



**Innovations  
in Dementia**

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**Report: Consultation meetings with people with dementia and carers**

**On behalf of the College of Social Work**

**25 November 2010**

## **Executive summary**

**The key points emerging from a consultation exercise with 25 people with dementia and carers on behalf of the College of Social Work were:**

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### **Media representation of social work:**

- There was a strong feeling that social work is portrayed very negatively in the media:
- Many people with dementia said that they associated social work with protection issues:

### **Direct experience of social work**

Generally, the experience of others was very positive.

The kind of support people feel they need, or might need from social work includes:

- A single reliable point of contact.
- Assertive outreach
- Practical help with living with dementia.
- Services which properly met the needs of people in earlier stages of dementia.

### **The attributes of effective social work support for people with dementia and carers included:**

- The ability to build a relationship with the person you are working with, so that you can find out what they need to live well:
- Knowledge about dementia:
- Needs to be a specialist in dementia.
- Knowledge about local services
- Understand about risks and rights
- Caring, but also professional, assertive and objective

### **The three most important things which the College of Social Work could do to make things happen for people with dementia and their carers are to:**

- Make sure that social work has proper standards that social workers have to follow
  - Make sure that social workers have the training they need
  - Listen to what people who use services want
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## Background

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Innovations in Dementia (CIC) was commissioned by the College of Social Work to talk to people with dementia and their carers as part of their ongoing consultation about the purpose and functions of the college.

### Recruitment

We contacted people through our newsletter, and through our Think-Tank of people with dementia.

People were invited to give their views either by email or telephone, or at meetings in either London or Swindon.

3 people with dementia and 1 carer attended the meeting in London.

13 people with dementia and 5 carers attended the meeting in Swindon.

2 people with dementia and one carer were interviewed by telephone.

All people with dementia were able to speak for themselves and give informed consent to involvement in the meetings.

### Consultation structure

We wanted to get an idea of people's experience and perception of social work, and what the College could do to make that better.

We made the meetings as informal as possible, loosely structured around six questions, but allowing time and space for individual narrative:

- How do you think social work is portrayed in the media?
- What is your personal experience of social workers?
- What kind of support do you want?
- What kind of values would a social worker need to do this properly?
- What do you think the College of Social Work can do to help make sure that you get the support you want?
- Would you like to be involved in the work of the College as it develops?

## Findings from the consultation

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We asked:

How do you think social work is portrayed in the media?

Social workers are often in the news, or portrayed in films or plays - what are the impressions that stick in your mind?

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Because dementia is a condition which most commonly affects people later in life - many people with dementia will have had very limited or no experience or understanding of social work before their diagnosis. For many people therefore, the way that social work is portrayed in the media is extremely important in forming their views on what social workers actually do, and what it means for them

### 1. There was a strong feeling that social work is portrayed very negatively in the media:

People with dementia -

- “Baby P - that kind of thing is what you hear about”
- “on tv - they are always guilty of being in the wrong”
- “the papers only pick up on problems”

Carers:

- “you only see the bad stuff - the papers like to say they are all incompetent”
- “awful”

### 2. Along with negative representations, many people with dementia said that they associated social work with protection issues:

- “you get the impression that having a social worker means that the police are involved - that you are having your kids taken away from you - you wouldn't want the neighbours to know”
- “Because you only read about what has gone wrong you don't know what social workers do - so when you get older and you might need one - you just forget it - you don't know what they do so you don't ask for help”
- “ I always assumed that social work is about protection, rather than helping people to live well”

**We asked:**

**What is your personal experience of social workers?**

**How did the experience make you feel? What went well - what could have been done better?**

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One couple - a younger person with dementia and their carer had had a very negative experience of social work.

