

# Dementia Friendly Communities: Schools and Intergenerational Work

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## **‘Pre-questionnaire’ baseline report**

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# Executive summary

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## Project overview

As part of the Dementia Friendly Communities work within the Prime Minister's Dementia Challenge, 22 schools were engaged in a pilot project aimed at tackling stigma and raising awareness and understanding of dementia in primary and secondary schools.

In order to assess the impact of the pilot project, the Association for Dementia Studies has been commissioned by the NHS West Midlands Strategic Health Authority to carry out an evaluation in three phases:

1. **Baseline** - to establish the initial knowledge of the pupils;
2. **Follow-up** - to see how their knowledge has changed following the implementation of dementia interventions within each school;
3. **Interventions** - to find out information about the interventions and see which were most effective.

This report presents the initial findings from the baseline phase, based on the responses to questionnaires completed prior to any dementia interventions being implemented.

## Summary of findings

- 13 of the 22 participating schools (59%) returned questionnaires, involving nearly 2500 pupils aged 7+ who will go on to take part in the dementia interventions;
- 30% of primary school pupils and 79% of secondary school pupils had heard of dementia, and awareness generally increases with age:
  - Primary school pupils were less likely to know about different types of dementia, and their main understanding was around memory loss;
  - Secondary school pupils had heard of different types of dementia, but Alzheimer's Disease was the most widely known.
- Both primary and secondary school pupils understand that dementia:
  - Does not affect everyone in the same way;
  - Is not a normal part of ageing;
  - Does not prevent people from enjoying a rich quality of life.
- Pupils recognised the importance of caring and the difficulties involved, and although it was seen as a mainly negative experience the carers themselves were respected and supported;
- Only 12% of secondary school pupils had heard of assistive technology;

- 10% of primary school pupils and 33% of secondary school pupils have met someone with dementia, and they tended to be more confident than pupils who had not met someone with dementia;
- Secondary school pupils understood how other people feel about people with dementia and how to address some of the more negative areas;
- There was an awareness of things that can be done to help people with dementia and things that people with dementia can do to improve their own lives.

## Overall conclusions

Basic understanding of dementia was better than anticipated, and this should be consolidated and expanded during the project. The dementia interventions should also aim to build on the range of positive views expressed by the pupils during this initial phase.

Pupils were able to consider both the person with dementia and their carers when discussing dementia, although caring was generally seen in a more negative light. Encouraging pupils to meet people with dementia and their carers could potentially help to increase their confidence and understanding of dementia and the caring role.

The main area where basic knowledge was missing was around assistive technology. This was a largely unknown subject, where the dementia interventions could significantly improve understanding and appreciation.

The project has the potential to affect the dementia awareness of a large number of pupils of all ages, and schools should be encouraged to continue participating in the pilot project. These initial findings provide a good set of baseline measures, and it will be interesting to see the impact of the dementia interventions in subsequent phases of the project.



# Introduction

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## Background to the project

Following the launch of the Prime Minister's Dementia Challenge<sup>1</sup> in March 2012, dementia-friendly communities have been prioritised as one of three national champion groups. As part of this, the Dementia Friendly Communities: Schools and Intergenerational Work project has been undertaken to tackle stigma and raise awareness and understanding of dementia in primary and secondary schools. The project will cover areas such as:

- Understanding dementia
- Appreciating the difficulties of being a carer
- Understanding assistive technologies and their applications

22 schools have been engaged in an initial pilot phase of the project, with each school implementing its own dementia modules and approaches during the academic year 2012-13.

## Evaluation of the pilot project

The project evaluation consists of three key phases:

1. **Baseline** – establish the knowledge of the pupils around dementia before they take part in any dementia modules at school;
2. **Follow-up** – establish the knowledge of the pupils after the dementia modules and compare to the baseline results to measure any changes;
3. **Interventions** – find out details of the dementia modules and approaches used by the schools to see what took place and which were most effective for the pupils.

This report focuses on the baseline phase. The Association for Dementia Studies (ADS) was commissioned by the NHS West Midlands Strategic Health Authority to design and analyse a 'pre-questionnaire' to assess the baseline knowledge of the school pupils. The questionnaire was developed in consultation with a number of teachers to ensure that it

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<sup>1</sup> Department of Health (2012). *Prime Minister's Challenge on Dementia – Delivering major improvements in dementia care and research by 2015*. Available online at <http://www.dh.gov.uk/health/2012/03/pm-dementia-challenge/> (Accessed 26/10/12)

would fit in with existing school guidelines and ways of working, as well as being understandable both by teachers and by pupils.

To cater for the different age ranges covered by the primary and secondary schools, two versions of the questionnaire were produced, although they essentially covered the same areas.

### **The Primary School Questionnaire**

Due to the younger age range of the pupils involved, this Key Stage (KS) 1/2 questionnaire was completed by the teacher as a group or 'circle time' activity, with one questionnaire representing the knowledge of each class. Instructions were sent to each school, together with the questionnaire, indicating that the questionnaire should be completed for each class before any dementia-related teaching began.

### **The Secondary School Questionnaire**

As the pupils are older it was agreed that they would be able to complete their KS3/4 questionnaires individually, rather than at a class level. Instructions were sent to each school, together with the questionnaire, indicating that time should be set aside for the pupils to complete the questionnaires before any dementia-related teaching began.

## **Report Structure**

This report presents the initial baseline findings from the 'pre-questionnaires' which were carried out at the start of the project and does not provide information about the interventions themselves.

The 'pre-questionnaire' results were analysed against a set of Key Performance Indicators (KPI) which have been grouped together under four main areas:

1. Understanding dementia
2. Caring for someone with dementia
3. Assistive and digital technology
4. Meeting someone with dementia

This report is structured with a separate section for each of these main areas, as well as two additional sections. The first of these is a section covering questionnaire response rates and basic demographic information from the participating schools. The main findings from the 'pre-questionnaire' responses are also brought together in a final conclusions section.

# Questionnaire response overview

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## Response rates

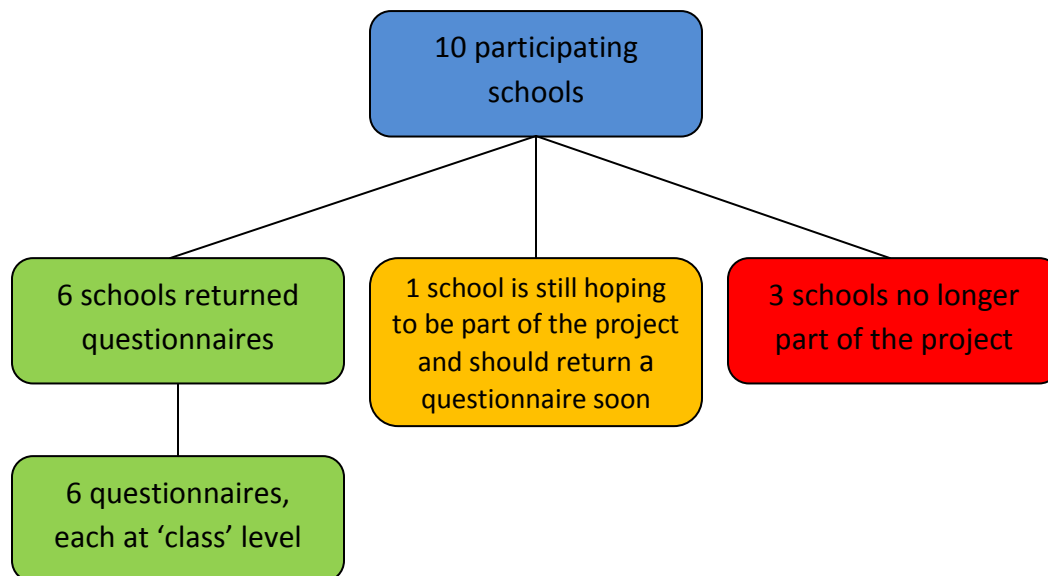
### Overall

Initially 21 schools were part of the pilot group, with an additional school joining in early 2013. These 22 schools comprised 10 primary schools and 12 secondary schools. Early response rates were not overly encouraging despite reminder emails being sent out by the project team. There was also confusion regarding what was being carried out in Devon, which affected up to 7 schools, as it was unclear if they were still part of the project or doing something separately which was being coordinated by a third party.

The most successful approach for eliciting responses was when the evaluation team contacted the schools directly to remind them about the project and to discuss any problems with them. The subsequent response rates are detailed below.

### Primary schools

The situation as of the end of February 2013 is shown in *Figure 1*, and the positive response rate for the primary schools was 60%.



*Figure 1: Responses from primary schools*

Three schools are no longer taking part in the evaluation, with reasons including:

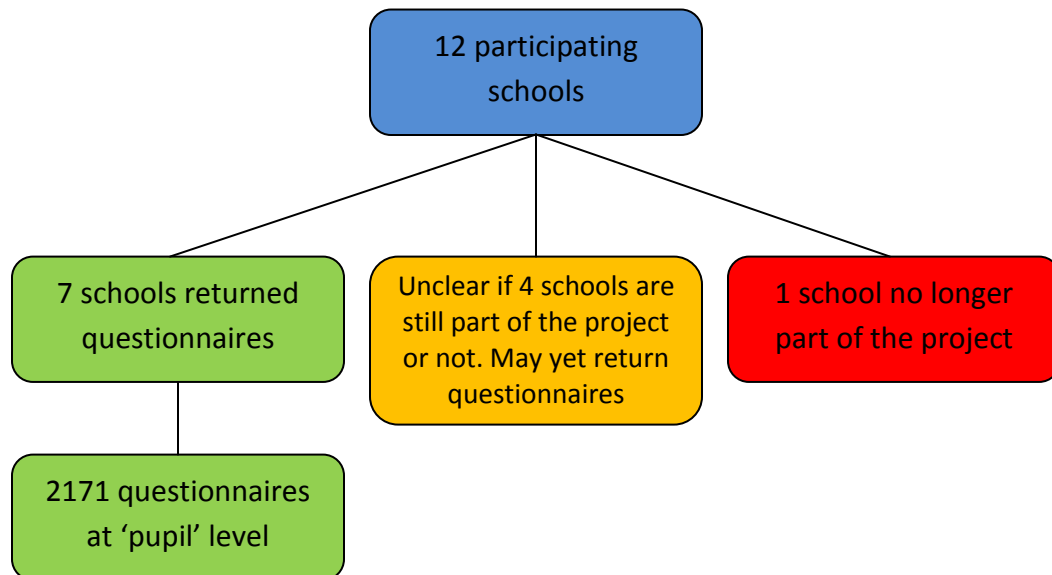
- Too difficult to implement a dementia intervention because of the age of the children;

- Attended a meeting about the project but never received any questionnaires or guidance. The school has now implemented their own curriculum independently of the evaluation.

One school is also still hoping to be involved but did not return its 'pre-questionnaire' in time for inclusion in this report. However, any response will be analysed and included in the report for the next phase of the project.

## Secondary schools

The situation as of the end of February 2013 is shown in *Figure 2*, with a positive response rate of 58%.



*Figure 2: Responses from secondary schools*

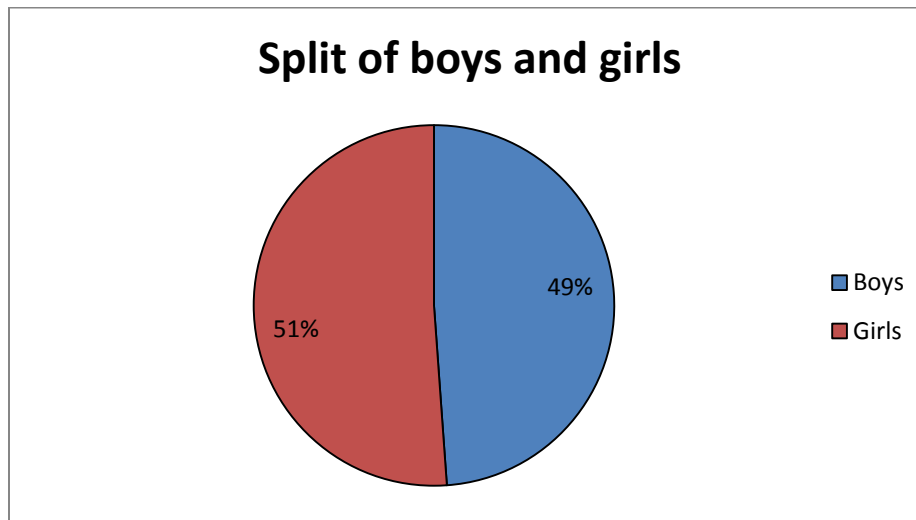
1 school is no longer taking part in the evaluation as they have not had time to do anything yet. However they are still hoping to implement a dementia intervention later in the term. Any responses that are received from the four 'unclear' schools will be analysed and included in the report for the next phase of the project.

## Demographic information

### Primary schools

One school did not give information about the pupils, so the following is based on the responses from the other schools, which covered 219 pupils. As can be seen from *Figure 3*, the boy/girl split was very even at nearly 50% for each. The pupils involved in the primary schools ranged from seven years old up to 11, so no work was done with the youngest potential age groups of 5-6 years old. As indicated by one of the schools no

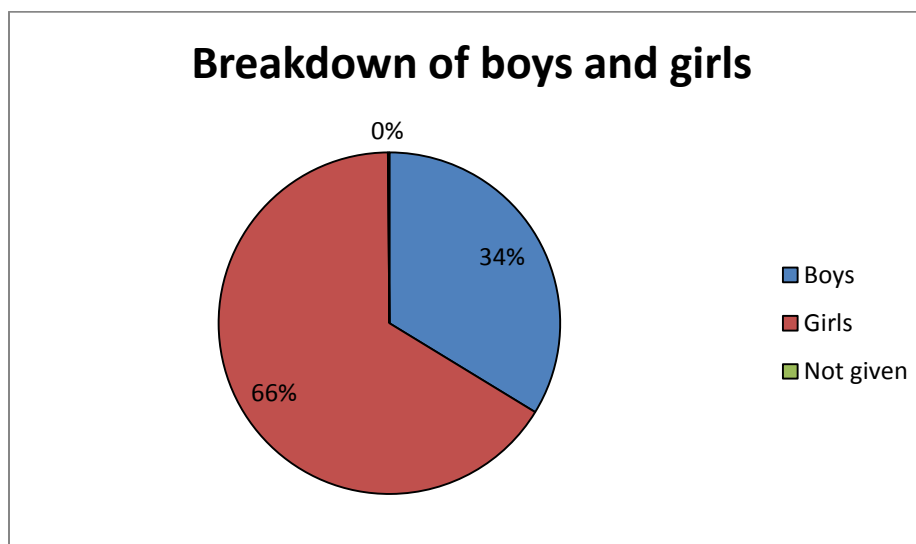
longer participating in the project, this may be because covering the topic with very young pupils could be considered too difficult.



