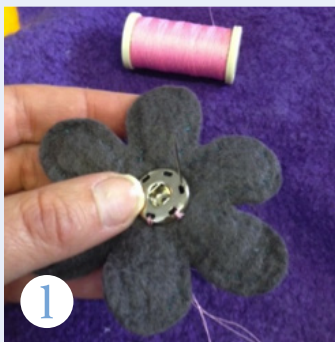
- Row 46 knit
- Row 47 Change colour and knit the next 16 rows in stocking stitch
- Row 63 & 64 Knit a contrasting colour (in this case bright pink in DK)
- Row 65 Change colour and knit 5 rows in stocking stitch
- Row 70 continue in the same colour and knit for 5 rows
- Row 84 K
- Row 85 P
- Row 86 K
- Row 87 P
- Row 88 Change colour and knit in rib for 6 rows
- Row 94 Change colour and knit for the 8 rows
- Row 102 Change colour and continue in stocking stitch for the next 6 rows
- Row 108 Change colour and continue in rib for the next 8 rows
- Cast off



Embellishment of the band

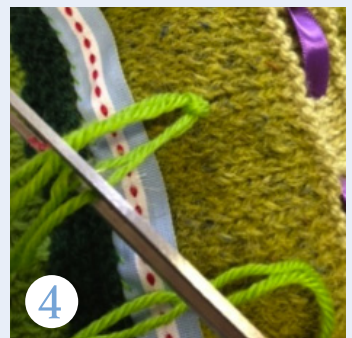
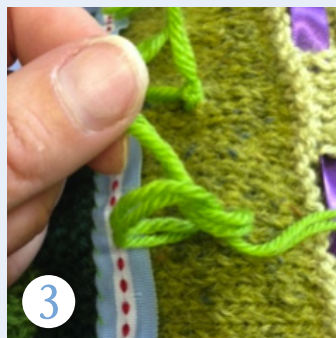
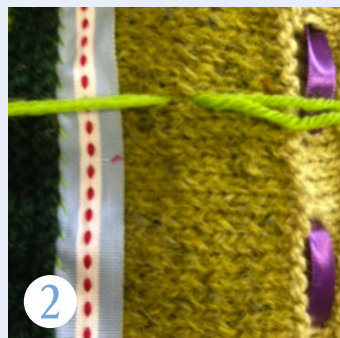
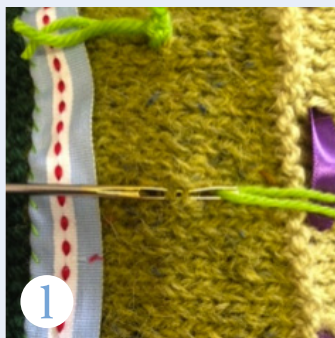
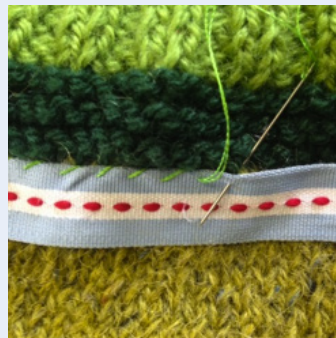
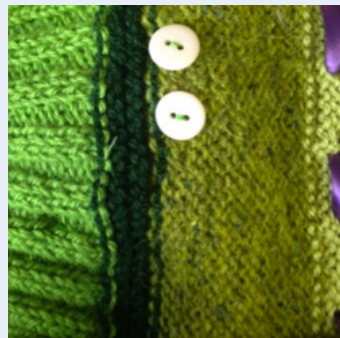
Now you can start to add buttons, ribbons, lace or labels. Really think about the textures, close your eyes and feel where best to place them. If you are thinking of sewing on a button choose a texture that really stands out from your knitting underneath. You could stitch some ribbon

on first to really contrast the textures. We have attached a hand stitched felt flower on the example above using a popper. Here we've attached a piece of ribbon to the flower to prevent it from falling off should the popper be used.



We've hand stitched pieces of ribbon, length of pom pom trim and name labels to the main body of the knitting and to the cuffs, creating different areas for fingers to play with.

Using a large wool needle we've hand stitched through the knitting and tied knots to create threads to play with.

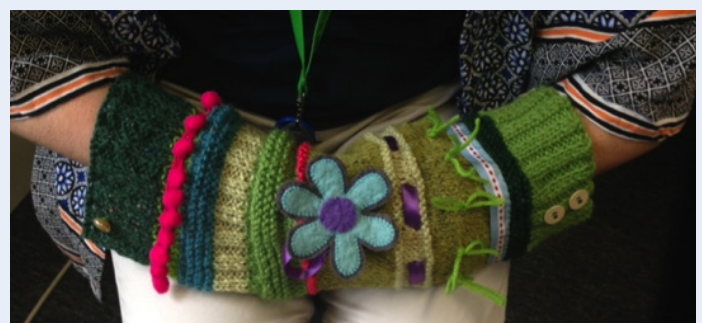


When you are happy with your finished piece, turn the right sides together and hem along the long edge of your knitting. Turn your sleeve through and you are finished!

This are just a suggested pattern, you can create your own and in any way you wish.

Look out for sensory cuffs and sensory cushions on the Moodle!

Created by Clare Spender – August 2016





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