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Attitudes to and knowledge of Dementia in Northern Ireland

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Contents

Acknowledgement

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Introduction

Dementia has been recognised as a public health priority in Northern Ireland policy documents since 1995 (DHSS, 1995) and the number of people living with dementia is estimated to treble by 2051 (DHSSPS, 2010). The economic costs of dementia are significant as are the costs to families. In 2010 a public consultation was undertaken in Northern Ireland as part of the process of developing a Regional Dementia Strategy (DHSSPS, 2010). This led to the launch of the Regional Strategy in 2011 (DHSSPS, 2011). In the context of current policy interest and the economic, social and personal costs associated with the rising number of people likely to be affected, it is important to explore the views of the general public. It is among the general public that we find those who may, in the future experience dementia personally or within their family and who also face the challenge of paying for, and providing, care. This report provides findings from a survey of the general public in Northern Ireland which explored attitudes to and knowledge of dementia. It was carried out as part of the 2010 Northern Ireland Life and Times Survey (NILT).

The Northern Ireland Life and Times (NILT) Survey is a nationally-representative social attitudes survey including adults aged 18 years or over and 1204 individuals were interviewed in the 2010 survey. More technical details of the survey methodology are given in the technical notes (see Devine, 2011). People living in institutions (though not in private households in such institutions) were excluded from the survey. The survey consisted of a main questionnaire that was undertaken using Computer Assisted Personal Interviewing (CAPI), as well as Computer Assisted Self Interviewing (CASI). The datasets and associated documentation can be obtained from www.ark.ac.uk/nilt .

Knowledge of dementia

Almost half of NILT respondents knew someone personally who had dementia, with about a quarter having a family member with dementia (see Table 1). Some familiarity with the condition is therefore apparent within the Northern Ireland population; however it is clear from other questioning that this does not always translate into a high level of knowledge about the condition.

Table 1: Do you know anybody personally who has dementia?

		%
Yes	Myself	<1
	Family member	24
	Friend	9
	Other	12
No		55

NILT respondents were asked a series of 'quiz' type questions which assessed their level of knowledge about dementia (see Table 2).

Table 2: Knowledge about dementia

		% correct answers
Dementia is a disease of the brain	True	94
Dementia can be cured	False	91
There are drug treatments that help with dementia	True	75
There are many different kinds of dementia	True	72
Dementia is part of the normal process of ageing	False	69
Dementia is another term for Alzheimer's disease	False	36
People who eat healthily and exercise are less likely to get dementia	True	29

There is a widespread basic knowledge of some of the features of dementia. The vast majority of people know that dementia is a disease of the brain and that it cannot be cured. Large majorities are also aware that there are many different kinds of dementia and that there are drug treatments that do help. Most people are aware that dementia is not a normal part of the ageing process; however relatively few people are aware that Alzheimer's disease is not synonymous with dementia and fewer still that people who eat healthily and exercise are less likely to get dementia. This last point is clearly an important message in terms of public education. It should be noted that while Alzheimer's disease is a dementia, not all dementias are Alzheimer's disease and we have coded it as incorrect if people responded 'true' to the statement Dementia is another term for Alzheimer's disease. Given that a significant minority of dementias are vascular related this is a key point to note for public awareness campaigns.

In terms of the overall level of knowledge most respondents were able to answer 5 or 6 items correctly but only a very small minority (3%) gave correct answers to all 7 items – see Table 3. In order to look more closely at differences across the population in levels of knowledge, respondents were classified as 'high', 'medium' or 'low' according to their scores on the dementia 'quiz'. Four or less correct answers was coded as 'low' knowledge, 5 correct answers as 'medium' and 6 or 7 correct answers as 'high'. Although this is a crude distinction it does reveal patterns in knowledge which may be helpful for future policy formulation.