*Figure 3: Primary school split of boys and girls*

### Secondary schools

Figure 4 shows that in the secondary schools nearly twice as many girls as boys completed the questionnaires. This is not surprising as two of the schools involved in the pilot phase were girls' schools.



*Figure 4: Secondary school boys and girls completing individual questionnaires*

As can be seen from Figure 5, 13 year old pupils formed the biggest group age-wise, followed by 12 and 14 year olds.

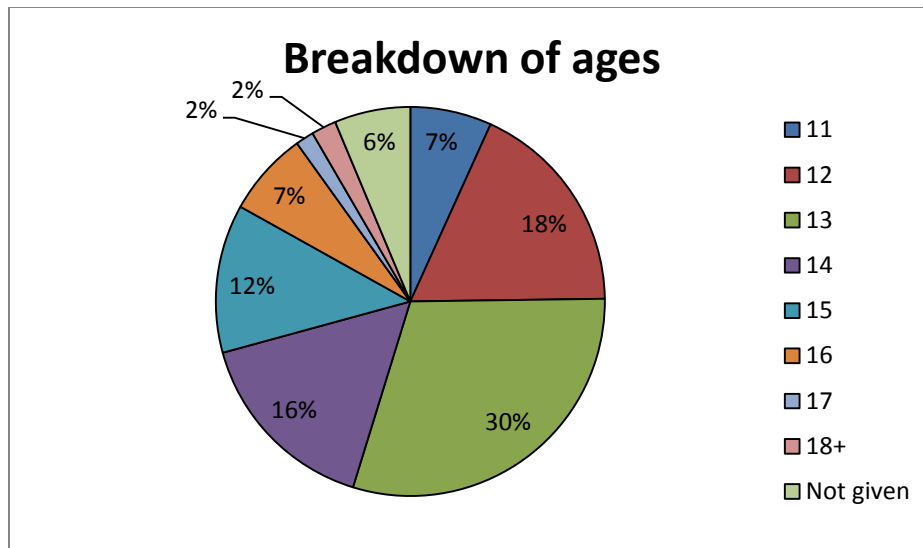


Figure 5: Ages of pupils completing individual questionnaires

Based on the breakdown of ages, it is unsurprising that the year groups most commonly represented were 8 and 9, as shown in Figure 6. It was good to see that the project was implemented across a range of ages and year groups as this will potentially have a wider impact than if it was only aimed at a specific group. However, it should be noted that this is how it was implemented in some individual schools, i.e. the intervention was carried out with a particular class of year group. Conversely, other schools took a 'whole school' approach and introduced their dementia intervention across all year groups and subjects.

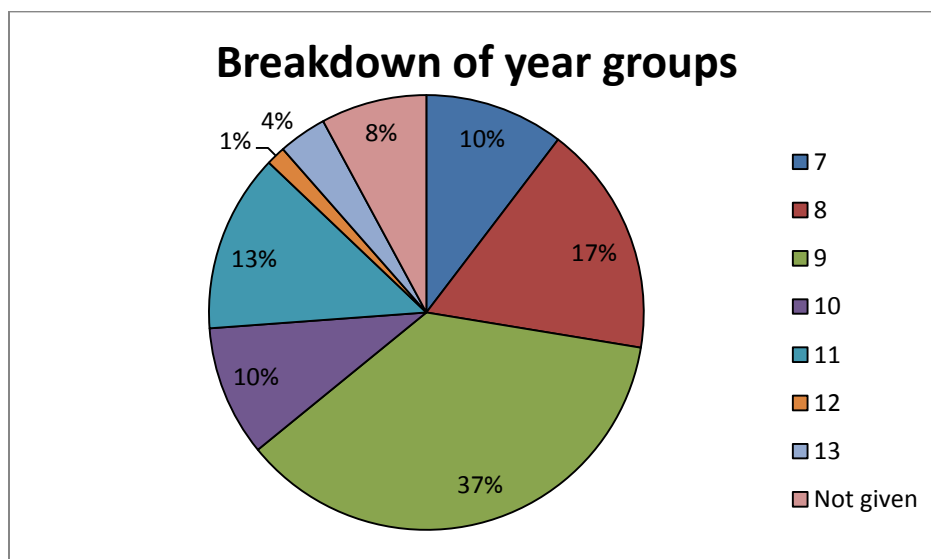
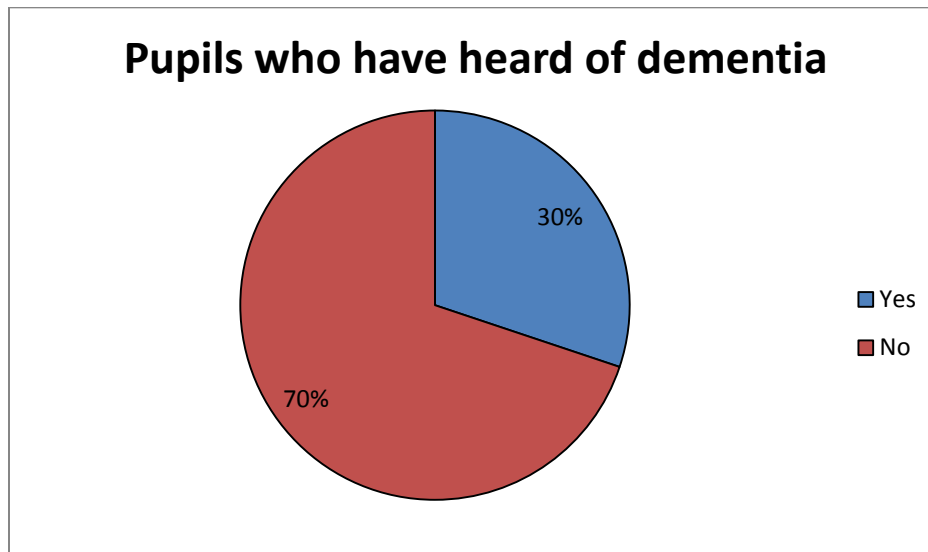


Figure 6: Year groups of pupils completing individual questionnaires

## Basic dementia awareness

### Primary schools

It was completely unknown what previous knowledge of dementia pupils would have, so the 30% of pupils who have heard of dementia as shown in *Figure 7* is very encouraging. It also sets a good baseline level against which the post-intervention questionnaires can be assessed in the next phase of the project.



*Figure 7: Primary school pupils who have heard of dementia*

### Secondary schools

As shown in *Figure 8*, 79% of pupils said that they had heard of dementia which is quite impressive and indicates a level of awareness that was perhaps not fully appreciated. On closer analysis, *Figure 9* demonstrates that there is a general trend that pupils in higher year groups are more likely to have heard of dementia than pupils in lower year groups. Combined with the results for primary schools, this indicates that basic dementia awareness generally increases with age.

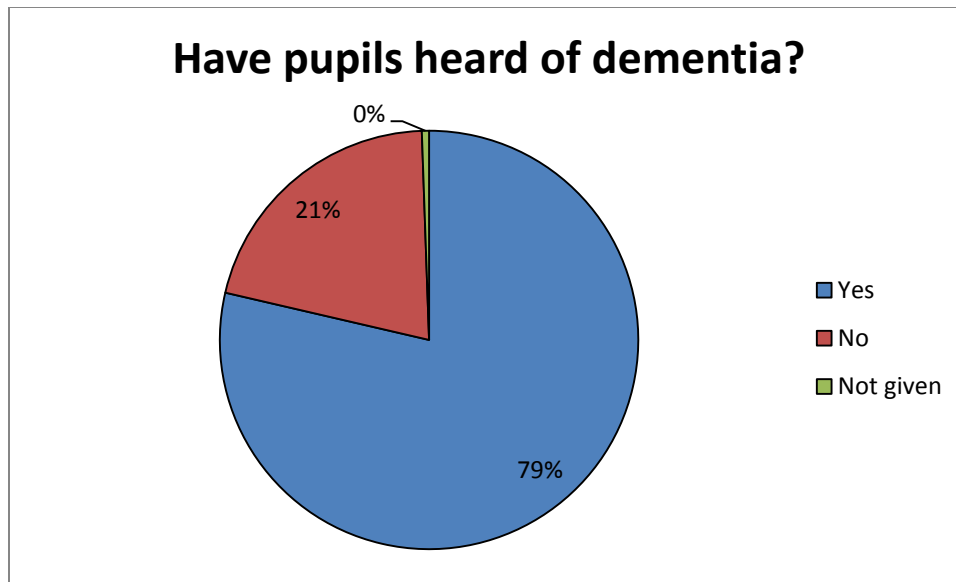


Figure 8: Secondary school pupils who have heard of dementia

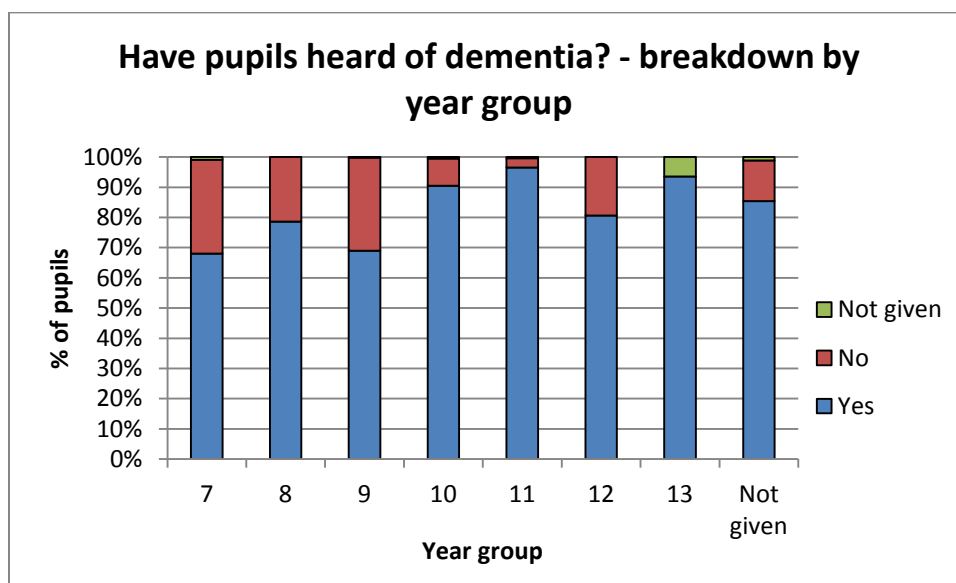


Figure 9: Pupils who have heard of dementia, broken down by year group



# Understanding dementia

## Most pupils have an understanding that there are different forms of dementia

### Primary Schools

As mentioned in the previous section, only 30% of primary school pupils had heard of dementia, but they were still able to describe what they thought it might be like to have dementia. However, their comments related to memory loss and forgetfulness, indicating that this was the only type or symptom of dementia that they were aware of. For example, “people with dementure [sic] can’t remember any new information” and it’s “sad because you don’t know who your family are”. The pupils generally felt that having dementia would be confusing, frustrating, upsetting, tiring and sad.

### Secondary Schools

Pupils were asked which types of dementia they had heard of, and as shown in *Figure 10* the most commonly known was Alzheimer’s Disease. However, Parkinson’s Disease Dementia was also known by quite a few pupils, and indeed all of the options given in the questionnaire were chosen by at least 100 pupils. This indicates that although pupils may not know details about the different types of dementia, they are at least aware of and appreciate that there is more than one type.

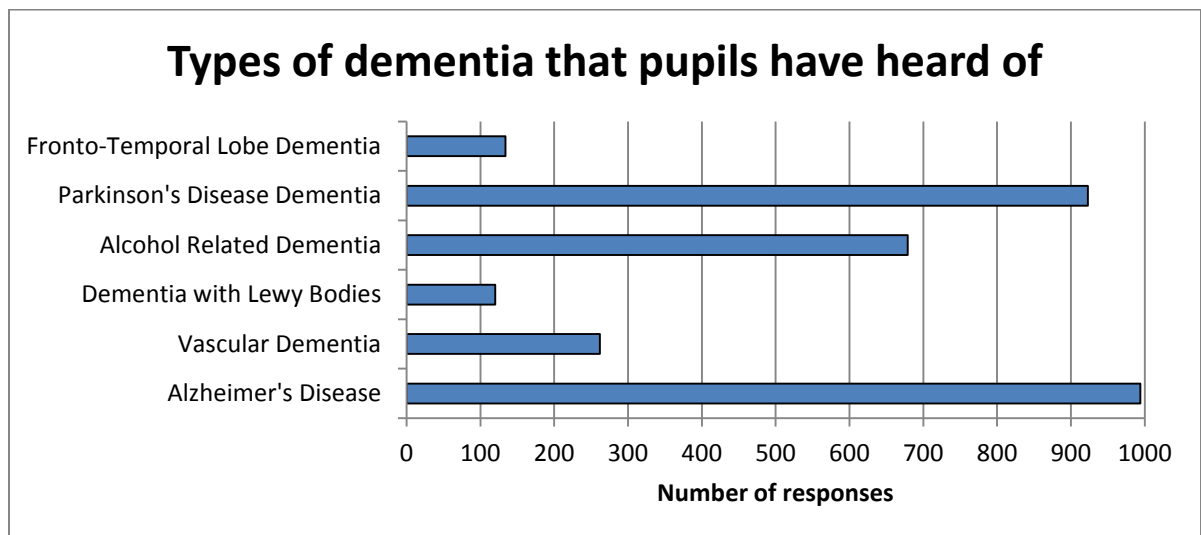


Figure 10: Types of dementia that secondary school pupils have heard of

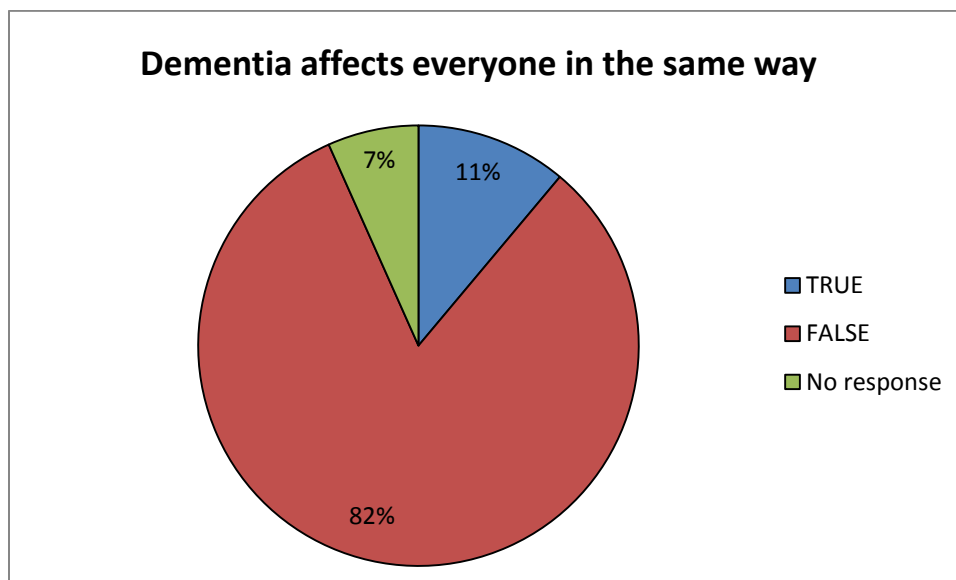
## Most pupils understand that dementia is not the same for everyone

### Primary Schools

Across all six schools, only six pupils agreed that dementia affects everyone in the same way, indicating that the vast majority think that dementia is not the same for everyone. The range of words used by the pupils in comments about what it's like to have dementia could also be seen as an indication that they think different people experience dementia in different ways, although they are all fairly negative. They included: annoying, frustrating, embarrassing, forgetful, sad, strange, weird, scary, tough, stressed, hard, painful, trapped, lonely, unliked, struggling with life, confused, upsetting, tiring, vulnerable, worried, unhappy, nervous, puzzled, depressed, dreadful.

