

Dementia Awareness & Intergenerational Exchange in Schools: A Pioneer Project supporting Dementia Friendly Communities

Final report

*“As these children grow up they’re going to be doctors, carers,
working in shops, whatever it is, all of us will need to have
that understanding of dementia and the community”*

(Co-ordinator, Gloucestershire)

*“Just because a person has Dementia it does not make them
an outcast. They still have feelings just like me and you”*

(Year 8 pupil, Newent Community School)

Teresa Atkinson

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September 2013

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Executive Summary

Background

Prevalence of dementia increases with age, and as we are faced with an ageing global population the impact of dementia is becoming a national and international concern. In the UK alone, approximately 800,000 people are currently living with dementia.

In response, the Prime Minister's Challenge on Dementia was developed to focus on three key areas:

1. Driving improvements in health and care
2. Creating dementia-friendly communities that understand how to help
3. Better research

As part of the dementia-friendly communities strand championed by Angela Rippon and Jeremy Hughes, an intergenerational exchange initiative was introduced. Despite schools being an obvious starting point for the development of dementia friendly communities, little work has been conducted with a pupil focus. The intergenerational exchange was based on work undertaken by Dr Karim Saad, the Regional Clinical Lead for Dementia in the West Midlands, in collaboration with the Association for Dementia Studies at the University of Worcester and the NHS West Midlands Dementia Pathway Team.

A pilot project was funded by the Department of Health, involving 22 schools as part of a Pioneer Group to trial different approaches for improving awareness and understanding of dementia amongst school pupils, with the aim being to extend the project to include other schools in the future. While it is understood that 19 schools proceeded to deliver a dementia curriculum, only 13 of these (six primary schools and seven secondary schools and colleges) participated in an evaluation of the project which was carried out by the Association for Dementia Studies and funded by the NHS West Midlands Strategic Health Authority.

Intervention

Each school adopted a bespoke approach to designing their curriculum intervention based around four Key Performance Indicators which were developed by a strategic stakeholder group:

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

Schools balanced theoretical knowledge about dementia and technologies to support people with dementia alongside the intergenerational exchange which provided a practical component giving pupils the opportunity to meeting someone living with dementia and their carers.

Impact of the dementia project

Key benefits

Key benefits reported by schools participating in the evaluation were:

- Increased awareness of dementia;
- Reduced stigma and fear;
- A recognition of the importance and relevance of learning about dementia in schools;
- An appreciation of the caring role and how to support carers;
- Increased awareness of how to help people with dementia to live well, and the challenges and negative attitudes they may face.

Widespread impact

Although over 2,000 pupils were directly involved in the projects undertaken by the schools participating in the project evaluation, the overall impact of the individual projects was in fact far more widespread than anticipated.

Impact on pupils involved in the project

The focus of the project was to enhance understanding and knowledge of dementia amongst pupils. Success in this area was captured by the evaluation, but a further, unanticipated effect was also noted in terms of pupils' own personal development.

- Impact relating to dementia:
 - Greater awareness and understanding of different types of dementia;
 - Greater understanding and appreciation of the caring role and support available;
 - Appreciation that people with dementia can have a good quality of life;

- Increased understanding of assistive technology and their benefits for people with dementia and their carers;
- More awareness of how to help people with dementia;
- Changed views of people with dementia and more aware of how they are seen by others;
- Greater confidence about meeting people with dementia, especially when they have actually met someone.
- Impact on personal development:
 - Enhanced understanding of the importance of a healthy lifestyle, embedding knowledge from the project and linking this to a reduction in the risk of developing dementia;
 - Development of transferable skills including enhanced confidence, leadership and interpersonal skills which permeate and impact upon their engagement in the wider curriculum;
 - Altered perceptions of older people more globally.

Impact on teachers involved in the project

A wider impact in relation to teacher knowledge and understanding was evidenced:

- Improved knowledge of dementia;
- Greater understanding of the importance and relevance of dementia in a school setting.

Wider impact within the school community

Although the impact within the school community has affected all involved, the following have been particularly beneficial for pupils and staff with family experiences of dementia:

- Greater awareness of dementia;
- Parents are able to have conversations about dementia with their children;
- Pupils have a greater understanding of the responsibilities and pressures facing parents or relatives who are in a caring role, either professionally or personally.

Impact outside the school community

- Being involved in the project helped some carers to see their loved ones in a different way and reconnect with them;
- Taking part in some of the activities had emotional cognisance for some of the people with dementia involved in the project;

- Community awareness of dementia is likely to have increased due to indirect contact with projects.

Depth of impact

In addition to a widespread impact, the depth of the impact of the project has also been surprising. Pupils were still able to enthuse about what they had learnt and reflect on how they felt about being part of the project a number of weeks after completion.

Many schools who have participated as a pioneer school are preparing to continue with their projects in the next academic year and beyond; incorporating new ideas, building on their increased confidence around dementia, and being more ambitious about what they believe is achievable.

Different approaches to the dementia project

Schools adopted a wide variety of approaches, resulting in bespoke projects. This reflects the ingenuity and resourcefulness of both the teachers and pupils involved, but also demonstrates what is achievable within a relatively short time span.

Individual projects ranged from simple to complex, over differing lengths of time, but the unifying fact remains that improvements were seen within every school regardless of their approach. Any school wishing to implement their own dementia project in the future should therefore be able to use the guidance, resources and activities identified in this report to identify an approach to match their requirements.

Many teachers identified from the outset that participation in the dementia project followed a steep learning curve not only in addressing their own preconceptions about dementia, but also in recognising gaps in their own knowledge base. Pupils approached the project with less trepidation and were generally very enthusiastic wanting to learn about dementia to address their 'fear of the unknown'. In looking to the future, whilst acknowledging teachers' natural caution in approaching a new and sensitive subject, the successes shared in this report should act as a catalyst to reassure teachers that whether large or small, simple or complex, change in knowledge around dementia for all age groups is achievable.

Recommendations for schools looking to implement a Dementia

Awareness and Intergenerational Exchange Project

The evaluation recognises that some teachers and schools faced a variety of challenges during the course of the project, but that for the 13 schools who took part in the evaluation these were outweighed by the vast array of benefits. Based on these

challenges, but also building on what worked well for schools, a series of recommendations were developed.

These recommendations should be considered by all those interested in implementing a dementia-focused curriculum, but may be of particular significance to educational authorities, Clinical Commissioning Groups, Health and Wellbeing Boards, the Department for Education, Public Health England and the Department of Health:

- The project requires a lead teacher who has time allocated to project planning and delivery. Where possible, this lead teacher should be supported by fellow teachers and administrative staff;
- In order to confidently deliver a dementia component to a curriculum, teachers themselves need sufficient knowledge and understanding of dementia and need to be able to access suitable resources. Teachers should draw on their knowledge of their own school's demographics to flexibly and creatively tailor their approach;
- Time allocated to the project should be ring-fenced within the curriculum to avoid competition from other subjects and events. When planning project timescales known events should be taken into consideration;
- Lead teachers should consider forging links with key local community resources based on what is available to them and the nature of their chosen intergenerational exchange. Examples include The Alzheimer's Society, the local Dementia Action Alliance, the Local Authority, academic institutions, local industry, art and drama resources, patient and carer groups, care homes and extra care communities, etc;
- Themes for the intergenerational exchange component should be as realistic as possible and the examples in this report are for guidance only. Wherever possible pupils should be given the opportunity to meet people with dementia and their carers;
- Appropriate support should be provided for those involved in any projects undertaken. Pupils and staff may be affected by any of the issues raised during discussions, especially those with family experience of dementia. When inviting people with dementia into the school building the suitability of the environment should be considered;
- Pupils should be encouraged to take ownership of the dementia curriculum in generating their own ideas and initiatives to foster partnership working and embed deeper learning.

Wider recommendations to support and sustain similar projects

School pupils are the citizens of the future, and have a key role to play in developing sustainable and inclusive dementia-friendly communities. Efforts to create dementia-

friendly communities must therefore involve schools. When taking this pilot project forwards in the future, the following should be considered to ensure its sustainability:

- Resources, projects and emerging activities should be shared with teachers via a website or appropriate online resources including social media;
- Providing information sessions for teachers should be considered an integral option for improving their knowledge of dementia;
- Consideration should be given to creating an award scheme which may be sponsored by the Prime Minister's Challenge on Dementia or through the provision of a national incentive to increase the uptake of schools embedding dementia within their curriculum.

Introduction

Background to the intergenerational schools project

Dementia as a global problem

Issues of an ageing population are becoming a national and international concern. For the first time in history we are set to see the number of people over the age of 65 outnumber children under 5 years of age in every country, with the exception of Africa, by 2016 (National Institute on Aging, 2012). In response to this, almost every nation has begun to take political, cultural and social steps towards creating a framework to support our oldest and most vulnerable citizens.

With the prevalence of dementia increasing with age there are approximately 800,000 people currently living with dementia in the UK, with this figure set to double over the next 40 years (Alzheimer's Society, 2013). In 2010 the total number of people with dementia worldwide was estimated to be 35.6 million (WHO, 2012). This figure is projected to double every twenty years. The total number of new cases of dementia each year, worldwide, is nearly 7.7 million, implying one new case every four seconds (WHO, 2012).

Although dementia mainly affects older people, it is not a normal part of ageing. Dementia is a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities (WHO, 2012).

Addressing the problem in the United Kingdom

In the UK the Government have responded to public concern through the Prime Minister's Challenge on Dementia (Department of Health, 2012), which set out their commitment to build on Living Well with Dementia: A National Dementia Strategy (Department of Health, 2009) to support those living with dementia and their carers. The Challenge focuses on three key areas:

1. Driving improvements in health and care
2. Creating dementia-friendly communities that understand how to help
3. Better research

The second strand of this Challenge has been championed by Angela Rippon and Jeremy Hughes in a bid to raise awareness about dementia and dispel many of the current misconceptions which impede the ability for people with dementia to live well. Stigma

and social isolation act as barriers to inclusion, preventing people from leading full and meaningful lives. Two-thirds of people with dementia live in the community – a significant and increasing number of them on their own – yet 62% of people with dementia who live on their own said they felt lonely (Alzheimer’s Society, 2013). The stigma around dementia is saturated in fear and negativity. People regularly report on the ‘burden’ of dementia, the ‘incurable and debilitating’ nature of the disease. Tackling these challenges

“can happen only with well-developed and executed political and public campaigns to support a societal shift towards acceptance and inclusion of people affected by dementia” (Alzheimer’s Society, 2012, p2).

The intergenerational exchange schools pioneer project

An intergenerational exchange initiative to the dementia-friendly communities work was introduced, focusing on the need for communities to invest in the future of their young people. Intergenerational programmes were developed in the 1970s in the United States

“in order to correct what was then perceived as a threat for its society: the growing distance and confrontation between different generations. Over the last forty years, these programmes have shown, in North America and elsewhere that they can help to eliminate, or at least diminish, some of the barriers preventing intergenerational contact and relations” (Sanchez et al, 2007 p12).

A key component of these programmes are activities that increase cooperation, interaction and exchange between the members of any two generations, involving sharing skills, knowledge and experience between young and older people (Ventura-Merkel and Liddoff, 1983), which act as vehicles for the purposeful and ongoing exchange of resources and learning for individual and social benefits (Hatton-Yeo and Ohsako, 2001). Decades later this approach is thriving in the States with examples such as the Harvard medical student who visits his 85 year old ‘mentor’ every week. With both parties enjoying clear benefits, this student went on to establish the Alzheimer’s Buddy Program, which pairs residents of a local care home with Harvard students capitalizing on creating bonds based on areas of mutual enjoyment and interest (Dementia Today, 2012).