Table 3: Level of knowledge about dementia overall

Number of correct answers	%
0	<1
1	1
2	4
3	12
4	24
5	35
6	22
7	3

There are clear differences across the population in terms of knowledge levels. Table 4 indicates that older people aged 65 or more are much less likely than younger people (aged 18 to 24) to know the facts about dementia. About a fifth of the oldest age group had a high level of knowledge compared with about a third of the youngest age group. Given that the older age group may be closer to facing this condition themselves or for caring for family members with dementia it is important for public education campaigns to be aware of this fact.

Table 4: Levels of knowledge about dementia by age

	18-24 %	25-34 %	35-44 %	45-54 %	55-64 %	65+ %
Knowledge of dementia						
Low	39	38	40	33	44	49
Medium	29	34	32	43	36	32
High	32	28	28	25	20	19

Perhaps unsurprisingly, those with the highest level of academic qualifications were also more likely to have a high level of knowledge compared to those people with no qualifications (see Table 4). This finding is also correlated with the previous one as older people are much more likely to have left school in the years when it was possible to leave without any formal qualifications. However the knowledge gap is even wider here. Individuals who have good GCSE grades or higher qualifications are about twice as likely as those without to know many of the facts about dementia.

Table 5: Levels of knowledge about dementia by highest educational qualification

	Degree %	Higher education %	A level %	GCSE A-C %	GCSE D-G %	No qualifications %
Knowledge of dementia						
Low	27	31	32	40	46	57
Medium	39	40	36	30	40	29
High	34	29	32	30	15	14

The importance of education (including self-education) is further underlined by separating out respondents into those who use the internet at home compared with those who do not. As before, older people will be disproportionately represented in the group who don't have access to or use the internet, but again the results show that people who use the internet at home are more than twice as likely to have a higher knowledge about dementia – Table 6.

Table 6: Levels of knowledge about dementia by internet usage

	Uses internet at home %	No internet at home %
Knowledge of dementia		
Low	34	56
Medium	36	31
High	30	14

For respondents who had direct contact with family members or friends suffering from dementia there was only weak evidence of higher knowledge about the facts of dementia. In many respects this is unsurprising. These individuals may well have built up an impressive knowledge base in terms of interacting with and supporting their family and friends with dementia, but it does not follow that they are therefore more aware of the basic facts or aetiology of the condition itself. Respondents who did not know anyone with dementia were indeed more likely to have low levels of knowledge but it was not the case that people with great personal contact had correspondingly higher levels of knowledge.

Table 7: Levels of knowledge about dementia by personal contact

	Friend or relative with dementia %	Don't know anyone with dementia %	All %
Knowledge of dementia			
Low	37	43	
Medium	37	33	
High	26	24	

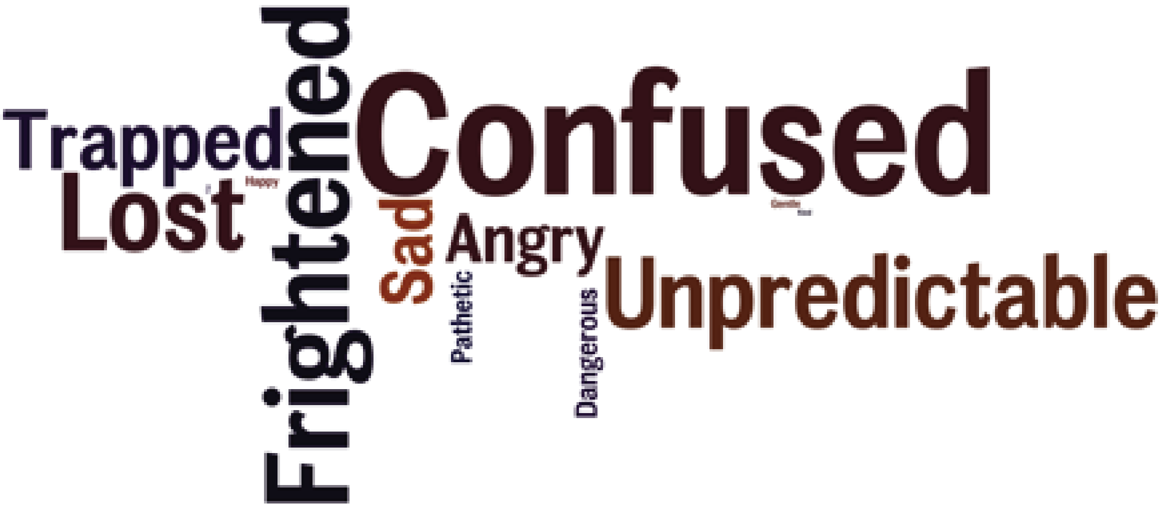
Table 8 shows that there was no difference between men and women in terms of their overall levels of knowledge.