### Secondary Schools

As seen in *Figure 11*, the vast majority of pupils said that dementia does not affect everyone in the same way, indicating that they see dementia as being a very individual illness.



*Figure 11: Secondary school responses to 'Dementia affects everyone in the same way'*

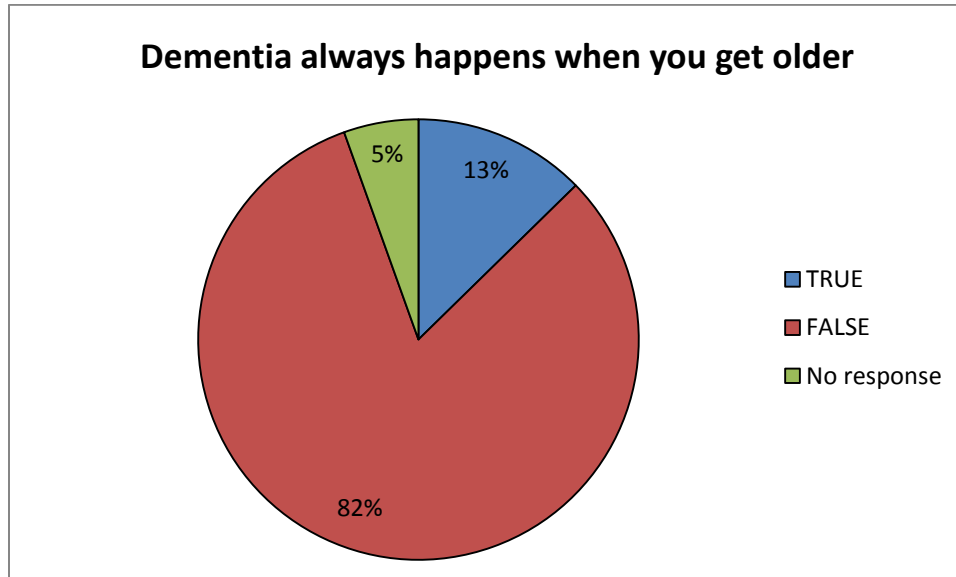
## Most pupils understand that dementia is not a normal part of ageing

### Primary Schools

In a similar way to the previous statement, only five pupils across the six primary schools agreed that dementia always happens when you get older, indicating that the vast majority do not think it is a normal part of ageing.

## Secondary Schools

As shown in *Figure 12*, the vast majority of secondary school pupils said that dementia does not always happen when you get older, showing that they agree with the primary school pupils.



*Figure 12: Secondary school responses to 'Dementia always happens when you get older'*

## Most pupils understand that people with dementia can enjoy a rich quality of life

### Primary Schools

Although 17 pupils agreed that there is nothing you can do to improve your life if you get dementia, this was again across all six schools indicating that most pupils felt that people with dementia can enjoy a rich quality of life.

### Secondary Schools

The vast majority of pupils felt that there is something you can do to improve your life if you get dementia, but the responses in *Figure 13* show that slightly fewer pupils had this positive opinion than for previous statements.

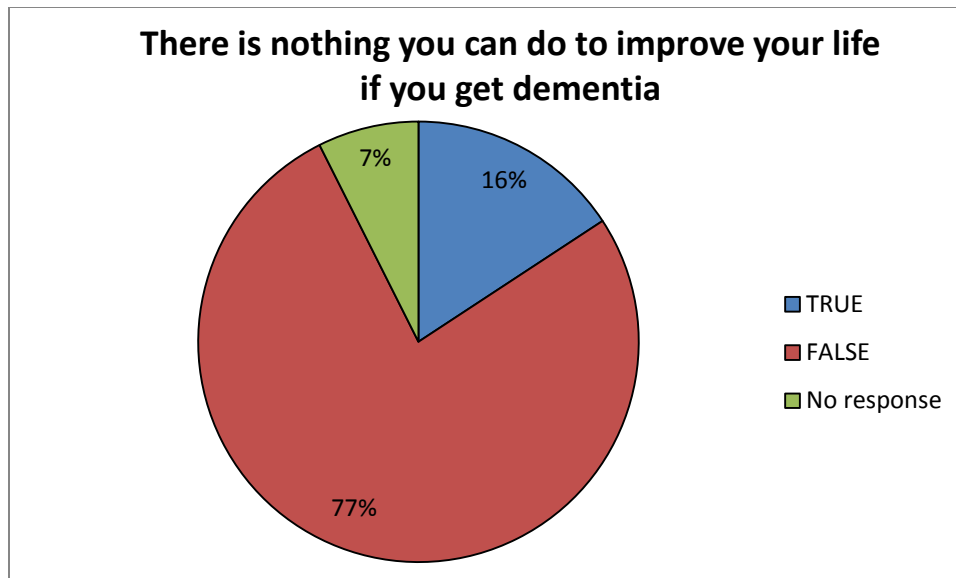


Figure 13: Secondary school responses to 'There is nothing you can do to improve your life if you get dementia'

The pupils across all secondary schools also displayed an appreciation that a person with dementia could enjoy a whole range of activities just as any 'normal' person would as their dementia *"doesn't effect [sic] what they'd enjoy"*. This was summed up by the response given by one pupil who said that people with dementia might enjoy *"bowling, having tea/coffee, being together and making friends with other people in the home, chatting about things, sharing memories/things they worry about, talk about family"*.

### ***Calm and relaxing***

Pupils thought that people with dementia would enjoy activities that were calm and relaxing, such as *"lying in bed, sitting down, resting, not doing anything physical"* or even just *"a cup of tea or a warm bath"*. Many activities they mentioned were solitary activities like sewing, reading, knitting and painting, and tended to be based indoors rather than outside. The types of activity given as examples by the pupils indicated that they thought people with dementia were still capable of being creative. There were however some conflicting views as to whether the activities could be mentally challenging or not, with some pupils saying that people with dementia would enjoy *"problem solving"*, chess, board games and jigsaw puzzles, while others thought that *"easy things"* and *"simple puzzles and games"* would be better.

The idea of repetition was mentioned by some pupils, indicating that they had made a connection between dementia and memory loss, with one pupil saying that a person with dementia would like *"reading the newspaper over and over again"*. An

understanding of dementia as an illness was also shown with some pupils saying that people with dementia would like *“to be cared for and looked after”*.

### ***Active and social***

In contrast to the calm and relaxing activities, many pupils said that people with dementia would enjoy doing things that were more active or had a social element to them and just *“being included”* would make a difference. Keeping physically active by going swimming or doing *“chair aerobics”* was mentioned, as was taking part in *“group activities with others that have dementia”* such as sports, bingo, dancing and cooking. Many activities were connected to the outdoors with gardening and walking rating highly, while going out on trips was also mentioned by a number of pupils.

The importance of *“doing things with your family”* was also raised by many pupils with one saying that *“spending time with your loved one if you forgot them or not”* would be enjoyable for someone with dementia. In addition to family, *“meeting new people”* was seen as an enjoyable social activity, and indeed the idea of *“trying new things”* or *“something they’d always wanted to do”* came up a number of times indicating that the pupils considered people with dementia to be capable of benefiting from new experiences. A common theme for many pupils was that of fun and enjoyment, in that people with dementia would enjoy *“something fun”*, *“fun days out”* and doing *“fun stuff altogether really”*.

### ***Keeping busy***

Although many pupils gave examples of activities or were able to describe the type of activity, a minority expressed the opinion that the activity itself did not necessarily matter, but the concept of *“keeping them occupied”* was more important and people with dementia could do *“anything to keep them busy”*.

### ***Managing the impact of dementia***

A number of pupils demonstrated an understanding of dementia and how to manage its impact to some extent through the use of *“memory games”* and reminiscence activities. These activities generally revolved around *“looking through old pictures they have”* and *“talking about there [sic] life”*.

Despite recognising that dementia affects people, the pupils very strongly saw people with dementia as being ‘normal’ and the same everyone else. This was reflected through the fact that they felt a person with dementia would enjoy *“anything a person without dementia would enjoy”*, *“normal stuff as they are still normal people”*, and *“just*

*because they have dementia they could still like anything". However the impact of dementia was not ignored as indicated by one pupil "they can do or participate in most thing any ordinary person can do, but some things could be difficult for them due to dementia".*

In addition, many pupils did not appear to consider that having dementia actually changes who you are as a person. For example, people with dementia would enjoy *"things that they enjoyed before they got dementia"* and *"doing things they did when they were younger"*. Even when the effects of dementia were acknowledged, such as memory loss, a few pupils managed to see the positive side saying that people with dementia would like *"not remembering the bad things"* that had happened to them.

### ***Person-centred approach***

Although most pupils appeared to see people with dementia as a group who would enjoy a range of activities, some pupils displayed a more person-centred understanding, seeing people with dementia as individuals. For example, one pupil said that they did not know what a person with dementia would enjoy *"as they all have diff[e]rent personalitys [sic]"*, while another said the activity would depend *"on their likes and dislikes"*. Another pupil said *"as dementia doesn't always affect people in the same way it'd be down to the person to know what they might enjoy"*.

### ***What people with dementia do not like***

As well as saying what people with dementia might like to do, some pupils expressed quite strong opinions regarding what they do not like doing. While going into a care home was not seen in a favourable light, the main area mentioned was around inactivity and the impact that would have. *"One thing they would not like would be to just sit in bed or sit in a chair all day because that might make them feel depressed because they feel like they can't do anything and that wouldn't be very good on top of the dementia"*.

### ***Pessimistic view***

Although the vast majority of pupils who responded to this question gave quite positive answers, a small number expressed pessimistic views about people with dementia and focussing on the negative effects, saying that they would enjoy *"nothing really, they forget everything"*. One pupil said that *"it must be frustrating trying to teach them something they might enjoy when they forget every time"*.

## **Most pupils have an appreciation of what can be done to help people with dementia**

### **Primary Schools**

Although one school said that pupils didn't know what could be done to help people with dementia as they didn't know what dementia was, comments from the other schools covered a range of ideas from pupils. These included practical assistance such as helping to care for them, feeding them, taking them to hospital or to see a doctor and raising money, and memory prompts like writing things down or having an iPad with reminders on.

The idea of reminiscence also came up in terms of talking about memories with family and showing them pictures of things, but there was also an overall feeling of just being nice to them and making them feel special. All of these comments indicate that the primary school pupils appreciate that there are many things that can be done to help people with dementia.

### **Secondary Schools**

#### **Helping people with dementia**

The secondary school pupils displayed a good overall understanding of dementia and highlighted a number of ways in which they felt people with dementia could be helped.

#### ***Minimising the impact***

Although not strictly responding to the idea of helping a person with dementia, a number of pupils commented on being able to reduce your chances of developing dementia in the first place by paying attention to different lifestyle factors and following a healthy lifestyle. *"People should pay attention to what they eat and drink"* and in particular the impact of alcohol was mentioned, *"try not to drink alcohol or drink and get drunk every night because it damages the brain cells"*.

Pupils were aware of the importance of early diagnosis, saying that people should *"go to the GP straight away when they get the symptoms"*, although they were slightly confused about the benefit as some felt that *"if you see it early I think it can be stopped"*. Having said that, the responses from many pupils indicated that they were aware there is currently no cure for dementia, but that there are *"tablets or medicine that slow down the progression of the disease"*. This was quite a sophisticated level of understanding that was not expected from the pupils.



### **Communication**

Many pupils saw communication as an important way of helping people with dementia and a way of maintaining normality, saying that you should *“listen and talk to them and treat them normally”*. It was interesting though that comments often said ‘talk to’ rather than ‘talk with’, although this may be more to do with the age of the pupils than a deliberate choice of words. The way people communicate and interact with people with dementia was picked up on by some pupils, with one saying that we should *“not treat them like children who need help, but adults who need help”*. This is quite an astute observation bearing in mind the age range of the pupils involved.

### **Care and support**

The need to provide people with dementia with *“the best possible care to suit their needs”* and *“make there [sic] quality of life better”* was the main area raised by pupils across all schools, and was mentioned from a number of different perspectives. In terms of overall care, it was considered important to show *“patience, support, reassurance, guidance”* and to *“make sure they are always being cared for and have what they need”*. Generally just being kind and nice to a person with dementia was commented on, with one pupil saying that *“even if they don’t remember them [friends and family] they may still recognise that someone cares”*.

Helping a person with dementia to remain independent was another area raised by the pupils, although it was seen from different angles with some pupils indicating a proactive approach where they should *“adapt task[s] so they can keep some independence”* while others suggested that help should not be forced on people with dementia but *“let them do what they want and help them when they ask”*.

In terms of who should provide care, both the family and professional options were covered. *“Regular contact with family members”* was seen as an important factor, as was having *“your family around you to support you”*. It was also felt that people with dementia could have a carer, but *“not someone from a care home, a close member of the family, to comfort them”* indicating the value that the pupils put on family involvement.

