

## Report of discussion from Women and Dementia events

### Summary

This report attempts to summarise discussions at project events in York on 6<sup>th</sup> November and at Dementia Congress in Brighton on 12<sup>th</sup> November 2014.

Assumptions, stereotypes and generalisations about women and gender differences are ingrained in our societies.

These assumptions often lead to expectations about women's roles in the field of dementia. The status of women in society is still perceived differently from the status of men, and this is reflected in the status of caring (both paid and unpaid) and services for people with dementia. This leads to inequalities, a perceived and real exclusion of men, and a lack of choice for many women because of expectations about their roles.

The hope is that changes in the gender balance in society will be reflected in the future of dementia care. However many assumptions about women including their caring role start in childhood.

Without data, information and knowledge we cannot have an informed debate, or begin to change the status of caring.

Gender issues in dementia will not go away. We need to recognise and celebrate differences and acknowledge where assumptions based on gender are harmful.

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The personal is political: women's experiences of dementia is a project funded by the Joseph Rowntree Foundation and run by Innovations in Dementia CIC and the Social Policy Research Unit of the University of York. It runs from January 2014 to September 2015.

## The events

The project event on 6<sup>th</sup> November brought together over 70 women (and three men) from across the country. Ages ranged from a few months old to women in their seventies. Some of the discussions were replicated at a session at Dementia Congress which about 35 people attended.

It is clear from the project to date and the discussions that there are issues around women affected by dementia – both women with a diagnosis of dementia, women who are caring for families and friends, and women in the workplace.

The figures don't lie. The statistics tell us that this is a women's issue.

“If it was all about men, would it be different?”

## Stereotypes, generalisations and assumptions

Any discussion about women will perhaps inevitably be caged in language that includes stereotypes, generalisations and assumptions. Like it or not these stereotypes and ways of thinking about women's roles are ingrained in many of the societies we live in. As with all generalisations, many of these assumptions and stereotypes are true for individuals. Undoubtedly these perceptions affect the choices that are made in the dementia field.

The discussions at the project events threw a spotlight on these assumptions and how these assumptions shape how women affected by dementia live, care and work.

Assumptions and stereotypes about gender differences that affect dementia care include:

**A focus on emotions.** The perception is that women are more in touch with emotions, have more empathy and follow their feelings more. The

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reverse of this: ie being task orientated, focussing on the practical, being scared of showing emotions, are perceived as masculine traits. A nurturing environment is not valued by society.

**Caring comes naturally to women.** There are still stereotypes about male breadwinners and female homemakers. Women are socialised from a young age into caring roles and so are expected to be able to have a caring role. If they can't or don't want to they feel guilty, whereas men who take on a caring role expect acknowledgement for their work and what they have given up. But women may also 'mother' people and over-care. It is acknowledged that some women become serial carers – caring for generations. The perception is that men (especially male decision-makers) don't value caring because they've never done it.

**Women can multitask and see a bigger picture.** There are also perceptions about women being able to multi-task and being able to see a bigger picture, and a perception that men bury their heads in the sand. This assumption affects how women are perceived to cope with a diagnosis of dementia and with caring for someone with dementia.

**Women lack power and voice.** There is a feeling that male carers want to protect their women who have dementia and speak for them, whereas wives may push their husbands with dementia to have active roles out of the house. There is a perception that certain women are less vocal than others – for example women from some BAME communities or women living alone. There is also a perception that female carers and care workers feel powerless and find it hard to advocate for people with dementia. And that female care workers are vulnerable in the workforce.

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## **Status of caring – both paid and unpaid**

Discussion about the status of caring – both paid and unpaid – is not new.

However looking at it through the lens of society's views about women's role can help to develop the debate.

The views of people at the event echoed many studies and reports that have highlighted the need for caring to be valued. There are calls for: more training, more qualifications, a career pathway, financial rewards (not least the living wage for care workers), and for caring to be valued as a profession. A question was raised of whether, if more men were involved in direct care provision, the status of the work would increase.

The assumptions outlined above have a real impact on the perceived value of caring for someone with dementia – in either a paid or non-paid role.

The fact that caring is undervalued can be linked to the language of caring and the caring role reflecting 'natural female' attributes. Caring is a woman's domain not just because of females traits but because care work is often part-time and fits with family commitments. It was also felt that women care workers might 'go the extra mile' ie exceeding the requirements of their paid role in terms of hours worked and the type of work undertaken.

Many women with dementia will benefit from having female care workers, not just in terms of personal care, but in helping them to maintain their identity for example through appearance and dress.

Issues that were highlighted include:

**Recognition of need for emotional support.** Many services for people with dementia and support for carers focuss on the practical. Emotional support is seen as important by women and is not easily available.

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**Female attributes are not valued in care.** Because kindness and empathy as seen as female attributes they are not valued in assessments of care workers' skills. Likewise career paths that mean less time spent with people with dementia may not be attractive to women who want to care and believe that caring is about relationships.