The intergenerational exchange initiative of the Prime Minister’s Challenge took its lead from work undertaken by Dr Karim Saad, the Regional Clinical Lead for dementia in the West Midlands, in collaboration with the Association for Dementia Studies at the University of Worcester and the NHS West Midlands Dementia Pathway Team. This

work developed an online resource (Teaching aids, 2012a, 2012b, 2012c, 2012d) to raise awareness of dementia in children and young people and addressed the findings of a survey which identified that awareness of dementia and services to support people with dementia among the general population was very low and that in particular young people had very limited understanding.

Benefits of engaging in just a one hour programme were noted to be:

- An understanding of dementia including its common causes
- An appreciation of the difficulties of being a carer
- A grasp of assistive technologies and their different applications

These elements were initially devised with Personal, Social and Health Education (PSHE), Design & Technology or Science teachers in mind. Together with the intergenerational exchange initiative of sharing skills, knowledge and experience between generations, they were brought together to create and expand an innovative pilot project. This pilot was led jointly by the Department of Health, the Alzheimer's Society and the Health and Social Care Partnership.

Although it was recognised that some schools across the country were already including dementia in their curricula, 21 schools were invited to become part of the Pioneer Group; schools who would lead the country in trialling innovative approaches to develop awareness and understanding of dementia in their pupil population. An additional school became involved with the project at a later date, creating a total of 22 schools.

Educating young people to become citizens of the future who are informed and prepared, not only enables them to develop their own sense of self but also to become active members of a cohesive community. Citizenship is part of the National Curriculum aiming to

“equip pupils with the knowledge and skills needed for effective and democratic participation. It helps pupils to become informed, critical, active citizens who have the confidence and conviction to work collaboratively, take action and try to make a difference in their communities and the wider world” (Department for Education, 2012).

Addressing sensitive issues through education is key to ensuring young people are ready to face the challenges of tomorrow and embrace the future with confidence. Focusing on dementia as an exemplar of a stigmatised, neurodegenerative disease was therefore hypothesised to be an appropriate subject upon which to model values including

compassion, respect and dignity, and to explore pupils' capacity for caring and resilience in the face of adversity, loss and marginalisation.

"It is so important to remove the stigma of dementia in society and achieve better community support and engagement for now and in the future, by educating children about the condition"

(Teacher, Christ Church C of E Primary School)

Evaluation methodology

In order to ensure the approach to raising awareness of dementia in schools was practical and viable, a stakeholder group was established which included representation from:

- Coventry and Warwickshire Partnership Trust
- The Strategic Health Authority West Midlands
- Swanshurst School, Birmingham
- The Association for Dementia Studies, University of Worcester
- Young Carers
- Kevin Knight, Independent Educationalist

The Association for Dementia Studies was commissioned to design an evaluation which could capture changes in young people's attitudes, knowledge and understanding of dementia as a result of the awareness-raising curriculum during the pilot project. The stakeholder group developed four Key Performance Indicators (KPIs):

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

Questionnaires intended to be administered before (baseline) and after (follow-up) the key interventions were designed, which for ease are referred to as pre- and post-curriculum intervention questionnaires. These were designed around the four KPIs and were trialled by pupils at Swanshurst School in Birmingham.

The questionnaires were designed for self-completion by pupils in secondary schools or colleges and for a circle time style teacher-led evaluation at primary level. Evaluation packs sent to the participating schools included:

- Pre- and Post-Curriculum Intervention **Questionnaires**
- An Alzheimer’s Society **Factsheet** on Dementia
- A key-stage appropriate **Information Sheet** about the project
- An **Outcomes Framework** linked to the KPIs

Schools were advised that the pre-curriculum intervention questionnaires should be completed prior to any dementia raising awareness to ensure genuine baseline data could be captured. A deadline for return of this phase was set for the end of November 2012 with a deadline for the follow-up post-curriculum intervention questionnaires at the end of June 2013.

It was anticipated that the intervening period would then be utilised by teachers to provide opportunities for their pupils to engage in a range of bespoke activities to enhance their understanding of the issues faced by people living with dementia and their carers. Wherever possible, the intergenerational exchange initiative was introduced to allow pupils to experience the issues surrounding dementia first hand.

The timeline for the pilot project is shown in Figure 1, highlighting the key evaluation and reporting activities that have taken place.

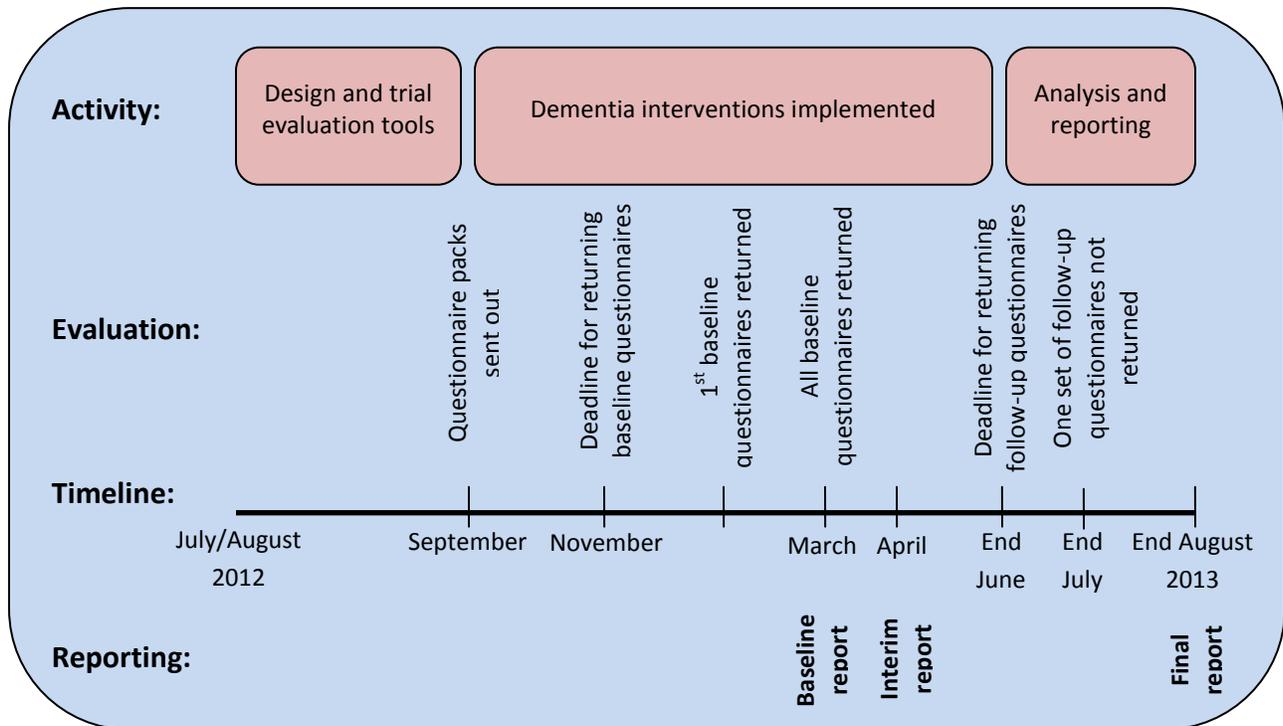


Figure 1: Intergenerational schools pilot project timeline

Report structure

The main findings from the project evaluation are reported here in the following main sections:

- Schools information – providing information about the response rates, approaches taken and demographics for the participating schools;
- KPI 1: Understanding dementia – Key findings relating to the first KPI, and the impact of the pilot project in this area;
- KPI 2: Caring for someone with dementia – Key findings relating to the second KPI, and the impact of the pilot project in this area;
- KPI 3: Assistive and digital technology – Key findings relating to the third KPI, and the impact of the pilot project in this area;
- KPI 4: Meeting someone with dementia – Key findings relating to the final KPI, and the impact of the pilot project in this area;
- Case studies – Further details about the approaches taken to include dementia, focusing on three of the participating schools;

The findings are then brought together in an overall project summary. It should be noted that the findings are based on the information obtained from the schools taking part in the evaluation process, rather than all of the schools who were part of the Pioneer Group.

In addition, two appendices are included to provide more detailed information from the evaluation, and information about the resources developed and used by the schools. The latter is included in the hope that it will help to develop a website of resources and ideas which will be accessible to teachers in a subsequent phase of the project¹ when it is anticipated that the number of schools involved will greatly increase. Appendix 2 is supplemented by an accompanying DVD containing all of the resources and information.

¹ <http://www.hscpartnership.org.uk/policy-and-consultancy/our-current-projects/intergenerational-and-schools-project/>

Schools information

Evaluation response rates

Overall

Of the 22 schools participating in the pilot project, 10 were primary schools and 12 were secondary schools or colleges. The response rates are shown below, where it can be seen that not all of the schools took part in the formal ADS evaluation process. Although some of these schools still delivered a dementia curriculum and carried out their own evaluations, they are beyond the scope of this report.

It should therefore be noted that the findings presented in this report only relate to the schools that participated with the ADS evaluation.

Primary schools

The situation with regards to primary school participation is shown in Figure 2, where it can be seen that the six schools taking part in the formal evaluation have remained fully engaged with the process.

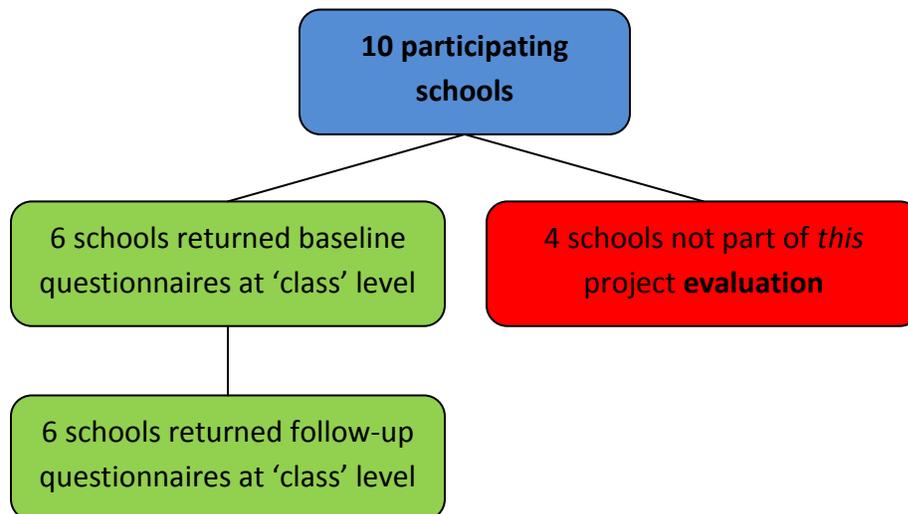


Figure 2: Responses from primary schools

Secondary schools and colleges

The situation for the secondary schools and colleges is shown in Figure 3. One of the schools taking part in the evaluation returned their follow-up questionnaires after the scheduled deadline, but has still been included in the analysis.