Table 8: Levels of knowledge about dementia among men and women

	Men %	Women %
Knowledge of dementia		
Low	40	41
Medium	35	35
High	25	25

Perceptions of people with dementia

There was a great deal of consensus across the survey participants in terms of how people perceived the characteristics of people with dementia. Respondents were shown a series of words and asked which ones they would use to describe the way that someone who has ‘had dementia for a long time’ appears. The word cloud below demonstrates visually the relative importance of each of the descriptors.



Clearly most people see those in the later stages of dementia as ‘confused’, ‘frightened’, ‘unpredictable’ and ‘lost’. Significant numbers of respondents also used the words ‘trapped’, ‘sad’ and ‘angry’, and small minorities listed ‘dangerous’ and ‘pathetic’. However it was very rare indeed for respondents to list positive attributes such as ‘gentle’, ‘happy’, ‘kind’ or ‘fun’. The total mentions of each of the descriptors are shown in table 9 below.

Table 9: Perceived characteristics of individuals who have had dementia for a long time

	% Yes		% Yes
Confused	90	Dangerous	16
Frightened	62	Pathetic	15
Lost	58	Gentle	6
Unpredictable	52	Happy	7
Trapped	44	Kind	4
Sad	38	Fun	3
Angry	36		

Across the different demographic groups there were subtle differences in the relative strength of feeling about different descriptors but almost without exception the same order of importance was maintained throughout. For example men and women listed the descriptors in almost exactly the same order of frequency, but women tended to select more words on the whole and were distinctly more likely than men to use the attributes ‘frightened’ and ‘sad’, although they did not favour the description ‘pathetic’.

Table 10: Perceived characteristics of individuals who have had dementia for a long time (men and women)

	Men %	Women %
Confused	89	91
Frightened	53	70
Lost	55	62
Unpredictable	50	54
Trapped	40	48
Sad	32	43
Angry	32	40
Dangerous	12	20
Pathetic	17	14
Gentle	5	7
Happy	6	9
Kind	4	4
Fun	2	4

It is people who are aged 55 or more who are more prepared to use the term ‘pathetic’ to describe those with advanced dementia (see Table 11). Still only about a fifth of this group use the descriptor but perhaps they are less concerned about the social acceptability of this term and more conscious of seeing their own generation in this position. However older people tend to select fewer descriptors in general than others and thus perhaps it has more weight because of that. Those respondents in their middle years were more likely to see people with advanced dementia as ‘dangerous’ – though still only about a fifth used this term. Young people were more likely to use the term ‘lost’ and less likely to list ‘angry’ or ‘dangerous’

Table 11: Perceived characteristics of individuals who have had dementia for a long time by age

	18-24 %	25-34 %	35-44 %	45-54 %	55-64 %	65+ %
Confused	82	87	94	92	93	90
Frightened	59	65	72	68	59	46
Lost	72	68	65	61	52	37
Unpredictable	45	54	52	65	54	39
Trapped	44	45	49	51	47	28
Sad	39	38	45	47	31	26
Angry	20	35	47	42	36	30
Dangerous	10	17	22	20	15	9
Pathetic	6	13	16	14	21	21
Gentle	7	9	7	4	4	7
Happy	4	7	9	8	8	7
Kind	4	7	6	4	0	2
Fun	3	4	4	3	1	2

In common with older respondents, those with no educational qualifications were likely to use fewer descriptors in general. That said, it is of course more likely among the older population that people will have left school without formal qualifications. The pattern was similar for those who left school with minimum GCSE qualifications (see Table 12).