From a professional perspective, a number of different roles were mentioned including nurses, specialists, GPs and care assistants, although the need for *“correct training”* and professionals *“who understand dementia”* was important. One area that saw families and professionals working together was the idea of support groups. This was raised by a number of pupils who felt that it would be useful for people with dementia to *“talk to a*



*doctor or relative” or to “talk to people that can help with your problem or other people with the same condition”.*

Place of care was also considered, with both hospitals and care homes mentioned, although the pupils again said that they needed to be appropriate for people with dementia as *“care homes should have facilities and workers that understand their conditions”*. Care homes were an interesting area with pupils expressing both positive and negative opinions. The positive views of care homes were that they were places where people with dementia *“can have proper help”*, and they were not necessarily the default option for a person with dementia but almost a last resort *“if they get really bad”*. Conversely, some pupils were adamant that there should be *“NO NURSING HOMES FOR PEOPLE WITH DEMENTIA”*, saying *“don’t put them in a care home they are better off[f] with family & friends”*.

### ***Being active***

Being active and taking part in activities was another area that pupils felt could provide a way of helping people with dementia, and mental, physical and social activities were all mentioned by the pupils. For example, *“encourage them to participate in mind challenging activities”*, *“keep them active if possible”* and have an *“active social life”*. It was even felt that activities could help people to maintain a positive outlook, *“encourage them to stay active and not to give up on everything”*.

### ***Memory techniques and reminiscence***

Various reminiscence activities were mentioned by the pupils, including looking at *“photographs of them & their life”* and having *“a box of memories and show them daily”*. They also covered different techniques *“to help jog their memory”* and ways of coping with dementia such as *“special clocks that say the date and time”* and putting up *“signs around the house so you remember what to do and not to do/touch”*. The pupils were effectively describing assistive technology, although they did not recognise it as such.

### ***Formal assistance***

In addition to help directly for the person with dementia, pupils talked about wider, more formal types of assistance such as research and financial input. Some pupils felt that there should be *“more research on how to prevent & cure dementia”* while others thought it was more important to *“raise money to do activities”* or *“donate money to help them pay for medication”*. Combining both options to *“give money to help them find a cure to dementia”* was also mentioned.

### ***Improving awareness***

Linked to formal assistance is the idea of improving awareness of dementia. Pupils commented on this from an individual level to *“make their family aware fully how/what dementia is”* through to a global level where *“awareness can be spread across the world, not just to people with dementia but all ages, all ethnics, all medical stages of people”*. As one pupil commented, *“everyone should learn about dementia so we can understand better what some people are going through”*.

### ***Pessimistic view***

Although the comments from most pupils related to positive or constructive things that could help people with dementia, there were also a few more pessimistic views expressed. However, these mainly related to the physical and medical side of things rather than the broader psycho-social options available, with pupils pointing out that *“there is no cure”* and *“that part of the brain is severly [sic] damaged”*.

### **Helping someone who is caring for a person with dementia**

In addition to ideas for directly helping the person with dementia, the secondary school pupils appreciated that helping their carer would also be beneficial. One interesting point that came out from pupils in different schools was that help should not be forced on carers, but rather you should *“ask if they need anything”* and *“help them out if they need any jobs done”*, with ‘ask’ and ‘if’ being the key words.

### ***Rest and recuperation***

A key theme expressed by many pupils was the idea of helping the carer by *“giving them time to have a break”* so that they could *“do something nice”* or *“do what they need to do without the worry of having to look after the person”*. This break could be anything from a day or a weekend to a proper holiday, and although most comments related to a break for the carer, the idea of having *“breaks away from each other”* was also mentioned, which would benefit both the carer and the person with dementia.

The main type of break talked about by the pupils were days out *“where they can be themselves and not worry about anything”* and *“do something the carer wants to do”*, to essentially *“give the carer some ‘me’ time for a few hours a week”* and *“let them think about themselves for a little while”*. However, some comments talked about *“a day trip altogether”* where both the carer and the person with dementia get to go out rather than having time apart.

### ***Moral support***

One of the main areas talked about by the pupils was moral support in its different forms, but to some extent it was done on the carer's terms. Providing reassurance and encouragement for the carers by *"always telling them when they've done a good job"* was mentioned by a number of pupils, as was being there for the carer and helping them out *"when they need you"* or *"when they feel tired or need a break"*. Pupils also felt it was important to *"be there for them as someone to talk to or someone to escape to"* but again it was *"if they need to talk"*.

Being understanding of the carer's position was another way in which the pupils thought you could help carers, and realised that *"they could be sensitive as they are helping someone that will eventually die so make sure you are nice and patient"*. Helping the carer to relax and reduce stress were also covered, as was trying to make the carer happy and *"cheer them up if they felt sad"*.

There was also a sense of being on the carer's side if they were confronted by negative attitudes, with one pupil saying that they would *"stick up for them if they got picked on for [caring]"*. The idea of the stigma of being a carer was mentioned by another pupil who commented *"if they don't want anyone to know[,] do not disclose that they are a carer"*.

### ***Practical help and support***

In addition to moral support, the responses from pupils talked a lot about providing more practical forms of help and support, but again there was a feeling of asking the carer if they needed help rather than just assuming that it was needed. One of the main areas of practical help was helping to care for the person with dementia. This could either be done by individuals to *"take turns taking care of them"* and *"make it a team effort"* with the carer, or by professionals such as a nurse who could care *"for a while and let the person have a break"*.

Another practical means of support was felt to be helping the carer with work, such as *"helping with housework"*, shopping, cleaning and cooking, and generally to *"do some of the jobs they would normally do but can't because their [sic] busy caring for the person with dementia"*. Providing financial help was also mentioned, but to a lesser extent, either by giving them money or *"raising funds to help them"*.

***Helplessness***

Although not mentioned by many pupils, there was a slight feeling of helplessness, rather than pessimism, in a few of the responses. For example, *“I don’t think I’d be able to help, there wouldn’t be much I could do but I would try and give as much information I knew about dementia”*.

***The pupils misunderstood the question***

The vast majority of responses were appropriate, it appeared that some pupils misunderstood or misread the question. It is not clear if this was due to their own language skills, the question being too difficult, the pupils rushing and not paying attention, or another reason altogether, but as only a small minority of responses were affected, it should not be taken as an indication that the question needs to be changed. The misunderstanding mainly involved the pupils thinking the question related to people with dementia rather than their carers, so they offered suggestions on ways to help people with dementia.

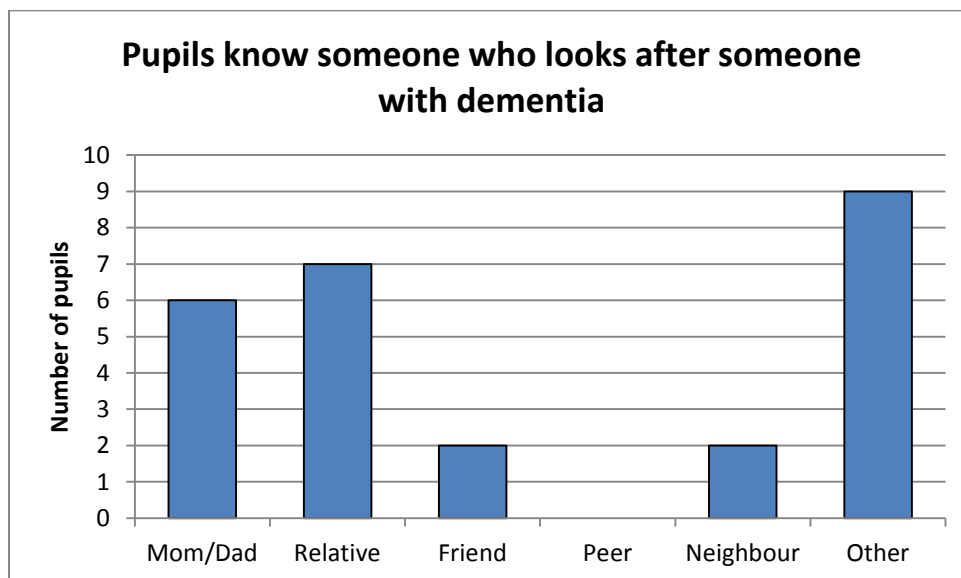
# Caring for someone with dementia

## Most pupils appreciate the caring roles that adults, children and young people may take on

### Primary schools

Although responses in this area were limited, the pupils did appreciate that caring could be carried out by a range of people. This was shown by the different people the pupils know who care for someone with dementia as seen in *Figure 14*, even though there were only a few responses relating to each caring role. Care staff were given as an example of 'Other' carers.

The lack of responses for 'Peer' could be due to two factors. Firstly, the pupils may not have known who this referred to, although as the questionnaires were completed as a group activity the teachers would have been able to explain. Secondly, due the young age of the pupils it is unlikely that any of their peers would be directly involved in looking after a person with dementia.

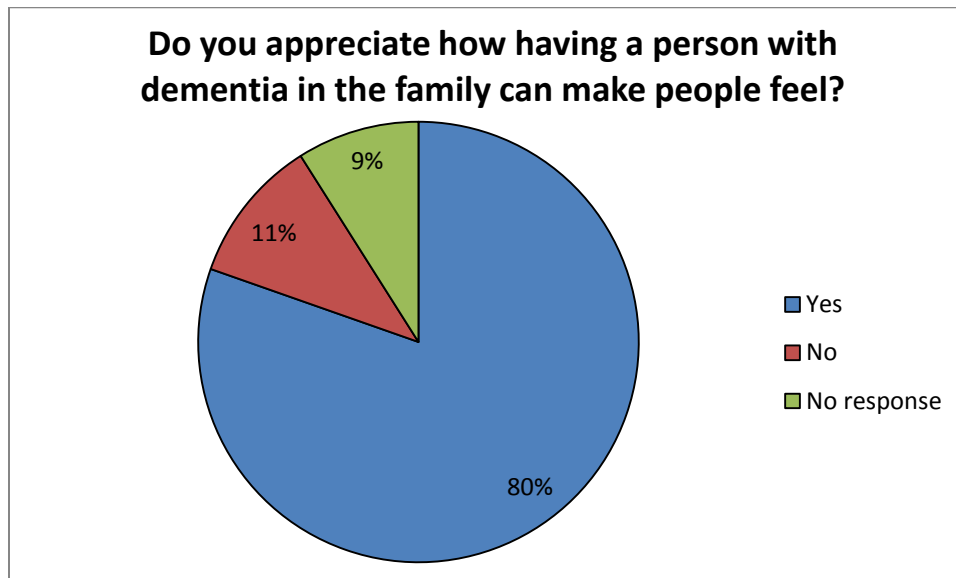


*Figure 14: Pupils know someone who looks after a person with dementia*

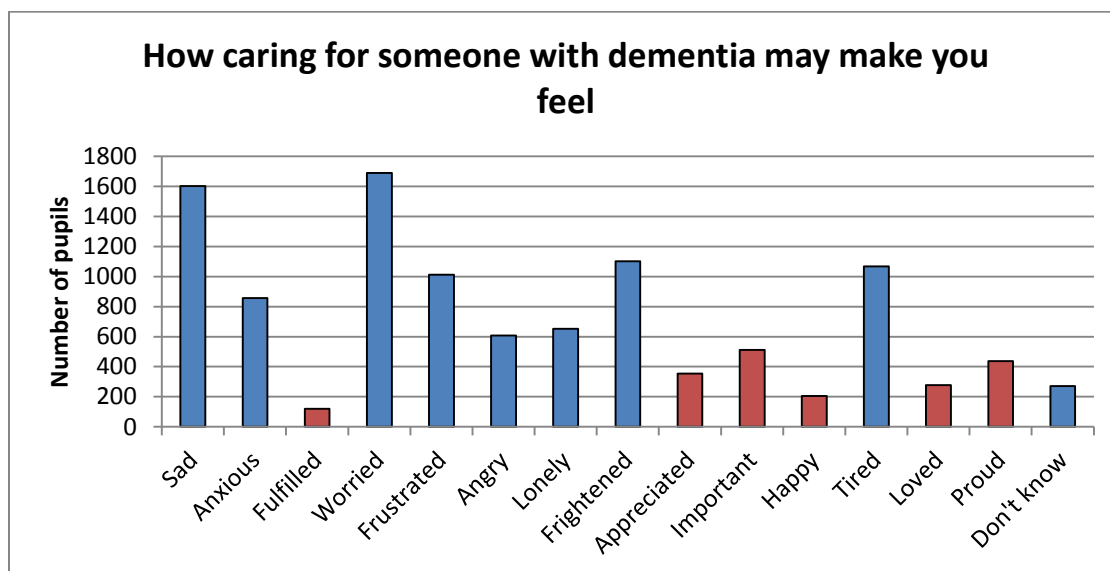
### Secondary schools

The responses shown in *Figure 15* indicate that the majority of pupils said they understand how having a person with dementia in the family might make you feel. This was reinforced by the range of emotions chosen by the pupils to reflect how they

thought caring for a person with dementia might make you feel, as seen in *Figure 16*. It is interesting to note that the more positive feelings (shown in red/purple) were chosen less often than the negative feelings, with 'Sad' and 'Worried' being the most common by quite a long way. This illustrates that the pupils see caring as being a mainly negative experience.



*Figure 15: Pupils appreciate how having a person with dementia in the family can make you feel*

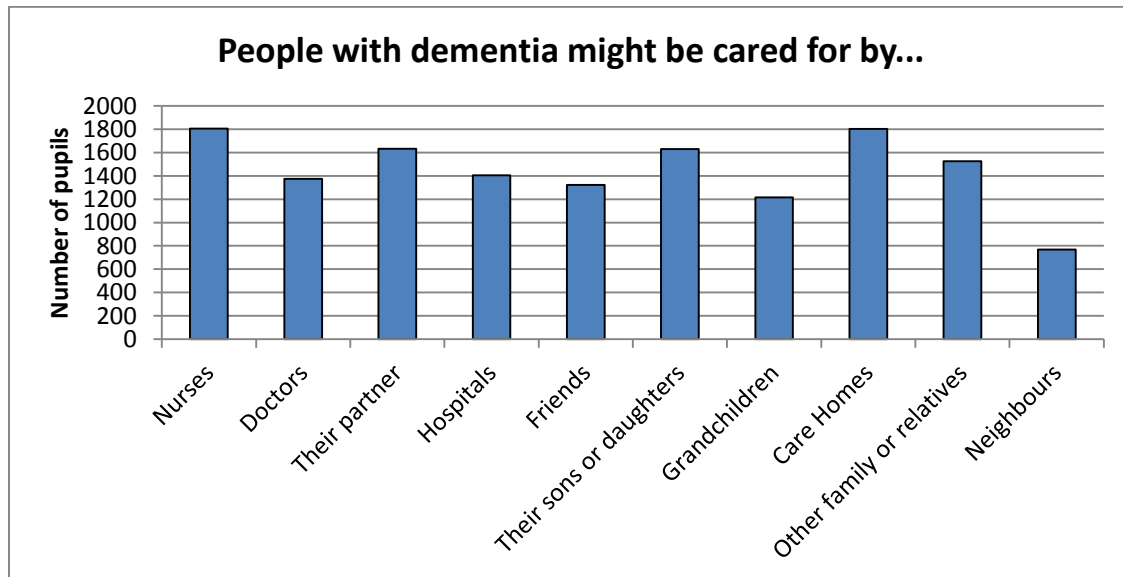


*Figure 16: Pupils appreciate how caring for a person with dementia can make you feel*

Although there were variations, it was noticed that many pupils fell into one of four main groups when saying who they thought cared for people with dementia:

1. Everyone
2. Everyone except grandchildren (the group the pupils were most likely to associate themselves with) unless they are old enough
3. Family only
4. Professionals only

The responses shown in *Figure 17* indicate that the pupils recognised that a range of people could be involved in caring, with neighbours least likely to be involved.