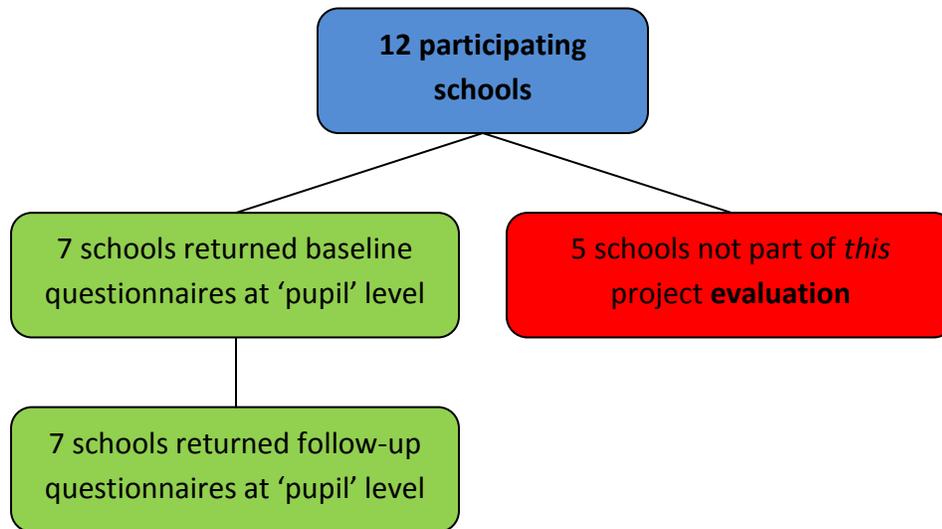


Figure 3: Responses from secondary schools and colleges

Participation with the evaluation

As can be seen from Figure 4, the Pioneer Group schools were primarily in the southern half of the country, with two main groups in Devon and Gloucestershire. Many of the Devon schools participated in a separate evaluation which was carried out at a local level and is not included in this report. The 13 schools that participated with the pilot project evaluation provide a good geographical representation of the Pioneer Group.

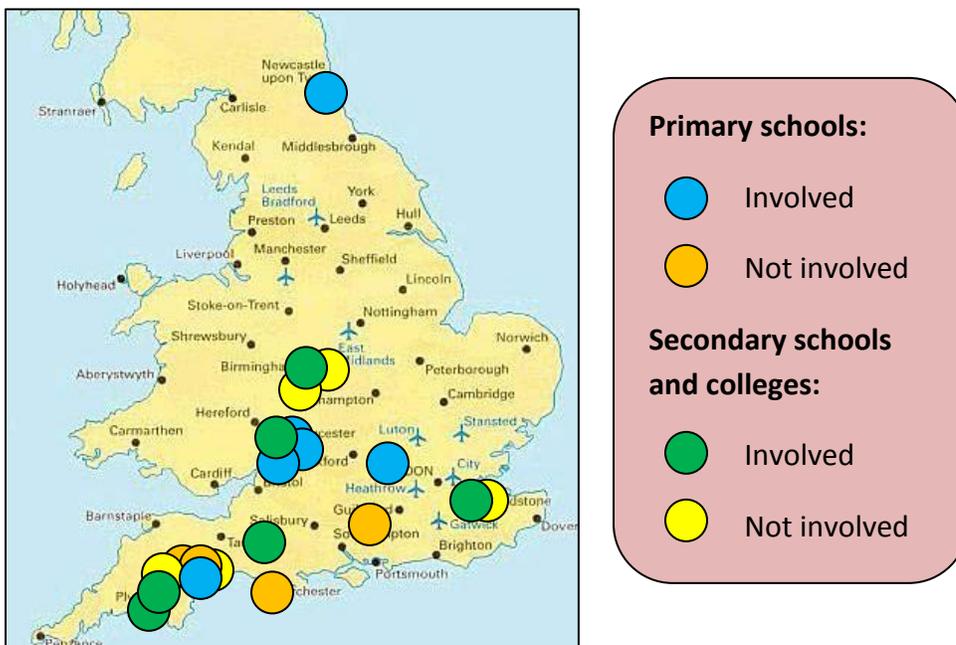


Figure 4: Location of primary and secondary schools and colleges participating in the evaluation

Overview of the schools involved in the evaluation and the approaches taken

Table 1 and Table 2 provide a detailed overview of the different approaches and example activities undertaken by the Pioneer Group schools that were involved in the pilot project evaluation. Further information about the activities can be found in Appendix 2. Although the tables provide an idea of the variety of work implemented, they do not do justice to the sheer scale and extent of different projects.

It is interesting to note that while some schools included similar topic areas, the ingenuity and resourcefulness of the teachers tasked with taking the work forward – and indeed the ingenuity of the pupils themselves – resulted in a variety of very individual projects. This should act as a catalyst to encourage all schools to recognise that incorporating dementia into the curriculum is achievable through an adaption of the recommendations, resources and activities identified in this report matched to meet the specific situation of individual schools.

In particular, time pressure in terms of the amount of time available to spend on the dementia project was often a factor when planning what would be achievable for each school. Consequently, some schools limited their projects to a few lessons within a single subject whilst others were able to incorporate dementia more widely across the curriculum.

In most schools the dementia project was co-ordinated by a lead teacher, but support from other teachers and their ability to devote time to the project was important for ease of implementation and shared workloads.

“free up somebody, the person that’s responsible to have a window of time allocated to dementia, otherwise it will really limit what they can do”

(Lead teacher, Northfleet School for Girls)

School	Ages	Year group(s)	Number of boys/girls		Main approach taken	Example activities
			Baseline	Follow-up		
Bernard Gilpin Primary School	7-11	3-6	64/51	70/56	Included in Year 3 PSHCE and Year 5 Science Definition of dementia Learning about the brain and dementia	Year 5 debate on dementia Choir/singing for the brain Visit from people with dementia and their carers School assembly
Christ Church C of E Primary School	10-11	6	14/15	14/14	5 lessons Worked with local care home	Pupils interviewed older relatives Pupil-led assembly
Copplestone Primary School	8-9	4	10/15	11/15	Visitors invited into school (e.g. GP) Linked with local care home Role play	Q&A sessions with visitors Making memory box Singing in local care home School assembly
Curzon C of E Combined	8-9	4	7/17	7/17	5 lessons Pupil-led research Visitors invited into school (e.g. Alzheimer's Society)	Visit to Singing for the Brain group Pupil-led assembly
Gretton Primary School	9-11	5-6	28 pupils in total each time		Lessons Peer-to-peer learning	Understanding dementia worksheet Pupils from Newent Community School came in and taught a lesson
Harewood Junior School	10-11	6	12/14	12/14	Lessons Peer-to-peer learning	Pupils from Newent Community School came in and taught a lesson Games & activities to show what it is like to have dementia
Overall	7-11	3-6	247 pupils	258 pupils		

Table 1: Summary of primary school approaches

School	Ages	Year group(s)	Number of boys/girls/unknown		Subjects	Main approach taken	Example activities
			Baseline	Follow-up			
Gloucestershire College	17-19	13	2/47/0	3/9/0	Level 3 Health & Social Care	Lesson with Assistive Technology Specialist Peer-to-peer learning	Taught a lesson on assistive technology at Newent Community School Raising awareness and fund raising across campus
The Gryphon School	14-15	10	0/13/0	0/12/0	BTEC Health & Social Care	13 lessons Visitors invited into school (e.g. carers, Alzheimer's Society, care homes) Interactive sessions	Visiting memory cafes Visiting care home
Newent Community School	12-13	8	107/83/0	101/82/2	PHSE	3-4 lessons Visitors invited into school (e.g. dementia specialist) Peer-to-peer learning	Pupils from Gloucestershire College came in and taught a lesson on assistive technology Taught a lesson about dementia at Gretton Primary School and Harewood Junior School Design a mug competition Games & activities to show what it is like to have dementia
Northfleet School for Girls	12-16	8-11	0/279/0	0/245/0	AS & A2 Health & Social Care PHSE	Lessons Visits to meet people with dementia	Life story work & tea party Games & activities to show what it is like to have dementia

School	Ages	Year group(s)	Number of boys/girls/unknown		Subjects	Main approach taken	Example activities
			Baseline	Follow-up			
Okehampton College	11-16	7-11	414/405 /2	314/304 /2	RE	Links to memory cafe Involving staff with experiences of dementia Creating dementia ambassadors	Afternoon tea Music group Dementia afternoon
Stoke Damereel Community College	11-18	7-13	209/322 /1	108/167 /2	English, Science, ICT/Media, Maths, Health & Social Care, Drama, Music, PE, Hospitality, Languages, Business, Careers, Humanities, Art	Whole school approach Visitors invited into school Links to organisations (e.g. Alzheimer's Society) Projects Going out into the community	Writing competition Creating memory boards Staging a fundraising play Creating a mural showing the dementia journey Meeting people with dementia
Swanshurst School	13-14	9	0/287/0	0/276/0	PSHE	3 lessons Visitors invited into school (e.g. people with dementia and carers) Creating dementia champions	Worksheets Games & activities to show what it is like to have dementia Meeting people with dementia and their carers
Overall	11-19	7-13	2,171 pupils	1,627 pupils			

Table 2: Summary of secondary school and college approaches

Overview of the schools involved in the pilot but not in the evaluation

As seen previously, not all of the schools in the Pioneer Group took part in the project evaluation, and indeed some ultimately decided not to implement a dementia project. In total nine schools did not participate in the formal evaluation, although six of these did continue with their own dementia projects. A summary of the reasons for their non-engagement with the evaluation is shown in Table 3 below.

	Reasons for not taking part in the evaluation process
Primary	<ul style="list-style-type: none">• No formal reason given• Decided not to participate in the project• Implemented their own dementia curriculum, but did not participate in the evaluation process• Felt that it would be too difficult to implement the project due to the age of the pupils
Secondary and colleges	<ul style="list-style-type: none">• Not able to implement their dementia curriculum in time to be part of the evaluation process• Implemented their own dementia project, but did not participate in evaluation process• For two schools there was confusion over the questionnaires at a local level which meant that they were not part of the evaluation process• Local issues regarding engagement with a care home meant that the school was not part of the evaluation process

Table 3: Summary of reasons for schools not being involved with the project evaluation

Overcoming preconceptions

Initial hesitation

Many schools, both those who chose to participate in the evaluation and those who didn't, identified initial teacher reluctance or uncertainty with regards to teaching children – especially younger ones – about a sensitive subject such as dementia.

One teacher cited their own feelings and preconceptions about dementia, combined with their lack of knowledge about the subject.

"I shouldn't have made a judgment [...] I thought 'They're going to find it so boring, dementia'"

(Lead teacher, Newent Community School)

In other cases, teachers struggled to see the relevance of dementia to school children.

"I thought 'What's this got to do with me?'"

"It was a mistake on my part not to have seen [the relevance] from the start"

(Co-ordinator for Gloucestershire schools)

Keen to teach

Once the teachers began to investigate further, to set aside their own preconceptions and to improve their own knowledge, feelings towards the importance of undertaking a dementia project quickly changed.

"It is absolutely about children's health and well-being 'cause of course we're all affected by people in our community who have dementia"

(Co-ordinator for Gloucestershire schools)

Keen to learn

Whilst it is important to understand initial teacher uncertainty, this must be balanced by pupils' responsiveness and enthusiasm to tackle subjects that are often the subject of contention and consternation. Recent research has demonstrated that younger people are generally more open to finding out about dementia than older people are with 25% of 18-24 year olds want to learn about dementia compared to only 15% of those aged over 55 (YouGov, 2012).

Feedback from the pupils re-enforced this finding. They were not only keen to learn about dementia but could also appreciate why it is such an important topic. Hopefully this proves to be the catalyst that schools need to encourage them to find new ways to tackle subjects that are currently seen as sensitive or difficult to implement.