Table 12: Perceived characteristics of individuals who have had dementia for a long time by highest educational qualification

	Degree %	Higher education %	A level %	GCSE A-C %	GCSE D-G %	No qualifications %
Confused	92	92	90	93	92	86
Frightened	65	71	65	70	60	49
Lost	70	67	64	60	49	46
Unpredictable	59	61	54	55	48	41
Trapped	53	48	45	47	39	36
Sad	39	38	41	43	36	32
Angry	42	36	32	44	33	31
Dangerous	21	17	18	16	17	12
Pathetic	21	29	11	15	23	12
Gentle	11	4	7	6	5	5
Happy	10	9	5	8	8	7
Kind	7	4	3	2	3	3
Fun	5	4	3	1	3	2

Table 13 shows that people who had no personal contact with someone with dementia also tended to use fewer descriptors in general but the pattern of responses was again consistent in that the same order of mentions was followed throughout. The term ‘angry’ was used more than might be expected given the lower level of responses overall.

Table 13: Perceived characteristics of individuals who have had dementia for a long time by personal contact

	Friend or relative with dementia %	Don’t know anyone with dementia %
Confused	94	86
Frightened	65	59
Lost	62	56
Unpredictable	57	48
Trapped	48	41
Sad	42	34
Angry	39	33
Dangerous	20	13
Pathetic	21	12
Gentle	9	4
Happy	10	5
Kind	6	3
Fun	5	1

People who have no access to the internet at home are, like older people and those with no qualifications, less likely overall to use the descriptors. The order followed is largely the same although the terms ‘sad’ and ‘angry’ were disproportionately more likely to be used (see Table 14).

Table 14: Perceived characteristics of individuals who have had dementia for a long time by internet usage

	Uses internet at home %	No internet at home %	All %
Confused	92	86	90
Frightened	68	47	62
Lost	65	42	58
Unpredictable	56	43	52
Trapped	50	31	44
Sad	39	34	38
Angry	37	33	36
Dangerous	17	14	16
Pathetic	16	13	15
Gentle	7	5	6
Happy	8	7	7
Kind	5	2	4
Fun	4	1	3

Attitudes towards people with dementia

Attitudes towards people with dementia are varied and further work is needed to explore different facets in more detail. On the one hand there is evidence of stigmatising attitudes towards people with dementia. Old stereotypes of the disappearing person or the living shell (Woods, 1989) continue to exist. High percentages of respondents agreed that once they have dementia the person you knew eventually disappears and there comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe (see Table 15). Paternalistic attitudes are widespread with almost three quarters of respondents agreeing with the statement People with dementia are like children and need cared for as you would a child. On the other hand there was also reluctance among many respondents to infringe on the rights of people with dementia. About half felt that other people took over making decisions for people with dementia far too much and a similar proportion agreed that As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more. Seventy one per cent of respondents disagreed with the statement There is no point in trying to talk to people with dementia as they won't be able to understand. About half of respondents disagreed that those newly diagnosed with dementia would be unable to take decisions about their own care. A massive 87% felt that people with dementia should be involved in activities in the community.

Table 15: Attitudes towards people with dementia

	Agree %	Neither agree nor disagree %	Disagree %
There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe.	83	5	11
Other people take over making decisions for people with dementia far too much.	48	26	26
Once they have dementia the person you knew eventually disappears.	75	11	13
As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more.	46	18	35
For people with really bad dementia I don't think life is worth living.	27	19	53
People with dementia are like children and need cared for as you would a child.	73	12	13
People with dementia should be involved in activities in the community	87	9	4
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	34	33	31
There is little or no benefit to be gained from telling someone they have dementia	37	21	41
People who have just been diagnosed with dementia are unable to make decisions about their own care	29	18	52
There is no point in trying to talk to people with dementia as they won't be able to understand	14	14	71

Women have slightly different attitudes to men. They are a little less likely to agree that There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe and more likely to feel that people with dementia are not treated like thinking human beings. They are also distinctly more reluctant to see residential care as the best option. However they are also a little more likely than men to say that eventually the person you knew disappears.