They raised a number of issues, which we will report in detail as they provide an important insight into the reasons why people with dementia and carers say what kind of help they want:

### **1. Lack of awareness of dementia and the impact on the individual:**

Carer -

- “When my husband was first diagnosed - two social workers came to see us - the social worker admitted that she didn’t know anything (about Picks Disease) but said that she looked on line - but the manager who came with her didn’t know anything they didn’t know what the disease was - how it affected him - So then he made a ludicrous suggestions - so despite the fact that as part of my husbands illness he was quite obsessed with anything sexual - the manager suggested that a 16-year old female neighbour could come in and make him a sandwich - despite the fact that the walls were covered in Erotica and he was at that time very, very disinhibited”

### **2. A lack of services and support appropriate to a younger person with dementia**

Person with dementia:

- “When she first came out she offered respite - and meals on wheels - I don’t want respite and I can cook - they only know about older people and I am not the same - it breaks their circle and they don’t know how to come back into it”

### **3. Focusing on the carer rather than the person with dementia**

Carer

- “The social worker refuses to see my husband - because of his condition he says what he thinks - despite the fact that her speciality was (older) people with dementia.
- I find it very offensive - that she looks at me while she is asking a question about my husband - they just don’t seem to understand that he can speak for himself.....and although she was his social worker she always wrote to me despite the fact that he can read and we kept on telling her to talk to him not me”

Person with dementia:

- “when they are presented with someone with dementia who can talk for themselves they are out of their comfort zone - they are scared”

#### 4. Lack of continuity of support

Person with dementia:

- “So I now have no social worker”

Carer:

- “Yes we got a letter saying that she was no longer his social worker but to contact the office if we need anything”

**More generally, the experience of others was overwhelmingly positive:**

People with dementia:

- “Those I have met have been very good”
- “They really helped me through the difficult times”
- “They were supportive and kind”
- “They motivated me to get going again - which I really needed”
- “She was very down to earth very helpful I got the impression she knew exactly what I was going through - which is so important with my dementia. Although contact has now finished - as my problem with behaviour is better - she is based at memory clinic so if I need her again she will be there”

One person with dementia however, felt that it would take a lot for them to make contact with social workers, and explained that:

- “My GP and the Alzheimer’s Society are the people I would go to - I feel that social workers would be very much a last resort - crisis situation only”

Another person with dementia had experienced problems with the support she had received, but explained that this was more to do with workload than the social worker herself:

- “They didn’t seem to understand what was going on for me - but I really think that they had too much responsibility - too much on 1 person”

Despite the overwhelmingly positive views, **a lot of concern was expressed about the “postcode lottery” factor** - and there was a strong feeling that what was available to some was not available to others depending upon where they lived

**We asked:**

**What kind of support would you want - now, or in the future?**

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A number of key issues emerged:

**1. Needing a single reliable point of contact.**

Most people were not actively using social work services, but many felt a real need to be “connected” so that they could receive support if they needed it in the future - whatever the future brings:

People with dementia:

- “it’s like waiting for the car crash” - but when I begin to crash who can I call to ask what to do”
- “I feel quite vulnerable - I’m OK at the moment, but if things did suddenly get worse it would be lovely if I just had a single number I could call to get help”

Carers:

- “I don’t feel like they are on board with us through this journey - and we need them to be - even if we don’t need the kind of help they can offer right now - just to know that someone is keeping an eye on the situation would be great”
- “at times of crisis how do you get help quickly”
- “The biggest thing is that if anything happens to me then my wife has no way of getting help - total isolation - I feel very vulnerable”

**2. There was a strong feeling that social work needed to be proactive in the support it offered:**

Carer:

“Some people with dementia are not able to be active in seeking help - so social workers needs to be much more proactive in offering support and “keeping an eye” just ringing up to see if people are OK would make a really big difference to people’s lives”

**3. Many people mentioned the importance of getting practical help with living with dementia.**

People with dementia:

“Getting the house adapted properly for dementia - I don’t mean in terms of ramps and stuff, but you know, maybe something like an emergence alarm, or help to make it easier to find my way round in the kitchen”

#### 4. There was much discussion of the needs of people in earlier stages of dementia.

People with dementia:

- “when I got my diagnosis, I thought - well now what? What am I supposed to do with myself?”
- “I get the impression that social work is only for older people with very high care needs - only for a crisis - rather than something that will help you to live well in the early stages”
- “When she first came out she offered respite - and meals on wheels - I don't want respite and I can cook - they only know about older people and I am not the same - it breaks their circle and they don't know how to come back into it”
- “give me something to do - that's my problem, that's what I need help with“
- “Yes, I need something to do”
- “even if their role is just to put you in touch with people that can help you in the early stages”
- “I want to live well”