"It's good to learn about dementia because there could be people with relatives who have dementia and they could have no idea how to treat them. Also it will teach people not to be scared when they shouldn't be"

(Year 6 pupil, Christ Church C of E Primary School)

"I think that other people should learn dementia because if they had someone in there [sic] family with dementia they would understand why they are angry or frustrated"

(Year 6 pupil, Christ Church C of E Primary School)

When it works well...

For schools participating in the project evaluation, the following comments indicate that implementing a dementia project has been a very positive and rewarding experience, and worth the effort needed to make it happen.

"I would definitely repeat the project again. Our children need to know that if they ever spotted someone in the local community who was lost and suffering from dementia, they can come alongside and reassure them and find help for them"

(Headteacher, Curzon C of E Combined School)

"I have found this project amazing to work on and really informative. I feel that this has helped people become aware of Dementia and hopefully even more people in the future"

(Year 8 pupil, Newent Community School)

In addition, after seeing the benefits of undertaking their own dementia projects many schools are intending to repeat them in coming years and building on them to include new ideas that they have been developing and that have been suggested by the pupils themselves.

"My head's been buzzing all year how, with the help of young people [...], we can take this forward"

(Co-ordinator for Gloucestershire schools)

Pupil information for schools participating in the evaluation

Primary schools

Although the primary schools carried out the dementia project with specific classes or year groups, it was noted that in many cases the work they did had an impact beyond the pupils who were directly involved in the project. For example, by presenting their work in assemblies to the whole school or via wall displays which could be accessed by all pupils, the number of pupils who became aware of dementia was substantially greater than the number of pupils completing the pre- and post-questionnaires.

This 'potential reach' of the dementia project is shown in Table 4 which indicates that although results presented in this report are based on the questionnaire responses for

247 (pre-intervention) and 258 pupils (post-intervention), they represent a much wider group of people.

In addition, it is also possible that staff at the schools may have improved their dementia awareness and understanding further through direct involvement in the project or more indirectly through exposure as a result of their school involvement. This impact is not captured in the raw numbers, but is an important consideration. Another indirect benefit arises through parent/relative-pupil interaction which may further extend the reach of the projects.

School	Questionnaire responses		Potential reach of project
	Baseline	Follow-up	
Bernard Gilpin Primary School	115	126	260+ pupils
Christ Church C of E Primary School	29	28	200+ pupils
Copplestone Primary School	25	26	190+ pupils
Curzon C of E Combined	24	24	140+ pupils
Gretton Primary School	28	28	100+ pupils
Harewood Junior School	26	26	290+ pupils
Overall	247 pupils	258 pupils	1,180+ pupils

Table 4: Primary school pupils taking part in circle time evaluation

As identified in Figure 5, the primary school pupils taking part in the dementia project evaluation achieved a fairly even gender balance. Although the evaluation did not focus on gender difference in any outcomes, it is useful to note that the projects undertaken were essentially generic rather than being gender specific so in theory should be effective in any school regardless of gender balance.

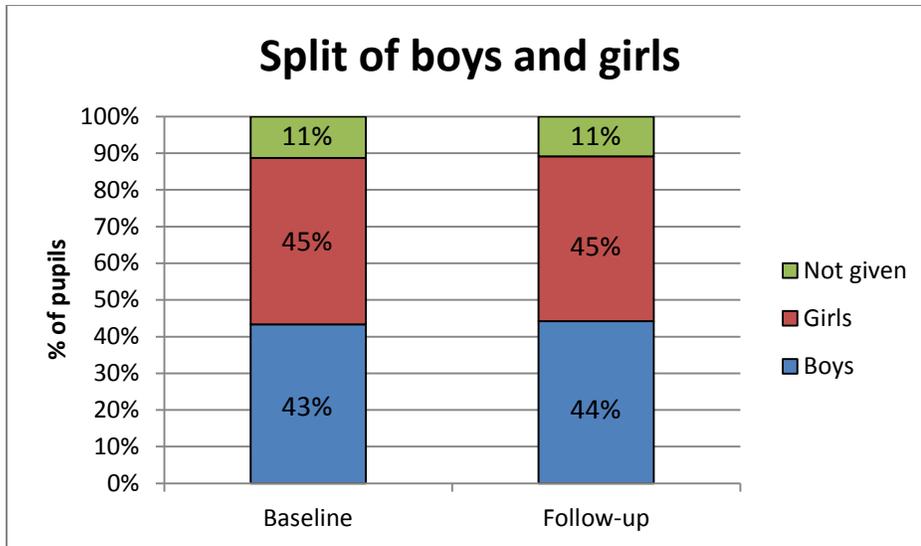


Figure 5: Primary school split of boys and girls

Secondary schools and colleges

As with the primary schools, the potential reach of the dementia projects carried out in secondary schools and colleges was a lot greater than the number of evaluation questionnaire responses as shown in Table 5. In fact the number of potential pupils reached was even higher for some schools as they also have Sixth Forms and/or offer courses for the wider public.

School	Questionnaire responses		Potential reach of project
	Baseline	Follow-up	
Gloucestershire College	49	12	7,000+ pupils
The Gryphon School	13	12	1,600+ pupils
Newent Community School	190	185	1,200+ pupils
Northfleet School for Girls	279	245	1,000+ pupils
Okehampton College	821	620	1,300+ pupils
Stoke Damerel Community College	532	277	1,300+ pupils
Swanshurst School	287	276	1,700+ pupils
Overall	2,171 pupils	1,627 pupils	15,100 pupils

Table 5: Secondary school and college pupils completing individual evaluation questionnaires

Figure 6 illustrates that the gender balance differs in secondary schools and colleges with girls outnumbering boys by approximately 2:1. The higher ratio of girls to boys reflects the fact that two of the seven schools participating in the evaluation were all-

girl schools. However, the approaches and activities developed by these two schools were not gender specific and would be appropriate in any school setting.

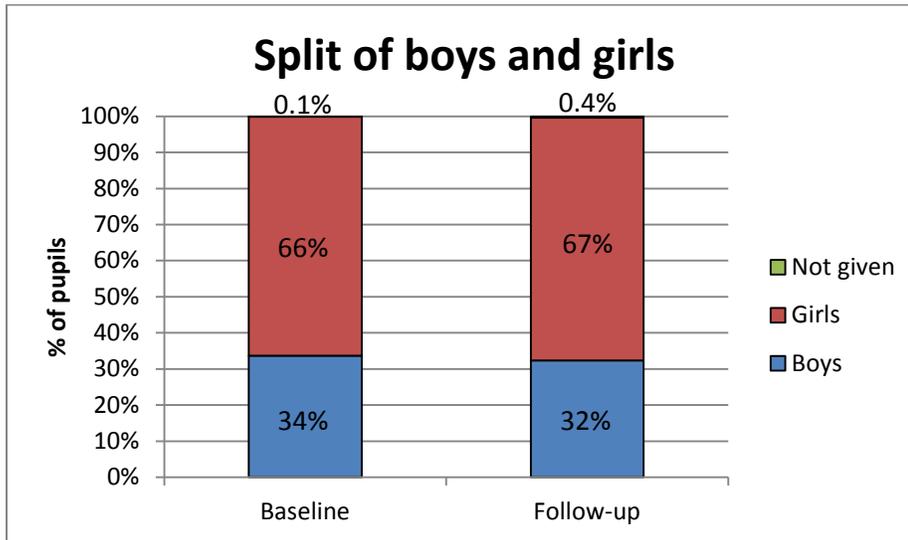


Figure 6: Secondary school and college split of boys and girls

As can be seen from Figure 7 there was a slight difference in terms of the breakdown of pupil ages at the two time points. It was seen in some schools that fewer responses were received at follow-up than at baseline, and these were largely due to the older pupils having time pressures and disruption due to extra tutoring, revision and exams.

Consequently, pupils aged 15+ who were most likely to be affected by exams formed a smaller percentage of the overall group, dropping from 23% to 13%. While this means that these pupils were unable to fill in the follow-up questionnaires, the majority were still able to participate in and complete the dementia project, so should hopefully have benefitted from the work in the same way as other pupils.

However, it was noted that some pupils actually missed out on some lessons due to exam related issues, and so were unable to complete parts of their projects. This resulted in teachers suggesting 'ring-fencing' time for the dementia project in the already crowded curriculum or carrying out the project well in advance of the exam season.

"Completing this project in term five with year 11 meant that many students were taken from PSHE for extra tutoring in core subjects and this meant that some books were not finished"

(Lead teacher, Northfleet School for Girls)

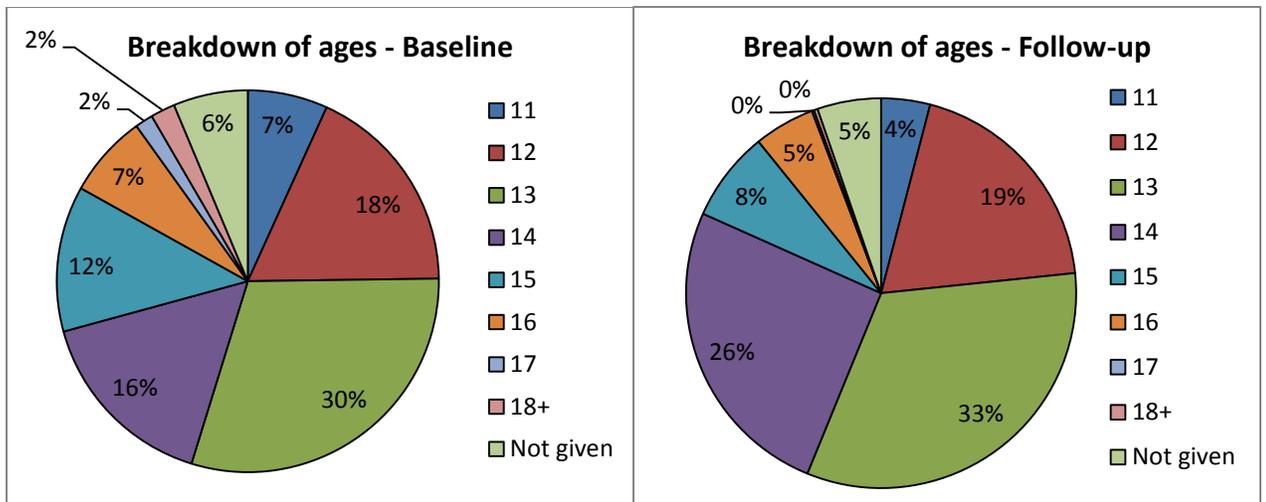


Figure 7: Ages of secondary school and college pupils completing individual questionnaires

Reflecting the results seen in Figure 7, Figure 8 shows that year groups affected by exams (Year 11 onwards) formed a smaller percentage of the responses, dropping from 18% to just 8%.