*Figure 17: Who might care for a person with dementia*

## Most pupils are aware that some of their peers may care for someone in the family with dementia and this may affect them

As seen previously, none of the primary school pupils knew of any peers who were helping to care for a person with dementia. Conversely, almost 20% of secondary school pupils claimed to know someone that was caring for a person with dementia. It is unclear whether these are friends of a similar age or family friends who may be of their parents' generation, but is a higher proportion than anticipated. Having an understanding of dementia and the caring role is therefore very important to ensure these potentially young carers are fully supported by their friends.

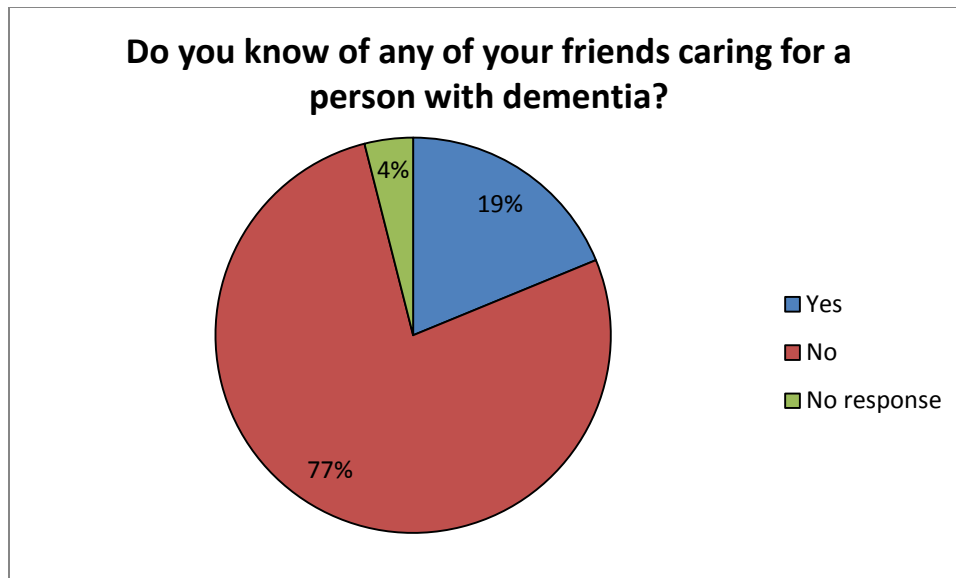


Figure 18: Secondary school pupils with friends caring for a person with dementia

## Most pupils have developed respect for those who are caring for a person with dementia and are aware of ways to be supportive

### Primary schools

When describing what it might be like to look after a person with dementia, the majority of words and phrases used by the pupils were negative, but suggested that they appreciated how difficult it can be. However, some pupils did view caring in a more positive way, with one comment saying that people looking after someone with dementia must be very caring. A selection of the words used by the pupils is shown in Figure 19.

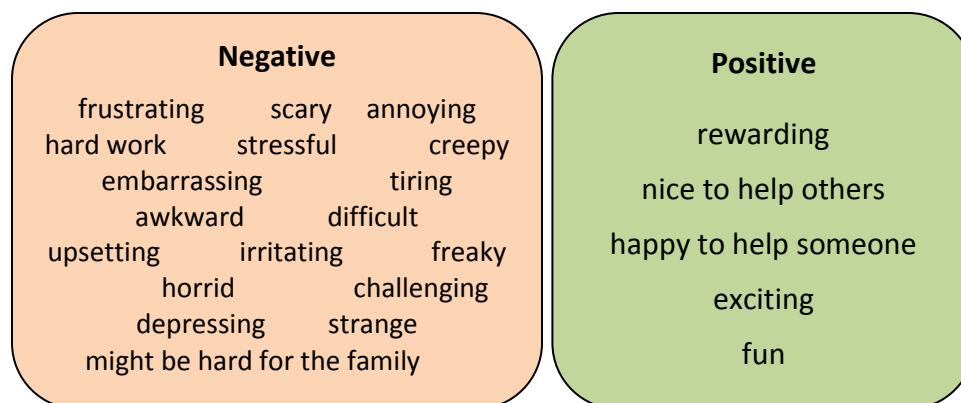
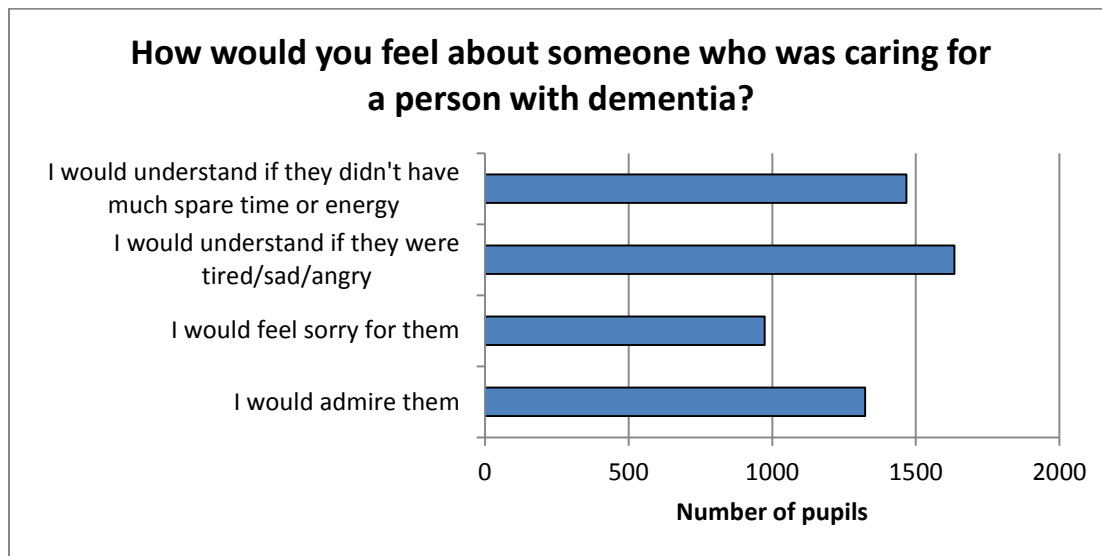


Figure 19: Comments relating to looking after a person with dementia



## Secondary schools

As shown in *Figure 20*, pupils were likely to be understanding of the situation that carers are in, and generally admire them for what they are doing. The pupils were least likely to feel sorry for carers, and it should be noted that one pupil commented that the reason they would feel sorry for the carer was because they were losing someone they love, rather than because of being in a carer role.



*Figure 20: How pupils feel about someone caring for a person with dementia*

In addition to the above, the moral and practical support for carers suggested by the pupils in the previous section illustrates their awareness of the caring role and ways to be supportive.

## Most pupils are aware of where to go to seek support if dementia in their family is affecting them

### Primary schools

As shown below, pupils were able to suggest a variety of potential sources for information and support about dementia:

- The internet
- Parents
- Professionals/experts – doctors, someone who works in a hospital, a chemist, nurses, someone who works in a care home
- A person with dementia

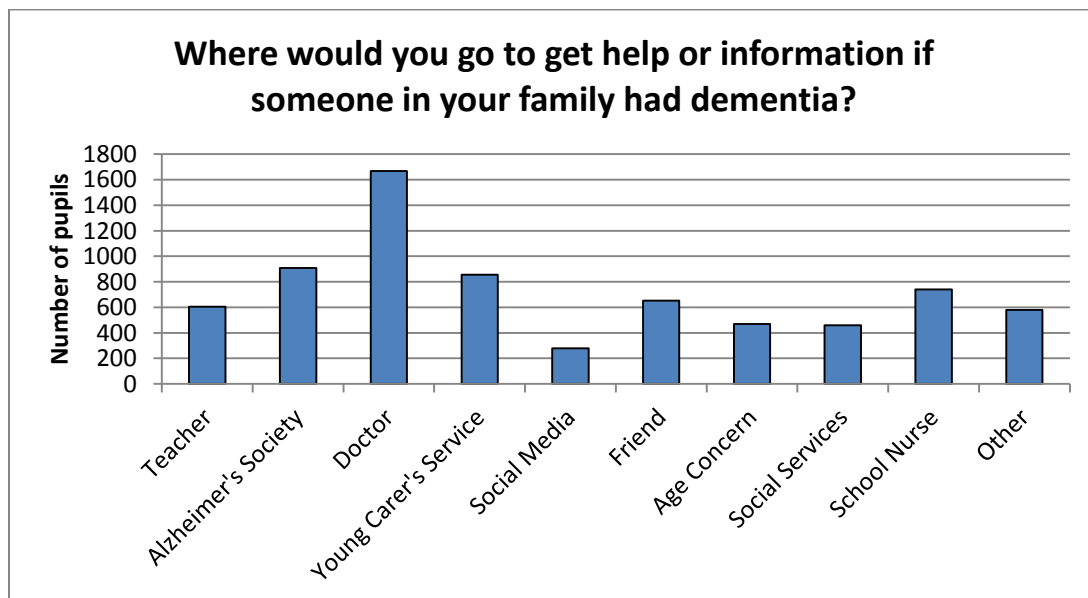
- Books
- Family
- Friends
- NHS
- Television
- Leaflets

## Secondary schools

The responses from pupils are shown in *Figure 21*, where it can be seen that Doctors were the most likely source of information and social media was least likely. However, all sources were chosen by a reasonable number of pupils. Some examples were given for the 'other' sources and included:

- The internet
- Parents
- NHS
- Counsellors
- Family

Overall the responses from both sets of pupils were largely the same.



*Figure 21: Sources of information and support*

# Assistive and digital technology

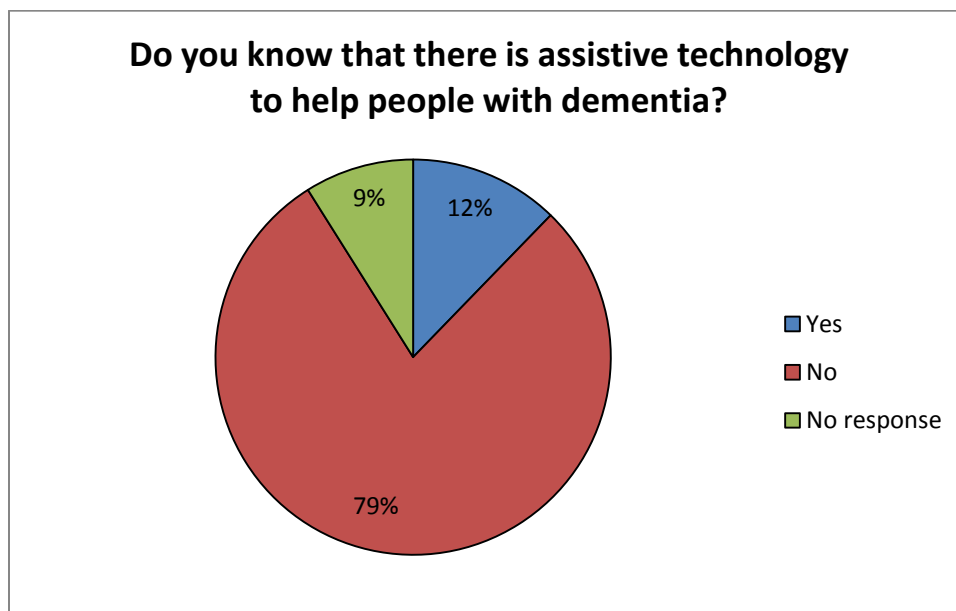
**Most pupils are aware that there are different types of assistive/digital technology and appreciate how these can improve the lives of people living with dementia**

## Primary schools

Although the pupils were not asked specifically about assistive technology, a few of their comments did briefly touch on the area as they mentioned *“memos to take pills”* and *“diaries to remind themselves”*. However, it is highly unlikely that they pupils would recognise assistive technology as a concept, suggesting that this is an area to build on.

## Secondary schools

Although the pupils talked about different techniques for coping with dementia that were essentially forms of assistive technology, the vast majority of pupils said that they had not heard of assistive technology or left the question blank (*Figure 22*). Of the pupils who had heard of it or knew it existed, many commented that they did not know specific types. However, some pupils did give a variety of answers as indicated in the comments in the following section.



*Figure 22: Pupils who have heard of assistive technology*

## **Types of assistive technology**

### ***Standard care aids***

Some of the responses related to general care aids such as wheelchairs, while others were aimed more specifically at older people, including *“the chair that helps you get up stairs”*, hearing aids, and *“a button around the house and when she falls or needs help she presses the button and the nurse carer would go”*. While these are all aids that people with dementia could use, they are not necessarily the types of technology we were hoping the pupils might know about.

### ***Memory-specific aids***

Although there were only a few responses in this category, pupils were able to talk about *“digital reminders”* for *“events they might forget”*, *“recording important stuff so they can play it back if they forget”* and *“digital memory books”*. One response was even more specific to people with dementia and was about *“alarms in their home to alert if they wander out of their homes”*.

### ***Everyday technology***

Some pupils were only able to mention everyday technology such as computers, *“laptop, radio, ipod, TV, ipad, phones”* which, as with standard care aids, may be applicable to people with dementia, were not types of assistive technology.

### ***Medical interventions***

The responses for a couple of pupils related to medical interventions which focussed on the brain, such as *“brain scanner”* and *“lasers to cut bad parts of the brain”*.

### ***Additional concepts***

The final few comments were sometimes vague concepts indicating that the pupils grasped the basic idea of assistive technology but did not know enough to give a full answer, such as *“machines to help people with stuff to make it easier for them”*.

## **How assistive technology improves the lives of people with dementia**

Despite not knowing many types of technology, the pupils were generally more able to suggest how it helps people with dementia, even though some of their ideas are not necessarily accurate. However, it should again be noted that the majority of pupils either did not respond or said they did not know.