Table 16: Attitudes towards people with dementia (men and women)

'strongly agree' or 'agree'	Men %	Women %	All %
There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe.	86	80	83
Other people take over making decisions for people with dementia far too much.	46	50	48
Once they have dementia the person you knew eventually disappears.	71	78	75
As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more.	42	50	46
For people with really bad dementia I don't think life is worth living.	26	28	27
People with dementia are like children and need cared for as you would a child.	73	74	73
People with dementia should be involved in activities in the community	85	88	87
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	40	28	34
There is little or no benefit to be gained from telling someone they have dementia	38	36	37
People who have just been diagnosed with dementia are unable to make decisions about their own care	32	27	29
There is no point in trying to talk to people with dementia as they won't be able to understand	15	13	14

As shown in Table 17, by far the most paternalistic attitudes towards people with dementia are held by older people. This group is more likely to feel that eventually all you can do for someone with dementia is to keep them clean healthy and safe. They are also more likely to feel that the person you knew eventually disappears and that people with dementia are like children. In addition, they are more likely to see residential care as the best option and many also feel that there is little benefit in telling someone that they have a diagnosis of dementia. Almost half feel that those newly diagnosed are unable to make decisions about their own care and a substantial minority believe that there is no point trying to talk to people with dementia as they won't be able to understand. In contrast, the 18-24 age group are very resistant to the idea that you should not tell people their diagnosis. They are also much less likely to feel that the person you knew disappears and that people with dementia should be treated like children.

Table 17: Attitudes towards people with dementia by age

‘strongly agree’ or ‘agree’	18-24 %	25-34 %	35-44 %	45-54 %	55-64 %	65+ %	
There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe.	81	78	73	81	89	94	83
Other people take over making decisions for people with dementia far too much.	45	47	50	46	48	50	48
Once they have dementia the person you knew eventually disappears.	42	69	76	83	85	81	75
As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more.	47	43	42	47	50	47	46
For people with really bad dementia I don’t think life is worth living.	9	27	21	31	33	33	27
People with dementia are like children and need cared for as you would a child.	51	68	67	78	82	83	73
People with dementia should be involved in activities in the community	92	91	86	88	82	81	87
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	35	35	23	25	38	49	34
There is little or no benefit to be gained from telling someone they have dementia	19	24	28	36	49	58	37
People who have just been diagnosed with dementia are unable to make decisions about their own care	22	24	20	24	31	51	29
There is no point in trying to talk to people with dementia as they won’t be able to understand	9	11	8	12	15	29	14

Respondents with few or no educational qualifications were also likely to display paternalistic attitudes (see Table 18). There was a more widespread sense that people with dementia are like children, unable to understand if you talk to them and unable to make decisions about their own care. This group was also more likely to see little benefit in giving someone a diagnosis of dementia, while residential care was considered more of an option. In contrast, the more educated respondents held opposing views about receiving a diagnosis, making decisions about their own care and their capacity to understand a conversation.