**Lack of support.** Caring is seen to be easy and natural for women, and women are seen as being able to cope with caring and living with dementia. Therefore, the need for support for carers (eg respite or emotional support) is not seen as a priority.

**Financial issues.** Society's undervaluing women in general leads to a lack of recognition of future earning potential and reinforces the thinking that caring is free.

### **Definitions of informal caring**

It was interesting to note that the women with a diagnosis of dementia who attended the event also defined themselves as still supporting and caring for others (as well as often continuing to work in paid or voluntary roles).

There is little discussion about different types of family caring and family carers.

There is a perception that women do hands on caring while male family carers often do financial and practical things.

There is little acknowledgement that people with dementia need lots of different support – and that includes support from carers who do not live with or even near their relative.

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## **A major theme is the expectations around women's roles in dementia**

“I am struck by my own assumptions concerning duty of care – being dismayed when a daughter faced with a parent's diagnosis chose not to care”

The stereotypes of women as first and foremost wives and mothers influence how women with dementia are treated and the services offered to them.

The project discussions have also highlighted the difficulties of the ingrained assumptions that women are 'naturally' good at caring and that society expects women to find the caring role easy.

Many women do want to 'make a difference' and many women do not think of caring as a burden but as a positive choice.

However the assumptions mentioned above often mean that there is an expectation from family and professionals that the women (wives, daughters and even daughters-in-law) in the family will do the caring. There is a feeling of duty and obligation which is not seen so much with male carers.

Assumptions about caring also leave women who are not natural carers in difficult positions full of guilt whichever choice they make.

“As the carer of a younger husband with dementia I was aware of an expectation that I could give up work to care for him”

There was also a feeling that if women develop dementia or take on a caring role, they have less to 'give up' in their lives than men – in terms of career, status or finances.

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## **Exclusion of men**

The discussion recognised that women's issues and experiences are mirrored by those of men.

There was a recognition that care work is not an easy profession for men. Many male care workers are underused, because there is a preference for female carers from people with dementia and their families.

More young men should be encouraged to be carers / care workers.

Male carers need to be given the confidence to care and it is recognised that men who find themselves caring may be learning new skills and may need support networks.

## **Generational differences**

There was a feeling that gender issues used to be at the forefront when talking about caring, but that this is no longer the case.

Many people expressed the hope that any issues around gender are based on generational assumptions. They hope that younger women carers are different from older ones and that young dads (who are hands on with their children) will care for their older relatives automatically.

## **Women living with dementia**

The women who attended the events all want to make it easier for the women who are getting diagnosed after them.

The women with dementia at the event were all working women, but found that the way they coped with their dementia and how it was received and perceived by others could be affected by their gender.

There was a feeling that there is room for women with dementia to support other women about women's issues.

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One care manager commented:

“We believe that we are meeting the needs of women whilst we fail Men in keeping them occupied. Should we have more sheds, work tools etc? But are we actually meeting women's needs through activity such as manicures, baking, music, films etc... Or are there many women who we care for who have past occupational needs that we haven't acknowledged? What about the women with careers prior to having children or retirement. Should we be offering more occupational activity for those people? Should we be inviting more women into the sheds?”

### **Conclusions:**

We need more information to have a more informed discussion:

- More research – and wider research from different angles (eg women's studies), including research into different caring roles, and different support options.
- More data from project evaluations – we want gender to be built into evaluations.
- Include gender issues in research proposals.
- Raise the profile of gender in discussions about health inequalities.

Practice needs to change:

- The system needs to recognise that caring is a choice not an obligation.
- Emotional support for people with dementia and carers needs to be as readily available as practical support.
- Professionals need to change their language and attitudes about women's roles in dementia – both in caring roles and in the services offered to women with dementia.

Awareness raising and education

- We need to work with professionals to explore their assumptions about women and dementia.
- We need to educate women to think differently about caring.

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- We need to work with more women's groups – feminist and more mainstream (mumsnet, WI, DEEP, networks of carers) – to put dementia on the women's agenda.

## Policy

- Policy makers need to accept that dementia disproportionately affects women.
- We need to have a system to value caring – both paid and unpaid – including 'female' attributes such as empathy and kindness.
- Support for families who reduce income to care for relative – eg family allowance
- More nuanced policy to reflect difference.

## Some observations

It is clear that this is a complicated issue. The project debates were nuanced and varied and the above narrative might seem simplified. Some of the complications include:

- The complexities of dementia, the need for person-centred care, and the need to recognise individual needs and experiences which are often not related to gender.
- Other issues – such as age, ethnicity, disability, class, education (intersectionality)
- Different understandings of feminism and framing the issue in terms of women's rights. There is some feeling that framing the above issues in terms of women's rights is not helpful. We need to be careful in the language we use and that we do not exclude or criticise men.

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Innovations in Dementia CIC

5 January 2015

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