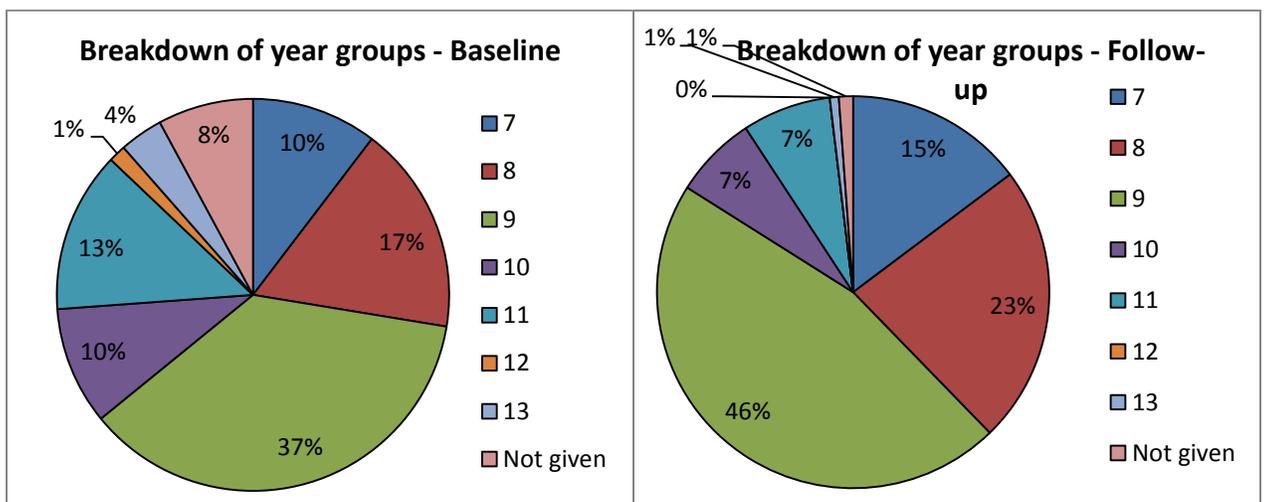


Figure 8: Year groups of secondary school and college pupils completing individual questionnaires

Summary

Challenges faced

Teachers' own preconceptions about dementia, combined with a lack of knowledge and a lack of appreciation of how it is relevant to school pupils were issues that had to be addressed within some schools.

Time pressures within the curriculum impacted on what it was possible for some schools to implement within a project. Some older pupils were also required to miss lessons and parts of the dementia project due to competition with other subjects and exams.

Recommendations and advice for other schools

- Identify a lead teacher to run the project with an appropriate time allocation and support from other teachers;
- Ring-fence time for the project to avoid competition with other subjects. This should cover teaching time within the curriculum and time for additional meetings or activities;
- When timetabling a project be mindful of other events such as exams to minimise the potential impact on lessons and activities;
- Where possible, involve pupils when designing activities as their ideas can add a new depth to the lesson plans.

KPI 1: Understanding dementia

Overview

“Dementia is an important topic that people must be aware of”
(Year 6 pupil, Christ Church C of E Primary School)

A range of questions were designed to explore pupils’ understanding and awareness of dementia to assess not only if they had heard of dementia, but also whether they were aware of different types and the impact it can have on individuals. In addition, feedback from the schools taking part in the evaluation was used to see how awareness and understanding of dementia had changed for a wider range of people, not just those directly working on the projects.

Key findings from the evaluation

Impact on pupils

- Figure 9 demonstrates increased awareness of dementia following the pilot project;

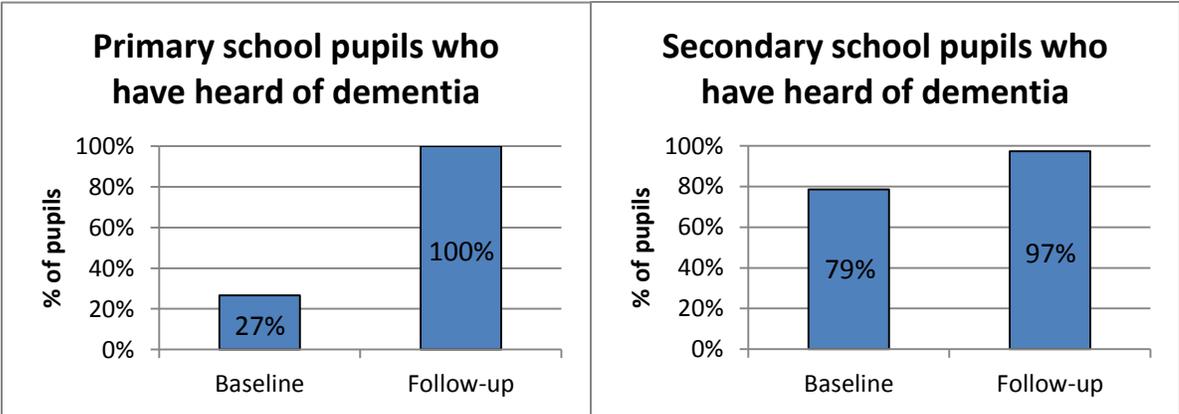


Figure 9: Primary and secondary school and college pupils who have heard of dementia

- Pupils increased their awareness of different types of dementia and could identify that it is not just related to memory problems;

“All I knew before was that it was just forgetting and I thought just old people forget things, but now there’s like so much more to it”
(Year 12 pupil, Northfleet School for Girls)

- Pupils were more aware that dementia is not a normal part of ageing and is not the same for everyone;
- Secondary school and college pupils appreciated that there are many things that people with dementia can do to enjoy a good quality of life and many ways in which other people can help them;
- Although not directly measured in the evaluation, it was noted that pupils were absorbing a wider message related to the benefits of leading a healthy lifestyle (i.e. not smoking, limiting alcohol intake, healthy diet, exercise) when it was linked to reducing the risk of developing dementia in later life.

Wider impact on pupils

In addition to improving the understanding and awareness of pupils directly involved in the dementia projects, there was an additional impact in relation to improved awareness of other pupils within the same schools. This indicates that a project undertaken by one class or year group can actually affect the whole school:

- Pupils were discussing dementia more openly as the stigma around dementia and the 'fear of the unknown' had been removed. Conversations were possible in a safe environment;

"I learnt that dementia is nothing to be scared of and should just be treated with patience and calmness"

(Year 6 pupil, Christ Church C of E Primary School)

- Information about the projects was shared with other pupils through assemblies;
- Activities and visual displays were often in common areas of schools such as hallways.

"The trees provided a very 'visual representation' of the project and were a great way of harnessing experiences of and initiating the conversation about dementia in our school. The trees were located in an area that students would pass regularly and it was great to see groups crowding around reading and discussing the labels."

(Teacher, Northfleet School for Girls)



- The projects also helped pupils who had family experience of dementia, as it enabled them to understand the changes in their relative.

"My great, great Aunt has Dementia and she sometimes forgets who I am and it really makes me sad but thanks to the Dementia project I can understand what's wrong"

(Year 6 pupil, Christ Church C of E Primary School)

Impact on teachers

- Teachers leading the dementia projects often needed to improve their own understanding of dementia in order to share information with to their pupils. Some teachers identified this as a *"big learning curve"*;
- Other teachers within schools where projects were taking place became more aware of dementia and took an interest in the projects;
- By removing the stigma, teachers were more likely to talk about dementia with a wider group of people;

"I've spoken about it to people I wouldn't have spoken about dementia to"

(Lead teacher, Newent Community School)

- As with some of the pupils, the projects have been helpful for staff who have been personally affected by dementia in their family.

Wider impact

- The project has helped parents, especially those who have family experience of dementia, both to understand dementia and to talk about it with their children;
- Dementia was seen as an important subject to cover, and parents were glad that it was being taught;

"Parents often talked to me about what the children had been learning"

(Teacher, Christ Church C of E Primary School)

- News coverage of the projects has also had an impact on the wider community, helping to raise awareness and make people affected by dementia feel less isolated (one lady saw an article about the Newent Community School project including the winner of the 'design a mug' competition. She asked if it would be possible to buy a mug as the words used were *"so appropriate"* to her situation, and was very touched to be sent one for free);



"I might forget your name, but you can love me just the same"

- A Consultant Psychologist in Gloucestershire is investigating if the project has had a wider impact on referrals or GP visits due to increased awareness in the community.

Resources and activities

- Experiencing what it might be like to have dementia, e.g. problems doing everyday things:
 - Tying your shoe laces with the wrong hand;
 - Drawing a star from its reflection in a mirror.

“Just by doing simple activities you can see how difficult it must be for them [...] that was quite a big learning experience ‘cause we didn’t expect it to be as bad”

(Year 12 pupil, Northfleet School for Girls)

- Getting people talking about dementia more openly and helping to reduce stigma:
 - Getting pupils and staff to write about dementia on luggage labels and hanging them on artificial trees around the school;
 - Getting pupils to talk to find out what relatives know about dementia;
 - Holding a competition with a dementia focus, such as designing a mug.
- Increasing awareness beyond specific classes:
 - Making a wall display about dementia which is visible to everyone walking down the hallway;
 - Putting on assemblies to other years/the whole school about the project.



Challenges encountered when addressing KPI 1

Teachers taking part in the evaluation said that they often felt they had little knowledge about dementia and needed to find out more about dementia before deciding what they should include in their lessons and how to incorporate this into the curriculum.

Furthermore, teachers did not necessarily know where to find suitable resources to support their lessons. Many developed their own ideas or adapted resources from other areas.

Recommendations and advice for other schools

1. Suitable information about dementia and resources for teachers should be more widely-available and accessible to make it easier for teachers to undertake similar dementia projects in the future;
2. Schools should establish links with professionals where possible as this can be beneficial in terms of supporting teachers and providing additional information around dementia;

“Having the input from an expert was reassuring for the teacher”

(Lead teacher, Northfleet School for Girls)

3. Due to the nature of some of the discussions that may take place when talking about dementia, schools should consider making support available for any pupils and/or staff affected by any of the issues raised, especially those with personal experiences of dementia.

KPI 2: Caring for someone with dementia

Overview

People within the school community may already be in a caring role for a person with dementia or know someone who is carer. Raising awareness and understanding of the difficulties faced by carers can improve both pupils' and staff understanding.

"I discovered that a number of the children and staff at the school had already been touched by family members, friends and neighbours having dementia, and were struggling to come to terms with what was happening to that person"

(Teacher, Christ Church C of E Primary School)

To assess changes in pupils' understanding of the caring role, they were asked questions around how carers may feel, where to go for support and information, and how carers could be helped. Additional feedback about the impact on carers was also captured.

Key findings from the evaluation

Impact on pupils

- Primary school pupils know more people in a caring role due to the contacts made by the schools during the projects;
- Pupils realised that carers can be from any group of people, but there was a greater recognition of the role played by informal or non-professional carers;
- Secondary school and college pupils have a better understanding and appreciation of the situation faced by people caring for a person with dementia, and were more likely to admire them than to feel sorry for them;
- Unfortunately, caring was still seen in a more negative than positive light;
- Pupils have more awareness of support groups and charities such as the Alzheimer's Society;
- They also have an awareness of the range of interventions to help carers, and are more aware of the need for carers to have a break. Pupils are more understanding of a carer's situation and are more comfortable with the idea of being someone they can talk to, indicating they are more confident in their own knowledge of dementia;
- As well as learning *about* carers, pupils learnt *from* them. By talking with carers they have developed more awareness of how to communicate with people with dementia which has helped to increase confidence;

"We had a dementia carer visit us and she gave us a talk. She helped with the understanding of the actual disease. Like speaking calmly, triggering memories and not correcting them if it doesn't harm them e.g. drinking out of a jam jar. Her talk made me more confident to talk to someone with Dementia and to not be scared to approach them"

(Year 8 pupil, Newent Community School)

- Pupils appreciated having the chance to meet carers and hear about their experiences first hand, and felt that it helped to improve their understanding of the caring role and the responsibilities involved.

Impact on carers

- In addition to the positive impact on the pupils, the project was also beneficial for carers who were involved;

"The benefits of this project have been immeasurable"

"For my part, as a Carer, it helped me to re-engage with Mum as a person, and not just somebody with a disease that needed looking after. It helped me remember the precious memories that can so easily be lost in the day to day routine of caring. It helped me offer a greater dignity and respect to her for all the richness that there is in her life, and to realise that the person hadn't disappeared, but was still there"

(Family carer who worked with Northfleet School for Girls)

- During the evaluation it was also noted that some pupils, whose parents either worked in a care setting for older adults or who had a relative with dementia, had been having more conversations focused on dementia. It is encouraging to see that the project has been a starting point for more open discussions around dementia with pupils taking an interest in parental roles and responsibilities as well as being more appreciative of the difficulties that they may face.