Table 18: Attitudes towards people with dementia by highest educational qualification

‘strongly agree’ or ‘agree’	Degree %	Higher education %	A level %	GCSE A-C %	GCSE D-G %	No qualifications %	All
There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe.	75	78	80	83	92	90	83
Other people take over making decisions for people with dementia far too much.	43	44	48	49	55	50	48
Once they have dementia the person you knew eventually disappears.	72	75	66	77	85	78	75
As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more.	35	39	49	51	51	50	46
For people with really bad dementia I don’t think life is worth living.	21	24	24	28	28	33	27
People with dementia are like children and need cared for as you would a child.	63	68	66	74	79	86	73
People with dementia should be involved in activities in the community	94	86	92	87	83	79	87
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	32	26	36	24	44	43	34
There is little or no benefit to be gained from telling someone they have dementia	25	27	31	34	55	48	37
People who have just been diagnosed with dementia are unable to make decisions about their own care	15	21	25	22	40	46	29
There is no point in trying to talk to people with dementia as they won’t be able to understand	8	7	11	9	17	27	14

Perhaps surprisingly there are no major differences in attitudes between people who have a friend or relative with dementia and others (see Table 19). However respondents who know someone with dementia are slightly more likely to feel that telling someone their diagnosis has little benefit. There is also more of a sense that the person they knew has disappeared and that for someone with really bad dementia life is not worth living. Regardless of whether or not these are judged attitudes perceived as being 'paternalistic', they perhaps reflect some of the pain that family and friends have endured caring for someone with severe dementia.

Table 19: Attitudes towards people with dementia by personal contact

'strongly agree' or 'agree'	Friend or relative with dementia %	Don't know anyone with dementia %	All %
There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe.	83	83	83
Other people take over making decisions for people with dementia far too much.	49	47	48
Once they have dementia the person you knew eventually disappears.	78	72	75
As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more.	45	47	46
For people with really bad dementia I don't think life is worth living.	30	24	27
People with dementia are like children and need cared for as you would a child.	75	71	73
People with dementia should be involved in activities in the community	89	85	87
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	34	34	34
There is little or no benefit to be gained from telling someone they have dementia	41	34	37
People who have just been diagnosed with dementia are unable to make decisions about their own care	30	28	29
There is no point in trying to talk to people with dementia as they won't be able to understand	14	15	14

There are fairly marked differences in attitudes between internet users and others, as indicated in Table 20. The former are less likely than most to feel that all you can do for someone with dementia is to keep then clean, healthy and safe. They are similarly less likely to perceive someone with dementia as like a child and less likely to feel that the person you knew eventually disappears. Internet users are also even more reluctant than others to feel that life is not worth living for sufferers of severe dementia. Residential care is less of an option for this group and they are also less likely to feel that a diagnosis should be kept from people with dementia.

Table 20: Attitudes towards people with dementia by internet usage

	Uses internet at home %	No internet at home %	All %
There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe.	79	91	83
Other people take over making decisions for people with dementia far too much.	46	51	48
Once they have dementia the person you knew eventually disappears.	73	80	75
As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more.	44	51	46
For people with really bad dementia I don't think life is worth living.	22	37	27
People with dementia are like children and need cared for as you would a child.	68	85	73
People with dementia should be involved in activities in the community	89	81	87
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	29	45	34
There is little or no benefit to be gained from telling someone they have dementia	30	53	37
People who have just been diagnosed with dementia are unable to make decisions about their own care	21	47	29
There is no point in trying to talk to people with dementia as they won't be able to understand	9	28	14

Capacity for independent living

Public views on the capacity for people with dementia to live on their own are very clear cut. Table 21 shows that there is very little sense that even those newly diagnosed with dementia have the capacity to live on their own, continue to manage their own medication and carry on driving. Furthermore the majority of people believe that those newly diagnosed should have an electronic device fitted so that they can be located if they wander. To some extent this last survey question in itself implies that 'wandering' is a likelihood, but nonetheless the findings as a whole present quite stark views on the perceived inability of people with dementia to function independently. When respondents were asked to consider the case of someone who has been living with dementia for a long time those respondents who would have argued for the independence of the newly diagnosed join with the rest of the population in advocating restrictions. No driving, no living alone, no responsibility for their own medication and increased agreement with the use of electronic tags.

There are few differences between men and women in their views on this except that women are slightly more likely to believe that those newly diagnosed with dementia could continue to live alone. This is in line with the earlier finding where more women than men were reluctant to advocate residential care.