### ***Improving memory***

One of the main ideas that the pupils had was that assistive technology can help to improve people's memory, but that this could happen in different ways. Firstly, it can help people to remember more or forget less as it *"keeps them from forgetting things"* and can *"make them remember things for longer before they forget"*. Secondly, assistive technology can be used for reminders as *"it reminds them to do stuff that they might normally forget"*. Finally, it could help to bring back old memories as *"it can jog their memory"* and *"they can remember more family memories"*.

### ***Making life easier***

The other main area talked about by the pupils was that assistive technology *"helps people with dementia with day to day life"*, and *"can give them more dignity"*. It *"allows them to be as independent as they can"* and *"makes them feel like they can be a part of society"*. Assistive technology was also felt to help people with dementia *"enjoy life a bit more"* and *"have fun through the hard time"* as they *"have some freedom to do the things the[y] enjoy"*. Overall, *"it gives them a better standard of life"*.

### ***Tackling dementia***

Other comments rightly or wrongly relate to assistive technology being able to help to tackle dementia, mainly by improving the condition, as it *"can't cure dementia, however it can make it better"* and *"might slow down the process of dementia"*. Some pupils indicated that they think it *"can help them live for a longer period of time"* or *"help them stay alive and healthy"*. Whether these ideas relate to the medical condition or improving quality of life is unclear.

### ***Other ideas***

The final comments suggest that assistive technology can be used for advice as it *"gives you information about what to do if you have dementia"*, and can be helpful for carers as technology such as *"alarms can alert carers to a fall"*.

## **Most pupils could make an informed selection of assistive technology tools to assist a person with dementia**

### **Secondary schools**

As pupils did not really know about assistive technology and many were unclear about dementia in general, it was quite difficult for them to say which would be the most helpful for people with dementia.

### ***Standard care aids and memory-specific aids***

Although some pupils suggested specific technology such as computers, hearing aids and mobility scooters, more vague concepts were also mentioned like *“something to keep you breathing well”*. This was also the case for memory-specific aids, where *“machines which stores [sic] what you are thinking”* were suggested alongside *“recording devices”*. The most specific responses were around *“alarms”* and *“a beep watch”* which provide alerts, and *“medication aids”* but there was little actually related directly to people with dementia.

### ***Additional concepts***

A number of additional ideas were suggested by the pupils, and these actually seemed to be more specific to people with dementia to some extent. For example, although it was not necessarily the answers we were hoping for, ways of getting advice or information about dementia were seen as important, such as the *“NHS website”* and *“Google has a big pot of information you can look at”*. A medical intervention like *“MRI”* and *“cat scan”* were also raised by some pupils.

One of the most dementia-specific areas was around the idea of ways to help promote independence or provide practical help, including *“things to help with cleaning so they can do it quickly and live life to the full”* and *“ones that people can do alone”*. The final area covered by the responses involved people rather than technology, with *“a nurse to take care of you”* and *“someone you can trust to talk to”* being seen as most helpful.

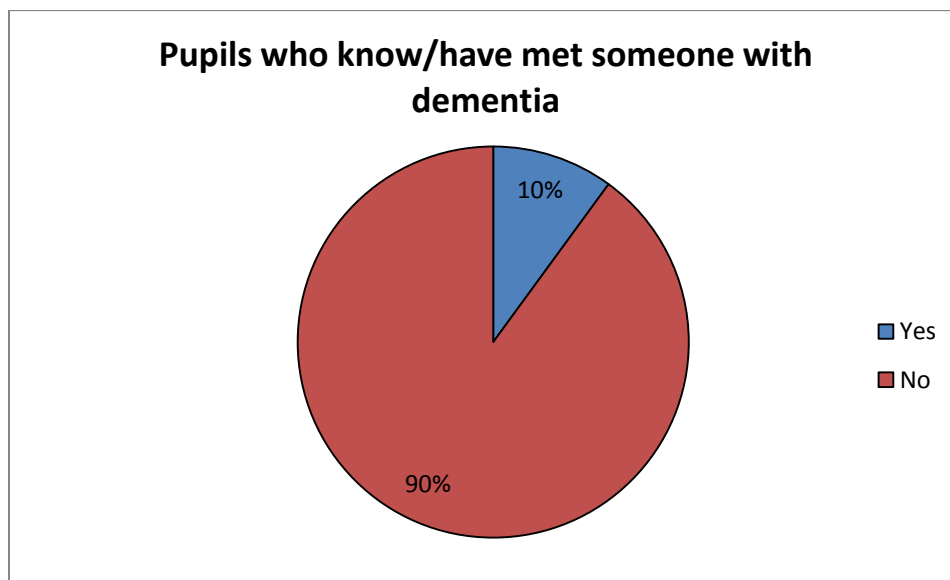
It should however be noted that although in a distinct minority, one pupil displayed a slightly unsuitable perspective that an *“electric shot might work”*.

# Meeting someone with dementia

## Most pupils have met a person with dementia

### Primary schools

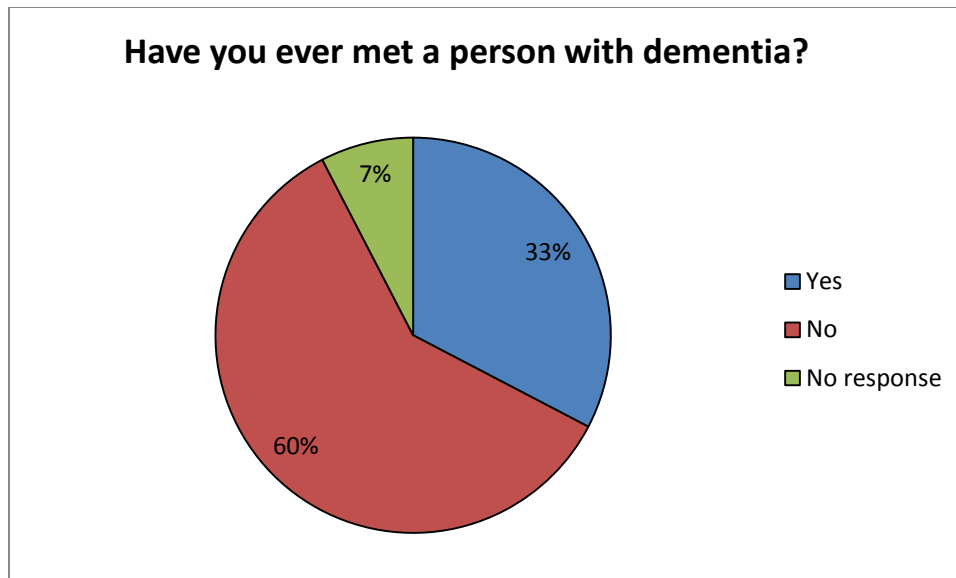
As can be seen from *Figure 23*, only a small percentage of the pupils had met someone with dementia. This is not overly surprising as the younger pupils are less likely to have grandparents in the higher-risk age ranges, and parents may be less likely to tell them specific details if anything is affecting their grandparents. Also, as the pupils are less aware of dementia overall, there would be less chance of them being aware that someone had dementia.



*Figure 23: Primary school pupils who have met someone with dementia*

### Secondary schools

A third of secondary school pupils have met a person with dementia as shown in *Figure 24*. Part of the reason for this could be the opposite of the points made for primary school pupils above. For both sets of pupils, these values form a good baseline against which to measure the impact of the dementia interventions as it is expected that at least some of the interventions will involve meeting a person with dementia.

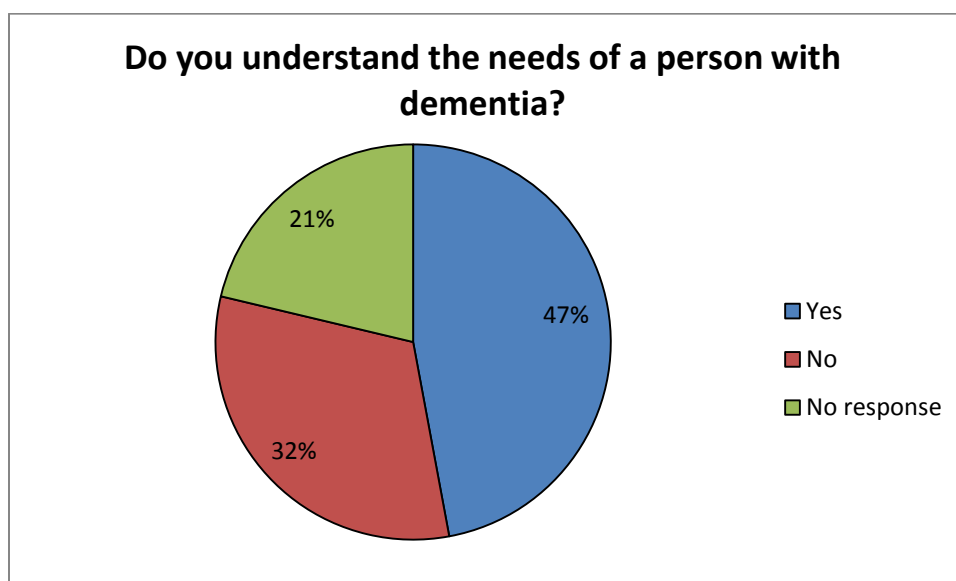


*Figure 24: Secondary school pupils who have met someone with dementia*

## Most pupils are able to recognise and understand the needs of people with dementia

### Secondary schools

Figure 25 shows that less than half the pupils claim to understand the needs of a person with dementia. While 47% is actually quite good, it is hoped that it will increase following the dementia interventions.



*Figure 25: Understanding the needs of someone with dementia*

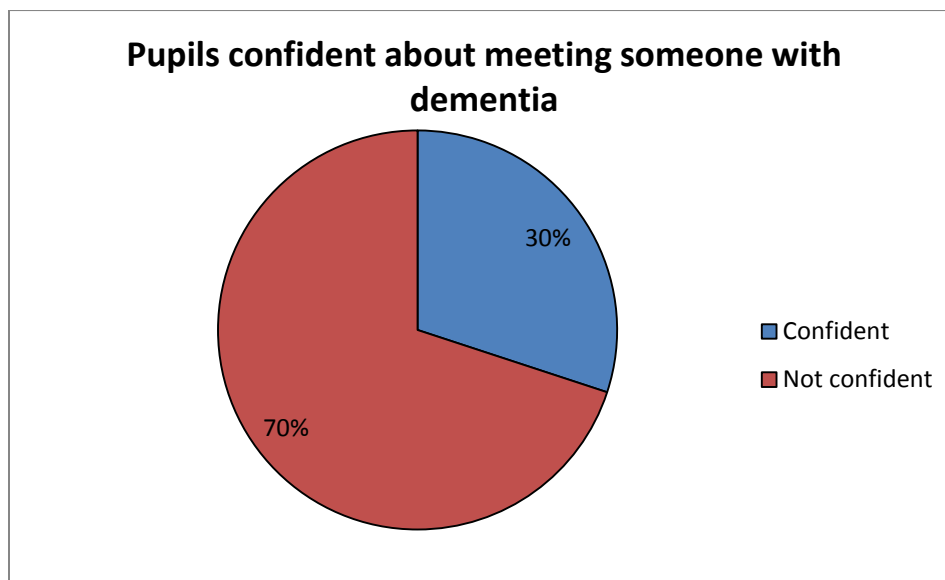


## Most pupils have increased their confidence in engaging with a person with dementia

As this report is only looking at the responses from the 'pre-questionnaires' in increase in confidence will not be seen. However, the results will provide a good baseline to compare the 'post-questionnaire' responses with later in the project.

### Primary schools

As seen in *Figure 26* 30% of pupils feel confident about meeting a person with dementia. Unfortunately the questionnaire did not capture follow-up information to know if there was any significant overlap with the 30% of pupils who had heard of dementia.



*Figure 26: Confidence of primary school pupils when meeting someone with dementia*

### Secondary schools

The responses shown in *Figure 27* indicate that although many pupils felt awkward meeting someone with dementia as they 'Didn't know what to do or say', almost as many claimed to feel 'OK'. This suggests that they did not consider the dementia to be a particular issue. It was also encouraging to see that only a handful of pupils 'Avoided people with dementia', which was the most negative option.

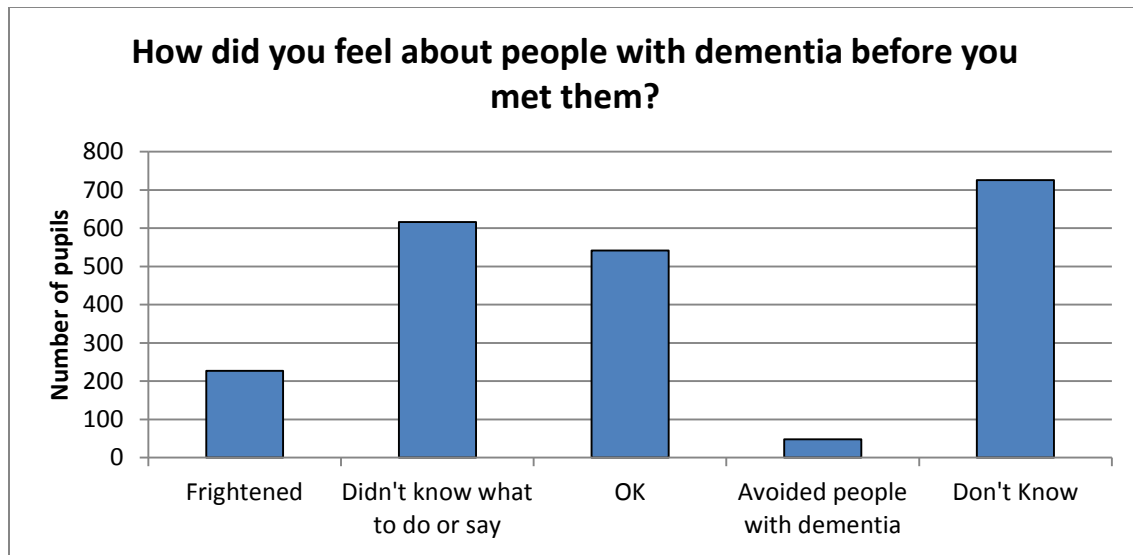


Figure 27: Pupil reactions to meeting someone with dementia

Although Figure 28 shows that most pupils rated their confidence as 3 (or essentially 'average'), it should be noted that more were in the two higher confidence bands than in the two lower bands – more than 30% in bands 4 & 5 compared to less than 30% in bands 1 & 2. This indicates that overall the pupils were generally quite confident.