"My mum cares for my gran, who has dementia"

"My mum works at a carehome [sic] and a few of the residents have dementia"

"My dad works with them and he gets stressed from constant care"

(Year 7 & 8 pupils, Okehampton College)

Resources and activities

The key activity to raise awareness of the caring role involved pupils meeting carers and having the opportunity to ask them questions. The carers were often members of the local community, but where appropriate some schools also took the opportunity to involve people from within their school such as teaching assistants who also had experience of caring for someone with dementia.



Challenges encountered when addressing KPI 2

The schools that took part in the project evaluation said that the main challenge they faced was identifying suitable carers and making contact with them.

Recommendations and advice for other schools

In order to find suitable carers to talk to pupils, schools can consider three main routes:

1. Explore your own school community to identify staff or parents who undertake a caring role and would be prepared to discuss this with young people;
2. Establish a link with local care homes who may be willing to share a professional view of caring. They may also be happy to provide additional information or even assist with dementia lessons;
3. Contact local branches of organisations such as the Alzheimer's Society or Dementia UK who would be able to assist in identifying carers willing to discuss their role with pupils.

KPI 3: Assistive and digital technology

Overview

From the baseline evaluation responses it became apparent that pupils initially had very little understanding of assistive technology. This area offered potential for maximum improvement, and questions to assess this improvement focused on the pupils' knowledge of different types of assistive technology and their associated benefits.

Key findings from the evaluation

Impact on pupils

- Figure 10 illustrates the percentage increase in the number of secondary school and college pupils having heard of assistive technology following the project;

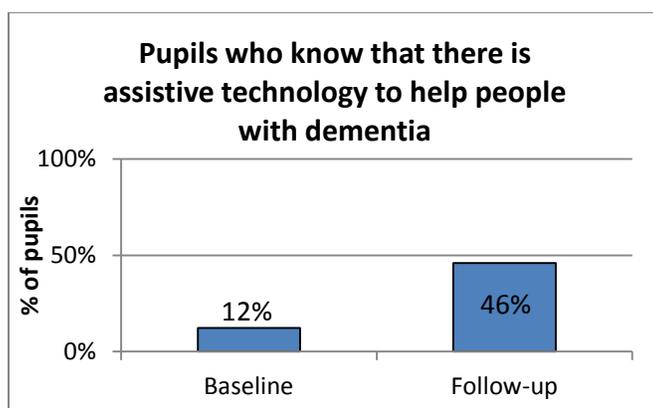


Figure 10: Secondary school and college pupils who have heard of assistive technology

- Not all schools had focused specifically on assistive technology during their projects, meaning that the impact for the schools that had chosen it as an area of importance is masked when responses are averaged across all schools. For example, Gloucestershire College invited a Specialist in assistive technology to come and talk to their pupils. These students then visited Newent Community School to share their learning with secondary school pupils using a knowledge cascade model. Both the pupils and teachers from the secondary school commented that learning from other pupils in this peer-to-peer way helped to embed learning in a far more effective manner than when presented traditionally by the teacher.



This effect can be clearly demonstrated by comparing Gloucestershire College to a school where there is no mention of an assistive technology focus within the project (Northfleet School for Girls, Kent);

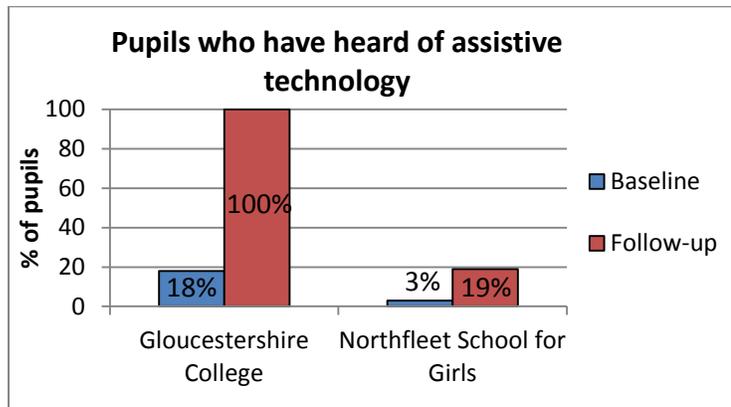


Figure 11: Different approaches taken by schools

- Following the project, pupils were more able to talk about a wide range of different types of assistive technology and how they can be beneficial not just for people with dementia but also for their carers. Key benefits were seen to be independence, support and safety for the person with dementia, enabling them to remain at home for longer, and peace of mind for carers and family;

“More technology around the house to help them with everyday life, so they don’t feel as if there [sic] isolated because of dementia”

“they are more independent, there is less worry for family members”

“it also keeps them out of care homes and it takes a lot of responsibility off [f] the carer”

“it makes the carers feel more reassured that there [sic] okay”

(Year 8 pupils, Newent Community School)

- Pupils were also able to talk about assistive technology when responding to other questions. For example, they felt that it could be a way to help people with dementia, or taking advantage of assistive technology could be something that people with dementia can do to improve their own lives. This suggests that the pupils have a deeper understanding of the role of assistive technology, rather than just being something that they have heard of in a specific situation.

Resources and activities

- Information about types of assistive technology:
 - Specialists visiting schools and talking to pupils;

- A worksheet explaining different types of assistive technology and getting pupils to decide which would be the best option in different situations.
- Wider dissemination:
 - Sharing knowledge between schools by getting pupils to teach each other.

Challenges encountered when addressing KPI 3

There were no specific challenges mentioned around this KPI, although the fact that some schools did not incorporate this aspect suggests that there may have been an issue related to teacher knowledge and understanding.

Recommendations and advice for other schools

1. Teachers need to know how to access information and resources about assistive technology;
2. Ensure lessons have a kinaesthetic 'hands on' element to enable pupils to experience the impact and benefit of assistive technology;
3. Utilise local contacts and companies who may be able to provide specialist information and demonstrations to pupils. This can either be through direct contacts locally where these are available or through the Alzheimer's Society.

KPI 4: Meeting someone with dementia

Overview

In a similar way to many illnesses or conditions that set people apart as being ‘different’ dementia is shrouded in misconception and ignorance. Many children are fearful of meeting someone with dementia simply because they don’t know what to expect; the ‘fear of the unknown’ can be overwhelming. Unless these issues are addressed at the earliest opportunity, the stigma currently attached to dementia cannot be challenged as young people grown into adulthood.

Meeting a person living with dementia was a key component within many of the schools’ dementia projects. The evaluation then sought to capture the changes in pupil confidence, attitude and opinion. Many of the comments captured within the evaluation also reflected the impact the project had on the person with dementia.

Key findings from the evaluation

Impact on pupils

- Where schools were able to create opportunities for pupils to meet a person living with dementia responses indicated a demonstrable increase in pupils’ levels of confidence;

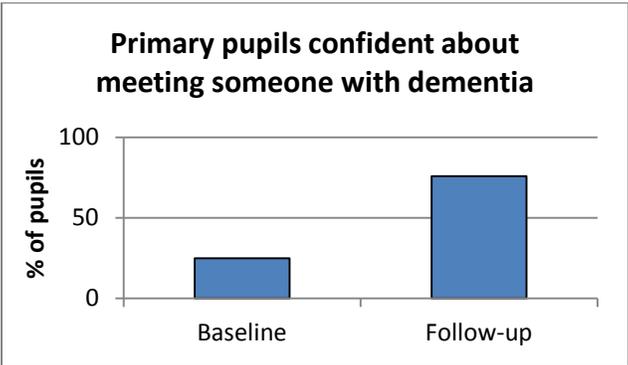


Figure 12: Primary school pupils who were confident about meeting a person with dementia

“The project has given the pupils more confidence and the ability to relate to people with symptoms of dementia”

(Teacher, Christ Church C of E Primary School)

"This project was an eye opener for me, to realise that you don't have to be scared or nervous about Dementia. If I spoke to a person or met a person with Dementia now I would be confident, in control and calm."

(Year 8 pupil, Newent Community School)

- Meeting a person living with dementia removed the 'fear of the unknown' for many pupils. Prior to meeting someone with dementia a pupil said *"I was nervous to meet them, really nervous, I didn't know what they'd be like"*. When asked why they were nervous the two Year 12 pupils from Northfleet School for Girls said *"not knowing what dementia was"* and *"the unknown really"*.
- Pupils felt better prepared to meet and help people with dementia;

"Before when we were meeting the service users I [...] was quite scared to meet them in case next time you go they've forgotten who you was (sic), but now that you know how to act with a dementia person it makes it easier"

(Year 12 pupil, Northfleet School for Girls)

"I didn't know how I would react to someone who is confused, but now I think I will have a better idea and not make that person feel uncomfortable"

(Year 8 pupil, Newent Community School)

- Pupil perceptions of people with dementia have changed;

"Before I thought it was a bit scary and I wasn't really sure at all, but after we spoke to him I realised he's just like any normal person and he can live the same way that we can, just with a bit of help"

(Year 12 pupil, Northfleet School for Girls)

- Pupils have a greater appreciation of how people with dementia are seen by others, and how potential problems around fear and stigma may be resolved. Many pupils felt that providing communities with the right information is central to fighting stigma and ignorance;

Wider impact for pupils

- In addition to changing pupil views of dementia, the project helped them to view older people in a more positive way. Where pupils had the opportunity to meet older people with dementia they were able to develop better relationships with people from a different generation;

"It's just amazing listening to them [...] really appreciating older people in a very different way"

"The students benefitted hugely from having the opportunity to be Dementia Ambassadors. Not just learning about the needs of a service user who has Dementia but through developing a relationship with an older adult and finding out about their life experiences"

(Lead teacher, Northfleet School for Girls)

"hearing their stories about like all their past life is really interesting, 'cause it's completely different to us today"

(Year 12 pupil, Northfleet School for Girls)

Impact for people with dementia

- In addition to pupil benefits, positive experiences were seen for people with dementia who have been involved in the projects;

"There were discussions about the issues surrounding the photos, people in her life, and her likes and dislikes. Invariably, Mum had a lovely smile when relating these events and issues. She seemed so much more animated than was her usual demeanour"

"Whenever Mum looks at the Life Story Book (which is often), she is always absorbed and interested"

(Family carer talking about his Mum who made a life story book with pupils from Northfleet School for Girls)

Resources and activities

- Inviting people with dementia into school to talk to pupils;
- Attending sessions such as 'Singing for the Brain';
- Forming links with local care homes;
- Visiting people with dementia in their own homes and creating a life story book.

“Seeing his face when he remembered something he obviously hadn’t remembered in quite a while, and when he told us about his late wife, ‘cause he got quite worked up about that, [...] and that was sad to see, but I was happy he could remember his wife”

“I think the best thing for me was talking to him and he said [...] ‘the more I look back, the more I can remember’ and he seemed very happy and he looked forward to seeing us every week”

(Year 12 pupils, Northfleet School for Girls)



Challenges encountered when addressing KPI 4

Some schools taking part in the evaluation said that they found it difficult to identify and approach people living with dementia to participate in their projects. For other schools there were issues around time constraints and managing the organisation of the activity.