Table 21: Perceived capacity for independent living (men and women)

'Definitely' or 'probably'	Men %	Women %	All %
Should someone newly diagnosed with dementia…			
Continue to live alone	15	21	18
Continue to manage their own medication	11	14	13
Continue to drive	3	5	4
Have an electronic device fitted so they can be located if they wander	65	64	64
Should someone who has been living with dementia for a long time…			
Continue to live alone	2	3	3
Continue to manage their own medication	2	2	2
Continue to drive	<1	1	1
Have an electronic device fitted so they can be located if they wander	69	69	68

Once again it is the oldest age group that tends to see those with dementia in need of control (see Table 22). Seventy nine percent of the 65+ age group think that someone newly diagnosed with dementia should wear an electronic tag. This is the highest proportion in any of the groups examined here. Interestingly, slightly fewer of this group believe that people who have had dementia for a long time should have an electronic tag. Possibly this is because they believe that those who have had dementia for a long time will be (or should be) in residential care by that stage.

When it comes to views on independent living the youngest age group aligns more closely with the oldest. While young people tend to have attitudes that are in many ways more respectful of the rights of those with dementia, very few advocate continuing to live alone, drive, or manage their own medication. However, again consistent with a rights perspective, they are more reluctant to advocate the use of an electronic tag.

Table 22: Perceived capacity for independent living by age group

	18-24 %	25-34 %	35-44 %	45-54 %	55-64 %	65+ %
Should someone newly diagnosed with dementia…						
Continue to live alone	7	18	22	18	24	14
Continue to manage their own medication	7	15	15	14	14	8
Continue to drive	0	4	5	6	2	5
Have an electronic device fitted so they can be located if they wander	62	64	59	57	66	79
Should someone who has been living with dementia for a long time…						
Continue to live alone	0	4	4	3	3	2
Continue to manage their own medication	2	4	2	2	2	1
Continue to drive	0	1	<1	1	0	1
Have an electronic device fitted so they can be located if they wander	64	70	66	70	68	73

As shown in Table 23, the more educated respondents are, the more they are willing to see a capacity for independent living in those with dementia. Around a quarter of graduates felt that somebody newly diagnosed with dementia could continue to live alone compared with only 12% of people with no formal qualifications. Similarly. graduates were more likely to feel that people could manage their own medication and were more reluctant to advocate the use of an electronic tag. While half of graduates felt that electronic tags should be used for the newly diagnosed, the figure was 73% among those with no formal qualifications.

Table 23: Perceived capacity for independent living by highest educational qualification

	Degree %	Higher education %	A level %	GCSE A-C %	GCSE D-G %	No qualifications %
Should someone newly diagnosed with dementia…						
Continue to live alone	23	26	14	21	12	12
Continue to manage their own medication	19	20	7	14	5	7
Continue to drive	8	5	1	4	6	2
Have an electronic device fitted so they can be located if they wander	50	58	66	66	67	73
Should someone who has been living with dementia for a long time…						
Continue to live alone	4	2	2	3	2	3
Continue to manage their own medication	3	1	1	2	4	2
Continue to drive	1	0	2	1	0	1
Have an electronic device fitted so they can be located if they wander	62	69	68	74	68	71

Personal contact via a friend or relative with dementia makes very little difference when it comes to the perceived capacity for independent living – see Table 24. Those without that personal contact are slightly less likely to believe that people with dementia newly diagnosed can live alone and slightly more likely to advocate an electronic tag, but the differences are small.

Table 24: Perceived capacity for independent living by personal contact

	Friend or relative with dementia	Don't know anyone with dementia	All
	%	%	%
Should someone newly diagnosed with dementia…			
Continue to live alone	20	16	18
Continue to manage their own medication	12	12	13
Continue to drive	4	4	4
Have an electronic device fitted so they can be located if they wander	62	66	64
Should someone who has been living with dementia for a long time…			
Continue to live alone	2	4	63
Continue to manage their own medication	1	3	2
Continue to drive	<1	1	1
Have an electronic device fitted so they can be located if they wander	67	70	68

People who do not use the internet at home are slightly less likely to advocate continued independent living than those who use the internet at home (see Table 25). They are also significantly more likely to advocate electronic tagging of those newly diagnosed with dementia, around three quarters do so compared with just over 60% of internet users.