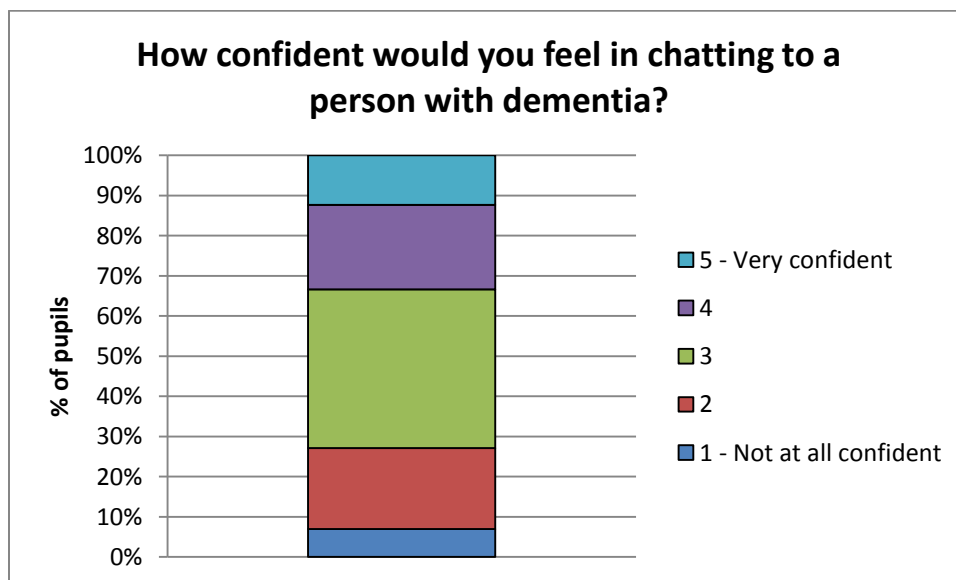


Figure 28: Confidence of secondary school pupils when meeting someone with dementia

When this information was looked at in more detail and separated for pupils who had already met a person with dementia and those who hadn't (Figure 29), it could be seen that confidence was higher for the pupils who had already met a person with dementia.

This suggests that knowing more about dementia can help to remove some of the fear that may be linked to it.

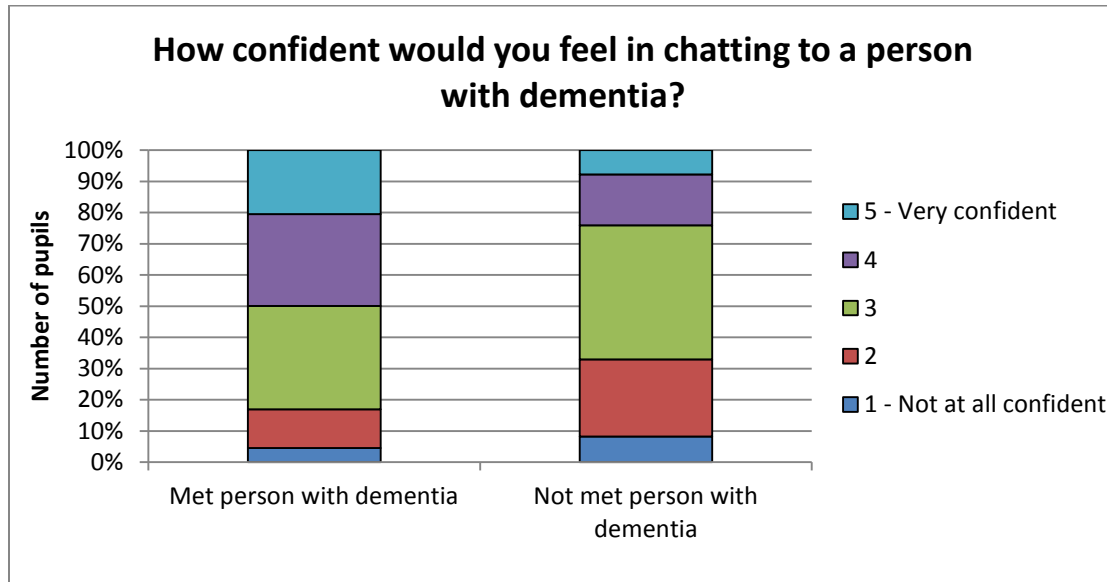


Figure 29: Confidence for pupils who had and hadn't met someone with dementia

## **Most pupils understand the difficulties and prejudices from the community that may be experienced by people with dementia and their carers**

### **Secondary schools**

As can be seen from *Figure 30*, most pupils felt that other people would not know what to do or say if they met someone with dementia, and would not understand them. While this may reflect the pupils own feelings as seen previously, reassuringly a reasonable number felt that people would generally be 'OK'.

The pupils were also able to provide a range of explanations as to why they thought people would react in the various ways, as demonstrated in the following comments.

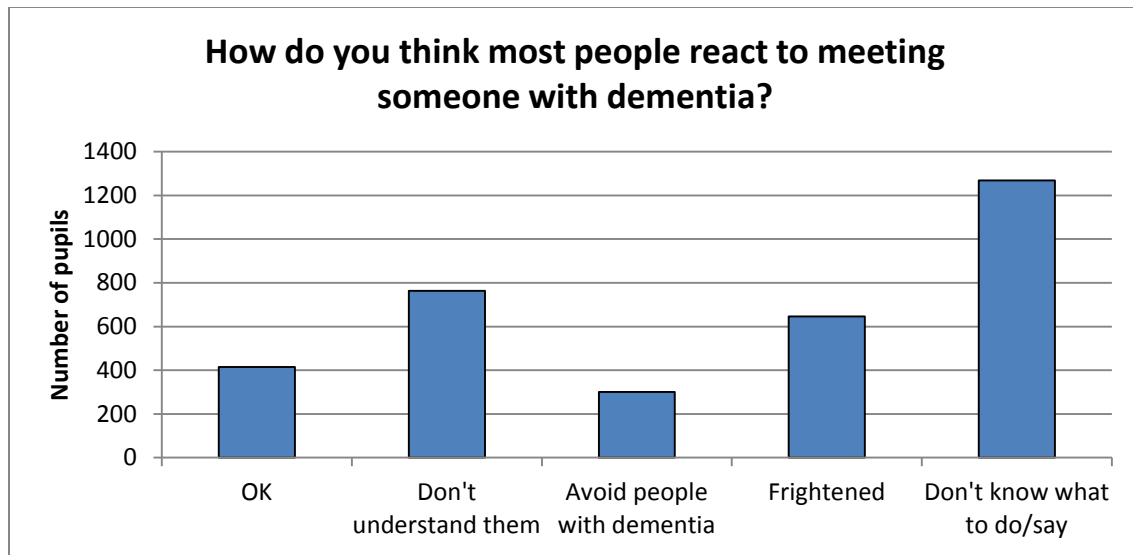


Figure 30: General public reactions to meeting someone with dementia

### **Lack of knowledge and education around dementia**

The main reason for people's negative views towards people with dementia and their carers related to the idea that there was a general lack of knowledge about dementia as *"it isn't spoken of enough"* and *"there is not enough focus on dementia, so many people do not know what it is, and how it affects the people"*. This lack of knowledge was expressed in a variety of ways by the pupils, including a fundamental *"most people don't understand the illness"*.

Not knowing about dementia meant that a person with dementia was seen as an unknown quantity so you *"don't know what to expect from them"*. Pupils also felt that for many people *"it's rare meeting people with dementia"*, and indeed some people *"haven't met anyone with dementia before"* so don't know what they are like.

The lack of knowledge was also felt to contribute to false impressions about dementia, with people having negative views because they are worried that they might catch it *"they might not know about the deiesise [sic] and they might think it is contagious [sic]"*. This was reinforced by some pupils raising the issue of stereotypical views and stigma around dementia. For example, *"they don't want to be seen with people with dementia"*, *"bad press, dementia has such negative connotations in the news"* and *"the media gives a bad portrayal of people with dementia"*.

### **Communication issues**

Other reasons for people reacting negatively towards people with dementia related to difficulties around communication, and this was also expressed by the pupils in a

number of ways. Some pupils felt that it could be difficult to understand a person with dementia *“because they are different and can’t communicate well”* or because *“sometimes people with dementia are talking about one thing then change to another thing and it can be quite confusing”*. *“People with dementia say really random things and it can make the situation awkward”*.

Other pupils felt that the problem could be because *“sometimes you don’t even know what to do or what to say”* and there was a lot of concern expressed about people being *“worried that they might say something wrong”*. The possibility of upsetting or offending the person with dementia also came up a number of times. For example, *“they don’t want to hurt the person’s feelings or upset them”* and *“they do not want to offend or upset the person”*.

Related to this is the idea that people are *“not sure how the person [with dementia] would react”*, so they may be *“scared that if they say the wrong thing, something might happen”*. Finally, covering all of these communication issues, some pupils thought that people may not be comfortable around people with dementia because it can be *“quite hard to make a conversation”*, and *“because people with dementia forget quickly, so conversation would just loop”*.

### ***People with dementia are seen as being different***

Pupils also felt that people had problems with people with dementia because *“some people think they are different”* and *“they wouldn’t be the same as other people”*, and in general *“they don’t like people who aren’t like them”*. The difference was generally related to memory problems and forgetfulness, with some pupils feeling that this could make it difficult for someone to spend time with a person with dementia. It was interesting to note that the forgetfulness was considered from two different perspectives, firstly that *“they’ve never been in contact with someone that might not necessarily know themselves”* and secondly, *“it would be a bit strange to have someone that you knew really well not know you at all”*.

Reassuringly, although many pupils felt that other people saw people with dementia as being different, they themselves considered people with dementia to be normal. For example, *“just because they have dementia it doesn’t mean that they are not normal”*, *“every one’s different and it does not matter whether they have got dementia”*, and *“they think there [sic] different but are actually the same as everyone”*. One pupil summed it up by saying *“having dementia doesn’t make you any different”*.

### ***An emotional response***

Many pupils felt that people having negative views or difficulties with people with dementia was connected to an emotional response to them, with one pupil saying that *"if it's someone you used to know, it's crushing to see a good person drain away"*. Another commented along the same lines, saying *"if you know them (before dementia) it can be quite a shock seeing them so differently. Also if you know them well[,] them forgetting you is very hard to take"*. A variety of emotions were included in the pupils' responses, such as *"they might be scared"*, *"they might be frightened or nervous"*, and *"they feel sorry for them"*. The pupils also felt that being with people with dementia could be an awkward situation for some people which *"makes them feel uncomfortable"*.

Some pupils thought that people could be worried about what it would be like to have dementia and *"glad they don't have it"*, because *"it's not a nice thing to have and your [sic] lucky to not have it"*. *"It's something that the[y] don't like thinking about [...] as they don't want to develop [sic] it in later life"*.

Conversely, a number of pupils felt that people would not have a problem meeting someone with dementia and any emotional responses would be more positive *"because they feel compassionate and want to help"*. Any initial issues could be quickly resolved because *"it is something new but after a while they will know what to say and do around them"* and *"they are just people"*.

### ***Wider discomfort with illness in general***

Although pupils recognised that many people could have problems meeting people with dementia, they felt that it was not necessarily the dementia that was the problem, but the idea of being with someone who has an illness, *"it is a disease, and diseases frighten people"*. For example, *"you are meeting someone with something wrong with them"* and there is a *"risk of dying"*.

Mental illness in particular was mentioned by a few pupils who said that *"in modern society old people or mad or homeless or anything like that are just strange and are sorta [sic] pushed away"* and *"a person with dementia has a mental illness and unless you're trained on how to look after that person there's nothing really you can do"*.

### ***The pupils misunderstood the question***

A few pupils appeared to misunderstand the question and commented on why they thought a person with dementia might find situations difficult, saying that *"I think they*

*feel lost and afraid” and “they feel confused and agitated and wonder why they are here”.* Although it does not answer the question, it does indicate that the pupils have a good understanding of dementia and are able to put themselves in the place of a person with dementia.

## **Most pupils understand how they could make a positive contribution to the lives of people with dementia**

### **Primary schools**

Although many pupils did not know what dementia is, a selection of comments showed that they were quite caring and generally wanted to help people. However, only some of the comments suggested how they could help people who actually have dementia. These included helping them with their memory issues by reminding them, writing lists or writing things down as memory prompts. They were also able to suggest more practical assistance such as taking them to see a doctor and taking them on holiday, although these are not necessarily things that the pupils could do themselves.

### **Secondary schools**

While many pupils did not necessarily identify things that they as an individual could do to help people with dementia, a range of options were given for things that could be done to help, indicating that the pupils had a good understanding of this area. For example *“make them feel equal to everyone else in society and make people aware of dementia to lift social stigma”* and *“make them feel normal because no one likes to be considered “broken””*.

### **Support and help**

Many pupils felt that they could help a person with dementia, and this help took a number of different forms. In terms of general and moral support they could *“respect them and look after them”* and *“help them through their tough times”*, while a more practical form of help was to *“help them out with the things they struggle with”*. Who the help and support was aimed at was also addressed, with pupils saying that they could provide help for the carer as well as for the person with dementia. This help was often expressed in terms of being there for people, such as *“make sure I’m always there for them if they need anything”* and *“be there for them so they aren’t lonely”*.

### **Treatment**

Another area where pupils felt they could help was treatment, where they could *“get them the attention they need”*. This treatment was in the form of medication that *“will*



*improve and slow down the process of dementia*", professional help from doctors and nurses, and putting the person with dementia in a care home. In addition, the pupils indicated how they as individuals could help by volunteering to *"help out at a care home"* or simply *"I could care for them"*. This illustrates that while the pupils appreciate what can be done to help people with dementia, they also recognise that there are things they can actually do themselves.

### **Formal and practical help**

A more practical form of help for people with dementia was also mentioned by a number of pupils, where they would *"help them with any tasks within my ability"*. Housework was one area considered by the pupils as they could *"help them by doing their shopping and cooking for them"* or *"try and help them with chores"*. Financial assistance was also mentioned as pupils felt that they could *"raise money for charities for people with dementia"* or alternatively *"I could donate some money to help them"*.

In addition, helping to *"raise awareness of the illness"* was seen as important which one pupil said could be done by having *"a TV advert so the world knows about it"*. At a more basic and individual level, another pupil said that in order to help a person with dementia they would first need to *"learn about the illness"*.

### **Memory-specific interventions**

Another way of helping related to the idea of interventions that were specifically addressing the memory difficulties encountered by many people with dementia. Some pupils felt that they could *"play memory games"* or *"talk about the past to jog their memory"* as this would *"help them to remember things"*.

### **Maintaining normality**

A number of pupils thought that a good way they could help people with dementia was to *"treat them like a normal person"* or *"treat them like they don't have dementia, so they feel the same as everyone else"*. Linked to this was the idea that pupils could *"help them to be independent"* so that they could live their own lives and feel like *"part of the community"*.