Where pupils travelled to meet people with dementia there was a cost element associated which became a concern. The actual co-ordination of the activity was referred to as a *“logistical nightmare”* by one teacher. However, this challenge should not diminish the enormous benefits resultant from these opportunities and creative ways to make this activity viable would be key to delivering a successful project.

Recommendations and advice for other schools

In order to identify people with dementia who would be willing to take part in a project, schools should try:

1. Contacting local branches of organisations such as the Alzheimer’s Society or Dementia UK;
2. Forming links with local care homes to see if pupils could be involved in existing activities;
3. Using any existing links that schools may have with professionals or the community where appropriate.

If people with dementia are invited into school it is important that staff are aware of how the school environment could affect them. Staff should take steps to minimise the impact of this by arranging any visit for a quieter time of day, having people available to meet and greet them at reception and using a suitable room for any lessons.

Where possible, work with people with dementia who are relatively close to the school in order to minimise travel costs and coordination.

If the project involves producing something which will be shared with the person with dementia such as a life story book, arrange for extra copies to be available for other family members.

Case studies

Swanshurst School, Birmingham

Swanshurst School is a specialist Science College for girls aged 11-19 based close to the heart of Birmingham. They chose to implement their dementia project with Year 9 pupils as part of their Personal and Social Education (PSE) curriculum. Three individual lessons were devised covering all four of the Key Performance Indicators. Approximately 300 girls aged 13-14 took part in the project and subsequent evaluation.

Swanshurst School has been chosen as a Case Study to exemplify the importance of meeting a person living with dementia



© BBC²



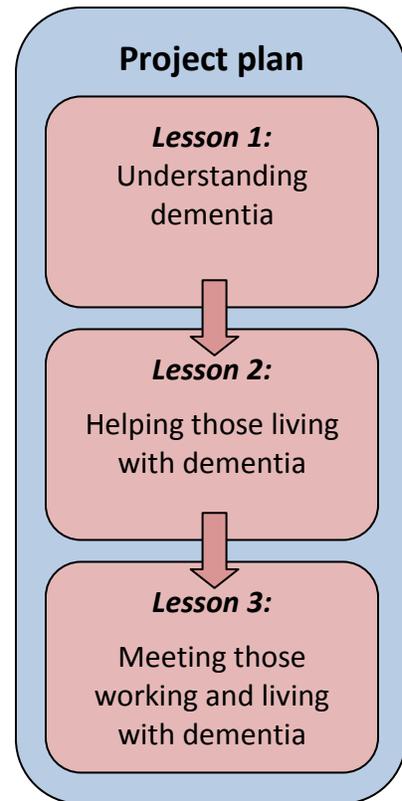
“Deciding to include dementia as part of our PSE programme was one of the best decisions I have made in so many ways”

(Lead teacher on dementia project, Swanshurst School)

² Stills taken from a BBC One O’Clock News report on dementia that was broadcast 08/11/2012.

What did they do?

Swanshurst School found that fitting extra lessons on dementia into an already overcrowded curriculum was not going to be easy, and decided that the best option would be to carry out a series of **three one-hour PSE lessons for all Year 9 pupils**. The project is summarised to the right, with further details below.



Lesson 1: Understanding dementia

Aim to raise awareness of dementia, develop knowledge and understanding about types of dementia, and understand how to reduce the risk of developing dementia.

- Introduce pupils to old age by guessing who digitally aged celebrities are (Worksheet)
- Understanding dementia (Power point presentation)
- Living with dementia (DVD clip)
- What do you know about dementia? (Worksheet)
- Appreciating what it is like to have dementia – communication difficulties and word-finding using the THAI game (Worksheet)

Lesson 2: Helping those living with dementia

Aim to appreciate the difficulties of being a carer, support available for carers, and types of assistive technology and how they can support people with dementia.

- Helping those living with dementia (Power point presentation)
- Different perspectives of dementia - Living with dementia (DVD clip and worksheet)
- Helping those living with dementia – different types of assistive technology (Worksheet)

Lesson 3: Meeting those working and living with dementia

Aim to be able to empathise with people with dementia and their carers, appreciate that a diagnosis of dementia is not the end, and know how to help and support people with dementia and their carers.

To support the lesson, the teachers chose two pupils from each class to become Dementia Champions.

- Meeting those working and living with dementia (Power point presentation)
- Responses to the 'Memory Lane' poem (Part of Power point presentation)
- Dementia Champions 'meet and greet' people with dementia, their carers and professionals who have been invited into school
- Pupils get the chance to talk to the people with dementia, their carers and professionals, and ask questions.

Did it make a difference?

The dementia project had a **positive impact on the pupils' knowledge** in terms of dementia awareness, awareness of assistive technology, meeting people with dementia and confidence meeting people with dementia. Embedding lessons on dementia within PSE worked well, enabling pupils to link their learning to the other curriculum areas. Pupils were able to consider the wider **impact of lifestyle choices** on health in relation to increased risks for developing dementia:

"I was aware of dementia but didn't really know much about it. I was amazed at all the different types of dementia. It hadn't occurred to me that smoking could cause dementia because of narrowing to the arteries to your brain"

(Year 9 pupil, Swanshurst School)

The lessons also had a **positive impact at a personal level** for some of the pupils involved:

*"My grandfather has dementia. I felt very strange with him when I was told because he didn't seem like my grandfather any more. After these lessons I can understand what it is like for him and have been more able to talk with him and to see that **he is still my grandfather**"*

(Year 9 pupil, Swanshurst School)

The **positive impact of meeting a person with dementia** and the power this had on pupils was evident:

*“My favourite lesson was the last one where we had the chance of meeting [husband’s name] and his wife [name] who had dementia. She was such a nice lady and you could see how much [he] loved her. She was a midwife and so was very intelligent and so it was very sad to see her now although you could see that she and [her husband] were still happy. It was **my favourite PSE lesson of the year**”*

(Year 9 pupil, Swanshurst School)

Swanshurst advice for others

- Making contact with the Alzheimer’s Society and local Primary Care Trust (or equivalent) is helpful when trying to identify people with dementia, carers and professionals to be part of lesson 3
- It can be helpful and easier to include dementia in a subject such as PSE where it would have natural links to the messages around healthy lifestyles that PSE aims to convey to pupils

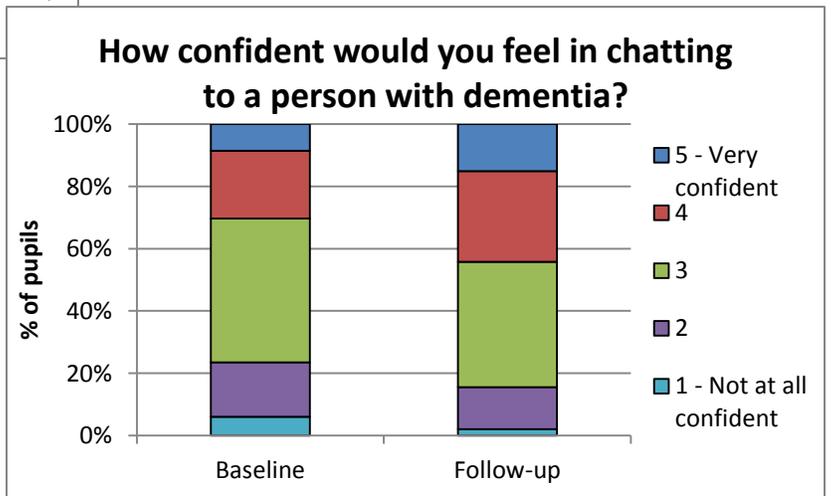
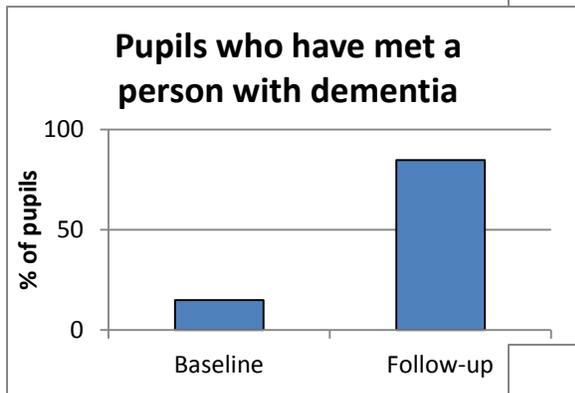
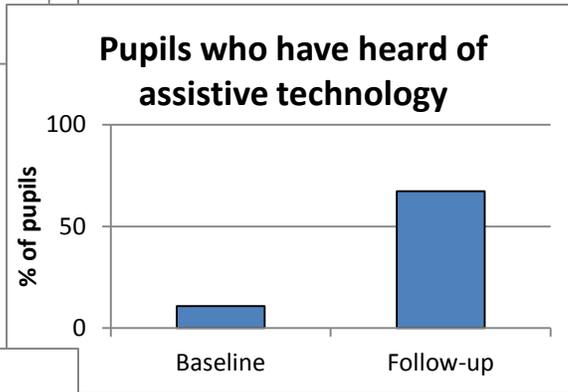
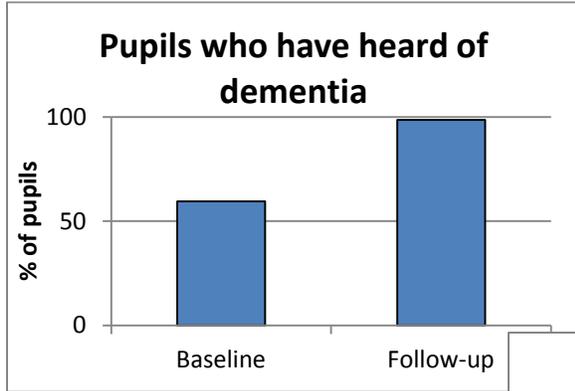
“I cannot think of a better way of getting the ‘don’t smoke, don’t take drugs, don’t drink to excess, and eat sensibly’ message across than this”

(Lead teacher on dementia project, Swanshurst School)

Key learning point

Swanshurst School demonstrated that it is possible to have enormous impact on pupil knowledge and understanding through just **three lessons**. Using the opportunity to **meet a person living with dementia** as a key focus, they **incorporated all four areas covered by the Key Performance Indicators**. This should be seen as an outstanding example of what is achievable within even the tightest of curriculum timetable constraints.

Swanshurst evidence of impact



The Gloucestershire schools

Gloucestershire is a County in the South West of England. Five Gloucestershire schools participated as pioneers in the dementia project, four of which worked together to share information; Gloucestershire College, Newent Community School, Gretton Primary School and Harewood Junior School. They were coordinated at Local Authority level and worked together to cascade knowledge using a peer-to-peer learning approach, with older pupils sharing their knowledge with younger pupils. Year 13 pupils presented lessons to Year 8 pupils, who in turn shared their learning with Year 6 pupils.

The Gloucestershire model has been chosen as a Case Study to exemplify the impact of strategic implementation and peer-to-peer education resulting in sustainable knowledge transfer



Gloucestershire College
teaching Newent
Community School



Newent Community School
teaching Gretton Primary
School and Harewood
Junior School



What did they do?

As one element of their wider dementia projects, four schools in Gloucestershire worked together to share knowledge using a **peer-to-peer learning approach**. The approach is summarised to the right, with further detail provided below.