**We asked:**

**What attributes would a social worker need to do this properly?**

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**The ability to build a relationship with the person you are working with, so that you can find out what they need to live well:**

People with dementia

- “I need someone to work with me to find out how to help me to live well - and they can’t do that unless they find out who I am”
- “and they need to know about the range of services - not just respite or meals on wheels - they were trying to fit me into the services they had rather than looking at me as a person and what my needs were”
- I work as a volunteer for the National Trust - and helping people to do that kind of thing really helps - but they need to know you first

Carers

- A little bit of time spent at the beginning getting to know the person and what will work for them will really help in the long run - and might even save money because it keeps people connected to their lives
- They need to be enabled and empowered and that can help them to lead a valuable life

**Knowledge about dementia:**

Carer:

- “if they had understood how dementia affects people that would have made a big difference - or at least have read up on what that dementia is - to turn up on someone’s door and not have an idea about what it entails is not on”

**Needs to be a specialist in dementia.**

There was a lot of support for the idea that there should be specialist social workers for people with dementia .

**Knowledge about local services**

Person with dementia

- “and they need to know about the range of services - not just respite or meals on wheels - they were trying to fit me into the services they had rather than looking at me as a person and what my needs were”

## Understand about risks and rights

Person with dementia:

- “I don’t need to be covered in cotton wool - and I need someone who will understand that I need to stay connected with that part of me”

## Caring professionals

Unsurprisingly, much mention was made of the caring qualities needed by social work professionals. Words like this came up a lot:

- Humanity
- Respect
- Good listener
- Sympathy empathy with patient
- Not cold or uncaring - be a friend
- A good heart

However, there was also a strong feeling that social workers needed to remain professional, and be proactive in the support they offer:

Carers:

- This is not something that the family or friends can do - and there will be times when we need help from someone with a professional knowledge - of services and of, especially things like benefits and all the rules and regulation of getting the right help.
- “Sometimes as family we have too much baggage - we can’t see the wood for the trees and we need someone to tell us what is going on in front of our noses”
- “a lot of the time we hear people say that well - you’re Ok you have each other, you look after each other, and of course you do, but that can never be the whole story, not for everyone - you need someone looking out for you both from the outside”

People with dementia:

- “They need to be decisive and not namby-pamby - sometimes we need a shove.”
- “Sometimes I have really benefited from being strongly encouraged to up my game - there is a place for the “oh dear you poor thing” approach but it needs to be well judged - and sometimes it’s not what you need.”
- “I will need help with areas I have less understanding of and need help from a professional with”

**We asked:**

**What do you think the College of Social Work can do to help make sure that you get the support you want?**

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We asked people to choose from this list the three most important things which the College of Social Work could do to make things happen for people with dementia and carers:

- give advice to social workers on how to do their jobs well
- make sure that social work has proper standards that social workers have to follow
- make sure that social workers have the training they need
- make people proud to be social workers
- make sure that social work is talked about fairly in newspapers and on television
- listen to what people who use services want
- help people to understand what social workers do

There was broad sympathy for:

- give advice to social workers on how to do their jobs well
- make people proud to be social workers
- make sure that social work is talked about fairly in newspapers and on television
- help people to understand what social workers do

But it was generally felt that these were important to social workers, but ultimately not to the same extent for people with dementia and carers.

**The three things which were felt to be most important were:**

- Make sure that social work has proper standards that social workers have to follow
- Make sure that social workers have the training they need
- Listen to what people who use services want

**We asked:**

**Would you like to be involved in the work of the College as it develops?**

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Many people said that they would like to be involved, and would welcome the opportunity to hear more about the college as it develops.

**Innovations in Dementia (CIC) would like to thank all the people with dementia and their carers who shared their thoughts and experiences with us.**

**We would also like to thank Linda Hughes and her team at the Forget-me-not centre in Swindon.**