### **Communication**

Communication was seen as an important way of helping people with dementia with pupils saying that they would *"talk to them and keep them company"*, *"have a normal conversation with them"* and *"listen to them"*. The style of communication was also



important with one pupil saying that you should *“talk to them like normal. I’m sure people with dementia could get talked to like they are kids”*.

Related to talking and listening was the idea of just visiting and spending time with people with dementia. For example it was important to *“spend time with them. Don’t avoid them!”* and *“spend time with them so they’re not lonely”*. One pupil linked this with the idea of volunteering, saying *“I could possibly visit a care home & visit those who have infrequent or no visits from friends or family”*.

### ***Understanding their perspective***

An important way of helping people with dementia was felt to be understanding and sympathetic towards their situation, and adapt your own behaviour as a result. For example, *“not to laugh if she asks the same thing more than once”* and *“do not pressure them when they can’t remember certain information”*. Trying to *“understand what they are going through”* was mentioned by the pupils, as was trying to improve how they feel and *“make them feel [sic] special and loved”*.

Coming out of this was the idea of person-centred care, with one pupil saying that to work out how they could help someone with dementia *“I would go and ask them about how they feel and what THEY want”*. Pupils also recognised that people with dementia were individuals, with one saying *“it depends what type of dementia they have because you will have to treat [sic] different kinds of dementia differently [...] so you have to do some things to suit the person”*.

### ***Activities***

A more ‘hands-on’ approach suggested by the pupils was to *“do activities with them”* and *“help them get out more often”*, although some responses such as *“take them on holiday”* may not necessarily be achievable by the pupils themselves. Person-centred care also came up again with some pupils specifying that they could *“take them out where they want to go”*. In addition to the more physical activities and going out, socialising was also mentioned by the pupils who would *“try and improve their social life by trying to get them friends”*. Overall, pupils felt that you should not *“exclude them in activities or conversations”*.

### ***Other ideas***

In addition to the areas above, a range of other ideas were raised in the responses such as *“get them a cat”*, *“I could make them more happy and make sure they have fun in*

*life*", *"be nice to them"* and *"look after them and make them feel safe"*, all of which are positive ways of improving the lives of people with dementia.

### ***Nothing***

Conversely, a couple of less positive responses were also seen. Although one was more along the lines of the pupil feeling helpless as *"I don't feel I could do anything"*, another was more negative as they felt that they would do *"nothing because I wouldn't bother to try to talk to them"*. However, it should be recognised that this negativity was only expressed by a single pupil and so did not represent the overwhelmingly positive responses from the vast majority of pupils.

## **Most pupils appreciate the positive impact of lifestyle choices on dementia outcomes**

### **Primary schools**

Although not specifically related to dementia, pupils were able to highlight the importance of keeping healthy by drinking water and eating the right food. Medical help was also mentioned in terms of taking medicine and having check-ups, as were ideas relating more to the way people with dementia could adapt their day-to-day lives to limit the impact of their condition. For example, establishing simple routines and maintaining an active and social lifestyle by getting out and about and forcing themselves to go out.

### **Secondary schools**

The pupils across all schools expressed a range of ideas of things people with dementia could do to improve their lives, including *"stay mentally active. Have a healthy lifestyle. Take any prescribed medication"* and *"exercise, go out more, have fun"*.

### ***Lifestyle factors***

There was a good recognition among the pupils of the importance of having a *"good lifestyle"*, which covered a range of lifestyle factors. For example, people with dementia should *"try to stay healthy"*, *"improve their diet"* and *"exercise more regularly"*. Diet was picked up on more specifically by some pupils who felt that they should *"ma[y]be try not to drink alcohol"* and *"eat healthier like less sugar and more omega 3"*, indicating that the potential impact of diet was appreciated by the pupils.

### ***Get treatment and help***

This was an area that many pupils appeared to feel quite strongly about, saying that the person with dementia should *“admit they have it so they can get the right help”*. It included a number of topics such as the importance of *“early diagnosis as it can give them a better and longer quality of life”* and seeking professional help, whether that be to *“visit a doctor regularly to see how they are doing. Take any medication that they are meant to”* or to *“go and see a specialist that can help that person”*.

One area that kept coming up was that people with dementia should *ask* for help, but also *accept* help when it is offered. For example, *“ask for help and not hide away, be heard”* and *“they can get people to help them and they should accept the help that gets given to them”*. Although this is directly answering the question, it does indicate that many pupils feel that to some extent the onus is on the person with dementia to be proactive where possible.

The idea of going into a care home also came up, but was seen as a positive option for people with dementia to choose as they can *“meet other people with dementia”* or *“get better”* in a care home. Linked to this was the idea of being supervised, although the extent of the supervision varied from having *“a carer to help them”* and *“keep going out with assistance”* through to being *“under super-vision [sic] at all times”* and to *“always have someone their [sic] for them”*.

### ***Memory-specific interventions***

Many pupils indicated that they thought people with dementia should try and do activities to improve their memories such as *“do mental exercises that can help their memory”*, and just *“try to remember as much as they can”* in general. Linked to this was the concept of reminiscence activities, where people with dementia could *“make a memory book”* or *“keep looking at photos”*.

While most of the responses in these areas were aimed at trying to reverse the effects of dementia and memory loss to some extent, other pupils suggested ways to use memory aids to adapt to the memory loss and limit the effects. The main interventions mentioned were to *“write down important things to remember”* and *“put labels around their homes”* to help them remember what to do. However, there was a twist on this idea from one pupil who was quite imaginative and had thought things through: *“they could write everything that’s important in there [sic] lives in a book then have a tattoo on their hand so every time they look at their hand they remember to look at their books”*.

### **Activities**

Being active was also an important area for pupils who thought that people with dementia should *“get out of the house, do enjoyable things that make them feel happy”*. They should *“have more of a social life”* to *“make sure they are not lonely”*, and *“try to stop themselves from becoming isolated and remain actively involved in the local community”*. However, a variety of people were suggested for who they should socialise with. For example, some pupils thought that they should *“go out with other people who have dementia”* or *“mix with young people”*, while others felt that they should *“talk to people like family or friends”*.

Physical activities were also mentioned, which were generally outdoors as it was felt that people with dementia should *“get out more and get fresh air and go for walks”* rather than *“being stuck inside”* all the time. There was also a strong sense of fun and enjoyment expressed by the pupils who said that people with dementia should *“get on with stuff they like and hobbies they enjoy”* as well as *“do more fun things”*.

### **Maintain normality**

Responses from pupils across all schools indicated that they thought it was important for people with dementia to try to maintain normality in their daily lives where possible, either by doing *“things they used to do before they got it”* or simply to *“live life as normal but take one step at a time”*, but above all to *“be themselves”*.

As part of this, pupils felt that people with dementia should *“try and be positive”* and *“try to make the best out of life”* rather than to *“think about what has happened in the past and forget about everything they have done wrong”*. The classic *“keep calm and carry on”* also came up, with pupils feeling that people with dementia should relax and stay calm rather than *“doing things that are too stressful”*.

### **Try new or different things**

Many pupils felt that people with dementia should not be limited by their condition, but should *“take every opportunity they can”* and *“try something different”*. This idea covered a range of options including *“take up a hobby [sic] or interest”*, *“meet new people”*, *“do things that they have always wanted to do”* and *“set them selfs [sic] a challenge to do something”*.

This was reinforced by other pupils who felt that people with dementia should *“make the most of life”* and make sure that they *“live their life to the full before it gets too out of hand”*.

### ***Pessimistic view***

Despite the range of positive ideas given by the vast majority of pupils, there were a few pessimistic responses saying that *“they can’t do anything”* and they can do *“nothing because there is no cure and they will die anyway”*. While it is possible that these pupils understood the question to be asking about ways to improve dementia rather than quality of life, it should be remembered that these pupils were very much in the minority. One pupil was more realistic and measured in their response, saying that *“some dementia sufferers can’t have control over their lives because it is so far advanced”*.

### ***The pupils misunderstood the question***

A few pupils misunderstood the question and their responses talked about things that could be done for people with dementia. Although not answering the question, they were positive suggestions such as *“treat them normally. Don’t act like they are different”* and *“help them, be kind to them”*, which indicates that the pupils still have an appreciation that quality of life can still be improved.

## **Most pupils understand why a section of a community may not empathise with people with dementia and their carers and have strategies to deal with this problem**

### **Secondary schools**

Having already realised that some people may not feel comfortable meeting people with dementia (as seen in a previous section), the pupils were able to suggest a variety of ways in which attitudes towards people with dementia could be changed. The overall feeling was summed up by one pupil who said *“I would encourage people to get to know more about the person inside and don’t just look at the dementia”*.

### **Education and awareness**

Education and awareness was a very broad area and covered a number of ways in which people could find out more about dementia, although all of them essentially reiterated the same point that people should *“talk about [dementia] more often”*. One pupil felt that the answer was to *“make dementia less of a taboo subject and easier for people to talk about. There should be more information about it because it affects so many people”*.

Pupils felt that one way to improve awareness would be to meet a person with dementia and their carer, as *“by trying to get to know a person with dementia, building relationship can change the way people feel with people that have dementia”*. This meeting could either happen when *“people with dementia come into schools”* or when people *“go and visit someone with dementia”*.

Providing information about dementia *“to help them realise the facts and info about the disease”* was also important, and the pupils had many ideas on how this could be done, such as leaflets, posters, TV adverts, the Internet and making *“social media aware of it”*. Some pupils were also clear on how not to give out information, saying *“don[']t make a tv [sic] advert like the one like water aid or something[,] make it positive cus [sic] people don[']t like sad stuff”*.

The type of information was also mentioned as it should *“not only tell them about the illness but tell them how patients feel”* and *“explain to them what the people are going through”*. This would enable people to put themselves in the place of someone with dementia, *“getting them to see what people with dementia go through and how hard it is for them”*.

The pupils were also clear that the information should not always focus on the negative side of dementia but seek to reassure people, for example *“tell them good stories about people with dementia so they wouldn’t be as scared/frightened”* and *“they should feel confident about talking to them because they are still able to communicate even though they have dementia”*. Some pupils attempted to put a positive spin on things by saying that *“it’s not all bad[,] they can sometimes rember [sic] their youth but not the last [couple] of years”* and *“when you have got the hang of it it won[']t be so hard to deal with but you will have some down days”*. Whether this is because they don’t necessarily fully appreciate the impact of dementia or they are simply trying to be positive is unclear.

### ***Show them people with dementia are normal***

An overriding message across many responses related to the fact that people with dementia are *“also normal human beings”* who are *“just the same as everyone else but just a bit more forgetful”* and therefore may *“need some help doing certain things”*. The pupils also said that you should *“just relax and talk to them in the same way you would to anyone else”* but did recognise that *“it is perfectly normal to be a bit worried at first”*. As one pupil summed it up: *“just engage in conversation with them and it will be fine[,] there [sic] not aliens”*.

### ***There is nothing you can do***

Although most pupils suggested ways to change how people feel about people with dementia, a few were less positive. One pupil was unsure what, if anything, could be done as *“people will always have it and people will always have different opinions”*, indicating that you can never get everyone to think the same way about something. This was reinforced by other pupils who were more pessimistic and said *“if that’s how they feel, that’s how they feel”* and slightly more strongly *“you can’t change nothing because if people judge other people there [sic] stupid and wrong”*.



# Conclusions

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## General observations

Although awareness of dementia varied between schools and age groups, the majority of pupils had a reasonable grasp of the memory loss element of dementia. There was relatively little reference to age or older people and hardly any mention of illnesses or suffering, but at the same time it was clear from the responses that pupils were aware that dementia is a progressive disease that mainly affects older people. Overall, the knowledge shown by some of the pupils was quite sophisticated and surprising, although there were also some misconceptions about dementia and areas where the dementia interventions should make a big difference for many pupils.

## Summary of findings

### Response rates and demographic information

- Overall, 13 of the 22 schools (59%) participating in the pilot project returned questionnaires;
- Nearly 2500 pupils aged 7+ were involved in the baseline phase and will take part in the dementia interventions;
- 30% of primary school pupils and 79% of secondary school pupils have heard of dementia, and awareness generally increases with age.

### Understanding dementia

- Primary school pupils were less likely to know about different types of dementia – their main understanding is around memory loss;
- Secondary school pupils have heard of different types of dementia, but Alzheimer's Disease is the most widely known;
- Both primary and secondary school pupils understand that dementia does not affect everyone in the same way and is not a normal part of ageing;
- Both primary and secondary school pupils understand that people with dementia can enjoy a rich quality of life:
  - Secondary school pupils in particular realise that people with dementia can enjoy a range of activities from calm and relaxing through to active and social, with some appreciation that they are individuals who would enjoy different things.
- Lots can be done to help people with dementia and their carer, but the needs of the two groups are very different.



### **Caring for someone with dementia**

- Secondary school pupils see caring as a mainly negative experience;
- Both primary and secondary school pupils recognise that caring can be done by a range of people, including their friends;
- They appreciate the difficulties of caring but support and respect the carers;
- There is good awareness of where to go for information and support around dementia.

### **Assistive and digital technology**

- Only 12% of secondary school pupils have heard of assistive technology, and even fewer were able to give examples;
- It was very difficult for pupils to say which types of assistive technology were best for helping people with dementia, or how they would help.

### **Meeting someone with dementia**

- 10% of primary school pupils and 33% of secondary school pupils have met someone with dementia;
- More awareness of dementia can result in higher confidence when meeting people with dementia;
- Pupils felt that it was unlikely that they or the wider public would avoid people with dementia;
- Secondary school pupils understand a range of reasons affecting how people feel about people with dementia and how some of these can be addressed;
- There is an awareness of a variety of things that can be done to help people with dementia;
- There is an awareness of a variety of things that people with dementia can do to improve their own lives.

### **Overall conclusions**

Basic understanding of dementia was better than anticipated, and this should be consolidated and expanded during the project. The dementia interventions should also aim to build on the range of positive views expressed by the pupils during this initial phase.

Pupils were able to consider both the person with dementia and their carers when discussing dementia, although caring was generally seen in a more negative light. Encouraging pupils to meet people with dementia and their carers could potentially help to increase their confidence and understanding of dementia and the caring role.

The main area where basic knowledge was missing was around assistive technology. This was a largely unknown subject, where the dementia interventions could significantly improve understanding and appreciation.

The project has the potential to affect the dementia awareness of a large number of pupils of all ages, and schools should be encouraged to continue participating in the pilot project. These initial findings provide a good set of baseline measures, and it will be interesting to see the impact of the dementia interventions in subsequent phases of the project.