Table 25: Perceived capacity for independent living by internet usage

	Uses internet at home %	No internet at home %	All %
Should someone newly diagnosed with dementia…			
Continue to live alone	19	15	18
Continue to manage their own medication	14	9	13
Continue to drive	4	3	4
Have an electronic device fitted so they can be located if they wander	61	74	64
Should someone who has been living with dementia for a long time…			
Continue to live alone	3	2	3
Continue to manage their own medication	2	1	2
Continue to drive	1	<1	1
Have an electronic device fitted so they can be located if they wander	68	70	68

Discussion

The results indicate that people in Northern Ireland have a reasonable knowledge of dementia. In terms of public health one of the most significant findings is that over a quarter of those surveyed (28%) viewed dementia as a normal part of ageing and this percentage rose according to the age of participants (42% in 65+ age group). The risk of developing dementia increases with age and a belief that dementia is a normal part of ageing has implications for help-seeking behaviour and the potential for early diagnosis. There is also a low level of awareness (29%) of the link between diet, exercise and prevention, with the percentage dropping significantly among younger adults (16% of the 18-24 year group). Both of these results are significant in terms of targeting public awareness and in the delivery of services.

Attitudinal results indicate that stigmatising attitudes towards people with dementia are common. Old stereotypes of the disappearing person or the living shell (Woods, 1989) continue to exist. By far the most paternalistic attitudes towards people with dementia are held by older people. This group is more likely to feel that eventually all you can do for someone with dementia is to keep them clean healthy and safe. They are also more likely to feel that the person you knew eventually disappears and that people with dementia are like children. In addition, they are more likely to see residential care as the best option and many also feel that there is little benefit in telling someone that they have a diagnosis of dementia. Almost half feel that those newly diagnosed are unable to make decisions about their own care and a substantial minority believe that there is no point trying to talk to people with dementia as they won’t be able to understand.

Nonetheless there are groups within the survey, particularly younger people and the more educated who appear conscious of the rights of the individual and it is noticeable that it is the oldest age group who hold the views most clearly centred around ‘care’ and control of people with dementia. The 18-24 age group are very resistant to the idea that you should not tell people their diagnosis. They are also much less likely to feel that the person you knew disappears and that people with dementia should be treated like children.

There is very little belief in the capacity for those with dementia (even those newly diagnosed) to lead independent lives. Very small proportions of respondents feel that those with dementia have the capacity to live on their own, continue to manage their own medication and carry on driving. Once again it is the oldest age group that tends to see those with dementia in need of control and 79% of the 65+ age group think that someone newly diagnosed with dementia should wear an electronic tag.

The publication of the Dementia Strategy for Northern Ireland at the end of 2011 indicates the level of government concern. Educational policies to improve public knowledge of the aetiology of dementia are important, as well as the delivery of health and social services. While Arai et al (2008) highlight the need to particularly target dissemination of information to groups who traditionally have had less contact with health and social care professionals, such as men, and younger people, many of the findings of the NILT survey indicate that low levels of knowledge and stigmatising attitudes towards people with dementia are most common in the older age groups. Change is essential if those affected are to be encouraged to seek help and support. The findings reported here will inform plans to address stigma appropriately (DHSSPS, 2011:97). There is worldwide recognition that in the absence of a cure and in the context of an ageing population the impact of dementia will be felt among an increasing proportion of the population and dementia strategies emphasise the need to improve public awareness. The data gathered through this survey provides insight on the general public’s current knowledge of dementia and their attitudes towards people with dementia. This information can be used to target public health education policies more effectively and to inform delivery of health and social services.

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