

# Spring 2015 Directive

## Part 1: Dementia

In the first part of the Directive, we would like you to write about dementia. We are using this term to describe the problems people face when they experience memory loss and difficulties with thinking, problem-solving or language. Please feel free to talk about your own experiences personally or with family members, friends or colleagues. If you have no experience of the topic, then please share your observations and reflections about how dementia patients in the UK are cared for.

Please start each part of your Directive reply on a new sheet of paper with your MO number, sex, age, marital status, the town or village where you live and your occupation or former occupation.

Remember *not to identify yourself or other people* inadvertently within your reply. It is best to use initials instead of real names.

### Memories

Do you have any memories of friends or relatives who had what we now understand to be dementia? Please write about this.

### Understanding and perceptions of dementia

What is your understanding of dementia and how it affects individuals? Where did you gather this knowledge from? (e.g reading, TV, other media, personal experience)

How far do you think the general public are aware of dementia and understand the condition? How do you think this has changed over the last five or ten years?

Do you have concerns about experiencing dementia in the future? Do you do anything to help prevent dementia developing? (eg vitamin supplements, exercises for body and the brain).

### Diagnosis

Where would you go if you or someone you knew needed professional intervention for dementia?

Have you personally had to access services for someone being diagnosed with dementia? How long did it take, what help was offered and was it appropriate?

Were there other types of services or support that you would have liked? Please give details.

## Care

Who should have responsibility for caring for individuals with dementia? E.g. the welfare state, individuals, or should families have to pay for services?

Have you, or has someone close to you, had experience of caring for someone with dementia? Can you describe this? Were family members involved in planning the care? Did you feel the staff involved had the correct knowledge, skills and attitude? Was specialist dementia care accessible?

Have you accessed or arranged care at home, or know people who have? Was enough help available? Was care consistent? Did they see the same person(s)? Were care visits long enough? Were there any services missing?

If you or someone you know has been cared for in hospital, how well did those delivering the care understand the needs of individuals?

Did you feel that the staff involved in the care had the correct knowledge, skills and attitude?

What was your experience of discharge planning and the actual process of discharge?

If someone you know is in a care home, how would you describe the care? Is it of an acceptable standard?

Please share any wider reflections about the current level of care for dementia patients in the UK.

## Relationships

If you have had experience of someone close to you living with dementia, how did it affect the person's relationships with friends, family members, and their partner? (Note: this might include intimate sexual relationships)

What sources of support did individuals concerned find helpful? How do you think services could be better?

## Autonomy

Should individuals with a diagnosis of dementia be allowed to drive? As dementia develops is there a point at which individuals should be stopped from driving? Who should make this judgement?

## Abuse

Are you aware of someone living with dementia who was abused or exploited? Can you describe this situation?

What happened? Who tried to help with this and how did they try to help?

How do you think people with dementia could be safer in the community whilst retaining their independence?

## End of life

If you had a diagnosis of severe dementia, how would you wish to be cared for at the end of your life?

What are your views about Euthanasia and dementia?

If you had a relative or friend with dementia, how would you want them to be cared for at the end of life: for example, psychological, physical, emotional spiritual and or faith etc?

## Part 2: The General Election 2015

A General Election has been called for Thursday 7<sup>th</sup> May 2015. What are your thoughts on this election? Are you excited about the possibilities for change, uninterested or indifferent?

Have you been following the news coverage in the run up to the election? Please give details about what media (newspapers, online, radio etc.) you use to keep up to date with the election news.

Did you watch the televised Leader Debates? What did you make of them?

Will you vote in the election? Do you feel that your vote counts? If you don't intend to vote please explain why.

In your opinion, what are the key issues for the UK? Are there any policies that are particularly important to you and will affect how you vote?

What are your hopes and fears for the next government?

**On the day:** Keep an election diary for Thursday 7<sup>th</sup> May describing your reactions to election issues; newspaper articles; TV or radio programmes and any conversations you have about the election. When the result is finally announced, describe your reaction.

If you come to this Directive after the Election, please write about your memories of the election day and share your thoughts on the new Government.

Please start each part of your Directive reply on a new sheet of paper with your MO number, sex, age, marital status, the town or village where you live and your occupation or former occupation.

**Remember** *not to identify yourself or other people inadvertently within your reply. It is best to use initials instead of real names.*