Step 1

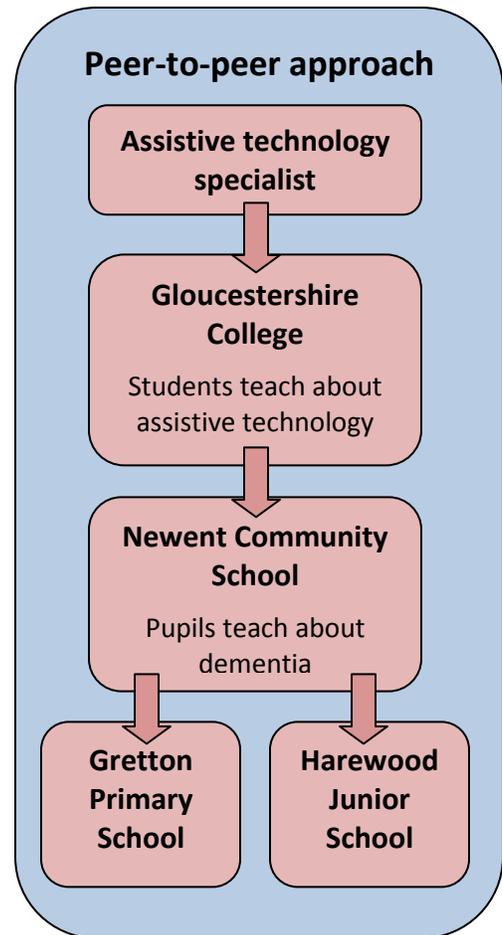
A specialist in assistive technology was invited to Gloucestershire College to teach its Year 13 Health and Social Care pupils about different types of technology and how they help people with dementia.

Step 2

Some of the Year 13 pupils go to Newent Community School to teach one Year 8 group of pupils what they have found out about assistive technology. They also use a memory game to give an idea of what it is like to have dementia.

Step 3

The group of Year 8 pupils split into four smaller groups and prepare lessons containing basic information about dementia. Two groups go to teach these lessons to Year 6 pupils at Gretton Primary School, and two go to teach Year 6 pupils at Harewood Junior School. Example activities they used were the memory game they had been shown by Gloucestershire College, getting pupils to tie their shoelaces with the wrong hand, imagining what it is like being in a foreign country but you don't know anyone or where you are, and acting out how dementia blocks messages in the brain.



Did it make a difference?

Pupils felt that the **peer-to-peer approach** improved their experience of education and enabled them to retain information better with pupils reporting *"it sticks in your head"* better if someone other than your teacher tells you. As part of the evaluation process a focus group with pupils from Newent Community School was held a few months after their lessons on dementia

and assistive technology. They were able to hold a very animated and enthusiastic discussion about a variety of different types of assistive technology:

"We had some college students come and visit us and teach us about dementia. They showed us the different gadgets a person with dementia might have like a pill dispenser. It would bleep when the person had to take his/her pills. Also there was a special button where if the person fell they could press the button and it would contact a phone care clinic. If the care clinic was unable to get a response from the person that had pressed the emergency button they would send an ambulance to check on them. I found this very useful and informative"

(Year 8 pupil, Newent Community School)

The pupils found the opportunity to participate in a teaching fun and enjoyed the feedback shared by pupils who had been involved in their lesson:

"One little girl said her Grandma had Dementia and she now felt much more confident as she understands a bit more about Dementia and she now knows how [to] talk to her Grandma with confidence"

(Year 8 pupil, Newent Community School)

The **sustainability of this approach** is evidenced as teachers continue to hear about the impact of the teaching sessions several months beyond the life of the project. One pupil reported finding the sessions helpful as they had enabled him to **teach him Mum strategies to cope with dementia** after his Granddad received a diagnosis.

A secondary impact of the dementia project was evidenced through pupils **own personal development**. Being involved in teaching others placed pupils in a leadership role, delivering information, answering questions rather than asking them and this helped to **improve confidence**. This confidence was seen as a transferable skill, supporting pupil learning in other areas of the curriculum.

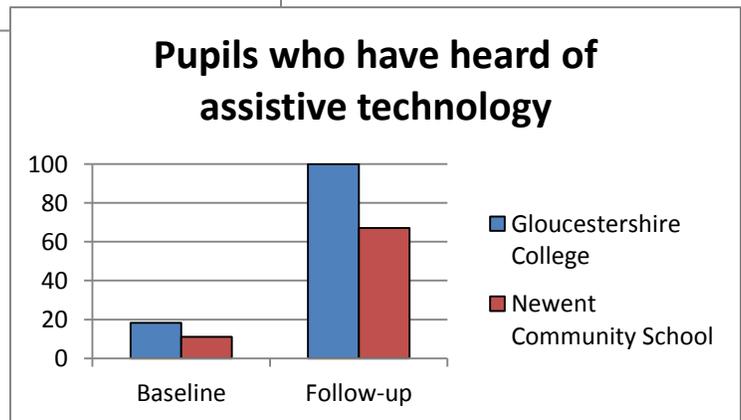
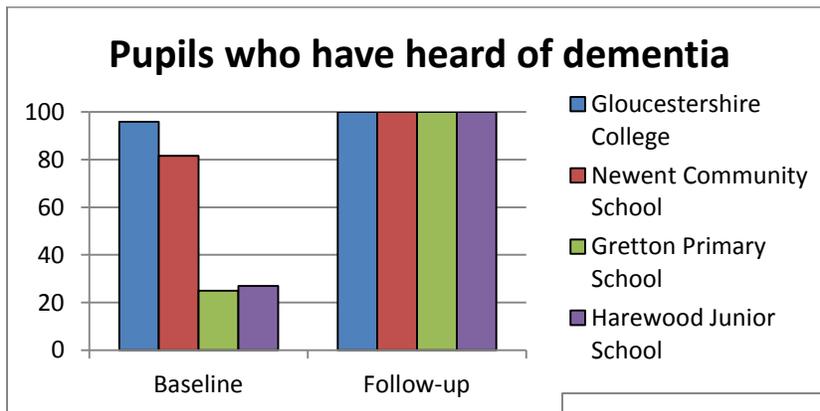
Gloucestershire schools advice for others

- Maintain a small gap between the ages of the 'middle' and 'younger' pupils as this is less daunting for all pupils involved
- Facilitate pupils working with smaller Primary schools – or smaller groups of pupils – this is less intimidating for the Secondary school pupils
- The peer-to-peer education model places the heaviest workload on the middle school, both as a receiver and disseminator of information and learning

Key learning point

The **peer-to-peer education approach** facilitates sustainable learning and fosters personal development. The key element of this successful approach was based on schools which had a **good existing relationship** facilitated by a **key member of personnel** at Local Authority level.

Gloucestershire schools evidence of impact



Stoke Damerel Community College, Plymouth

Stoke Damerel Community College is a specialist college for mathematics and computing located in the heart of Plymouth near to the River Tamar. They chose to implement an ambitious dementia project involving the whole school across all subject areas. Over 500 pupils from Year 7 through to Year 13 participated with the College forming a number of links within the local community.

Stoke Damerel Community College has been chosen as a Case Study to exemplify the impact of a whole curriculum approach



What did they do?

Being located in Plymouth meant that Stoke Damerel Community College was well placed as a pioneer school as it was within a region which has been extremely proactive in its bid to become a **dementia-friendly community**. The college was able to capitalise on existing work and links to adopt a **whole school approach**, incorporating dementia into all of its subject areas and **reaching all pupils**.

A flavour of the main curriculum areas covered to include a dementia element is provided below, which gives some appreciation of the scale of the project.

Whole school approach	
English – creative writing competition	Business Studies – fund raising activities
Science –the biological side of dementia, diet & food plans	Media – working with people in care homes to find out about reminiscence, then creating ‘Memory Sticks’
Maths – designing a memory card game	Drama – creating and performing a play about the effects of dementia
Health & Social Care – working with people in care homes to create ‘Picture memory boards’	PE – bowling alongside elderly people
Music – drumming performance around mental health & well-being. Song competition. Music for dementia play	Media – creating a video and leaflets to raise awareness
Art – designing posters to advertise a dementia-friendly community	Humanities/RE – looking at services helping people with dementia
Languages – designing a memory card game in different languages	Careers – volunteering, working in memory cafes

Working with the community

Plymouth Dementia Action Alliance

Alzheimer’s Society

Age UK

Plymouth City Council

Plymouth University

Local care & residential homes

Local theatre group

People with dementia

Did it make a difference?

Awareness of dementia has increased from 73% to 94% of pupils.

Integrating dementia into a wide range of subjects has helped to remove the stigma around the condition, and made it possible for pupils and staff to have open conversations and discussion about dementia in a way which has not been previously possible.

Stronger links have been formed between the school and the increasing dementia-friendly community.

Pupils are sharing information between subjects, especially when presenting to others, and this is helping both pupils and teachers to learn more about dementia.

Pupils and staff are more able to understand what is happening if they have relatives with dementia, and feel able to talk about it with friends and colleagues.

Pupils have also developed their interpersonal skills. They are more able and confident to talk about their work in front of larger audiences.

"We took some of the Media, Health and Social Care and Art students to make a presentation at a Conference at the University of Plymouth. They all did really well in front of an audience of health professionals and academics - it was particularly good to hear the art students explain the thinking behind their posters and how it connected to what they had learned about dementia from dementia carers"

(Teacher, Stoke Damerel Community College)

Stoke Damerel Community College advice for others

It was useful for all staff to take part in a dementia training session to ensure they had the correct information and knew how to address any issues that arose.

The most successful activities and subjects were those that:

- Enabled the pupils to interact in some way, for example with each other, with older people in general, with people with dementia, or with professionals
- Fully integrated dementia into the curriculum, i.e. longer projects rather than single lessons

Having links such as the local Dementia Action Alliance and City Council made it easier to establish contact with different organisations. For schools where this is not the case, forming key links with local dementia groups would be very important.

Implementing a project on such a large scale can have an impact on teachers' workload, so time must be allocated to account for this. Enthusiastic and interested teachers also make the whole process easier.

"The success of the project will stay with the staff and students for the future to come."

"We know that the project will continue to run and develop"

(Lead teacher, Stoke Damerel Community College)

Key learning point

Feedback from Stoke Damerel Community College has shown that with the right attitude, time and support it is possible to take a **whole school approach** towards dementia. Dementia has transitioned from being a "scary subject" for teachers as well as pupils, to a topic that is openly discussed.

Overall summary

Participation and approaches

Overall, 19 out of the 22 schools from the Pioneer Group implemented a dementia curriculum, with 13 of those participating in the project evaluation carried out by the Association for Dementia Studies

The schools carried out very individual projects using a variety of approaches of differing scale and extent, including:

- Relatively short projects over a few lessons within a single subject area;
- Peer-to-peer learning between schools;
- A whole school project across all subjects.

These approaches require different amounts of time and effort to implement, but have all been seen to have a significant impact on pupil knowledge and understanding. They could easily be adopted and adapted by any school hoping to implement their own dementia project in the future. In addition, a wide variety of resources and activities were developed during the dementia projects which could be used by other interested schools.

Teachers' initial views of taking part in a dementia project were often clouded by their own preconceptions and lack of knowledge about dementia. However, in proceeding with the projects teachers realised the relevance of the work and acknowledged the resultant benefits were worth the effort needed to make the projects happen.

Impact of the dementia project

Key benefits

At a high level, some of the key benefits seen by schools participating in the evaluation were:

- Increased awareness of dementia;
- Reduced stigma and fear;
- A recognition of the importance and relevance of learning about dementia in schools;
- An appreciation of the caring role and how to support carers;

- Increased awareness of how to help people with dementia to live well, and the challenges and negative attitudes they may face.

Impact at different levels

From the information gathered during the evaluation it was evident that the impact of the project was far wider than anticipated. Figure 13 demonstrates that the impact was by no means limited to the 2000+ pupils and teachers who were directly involved in the individual school projects.

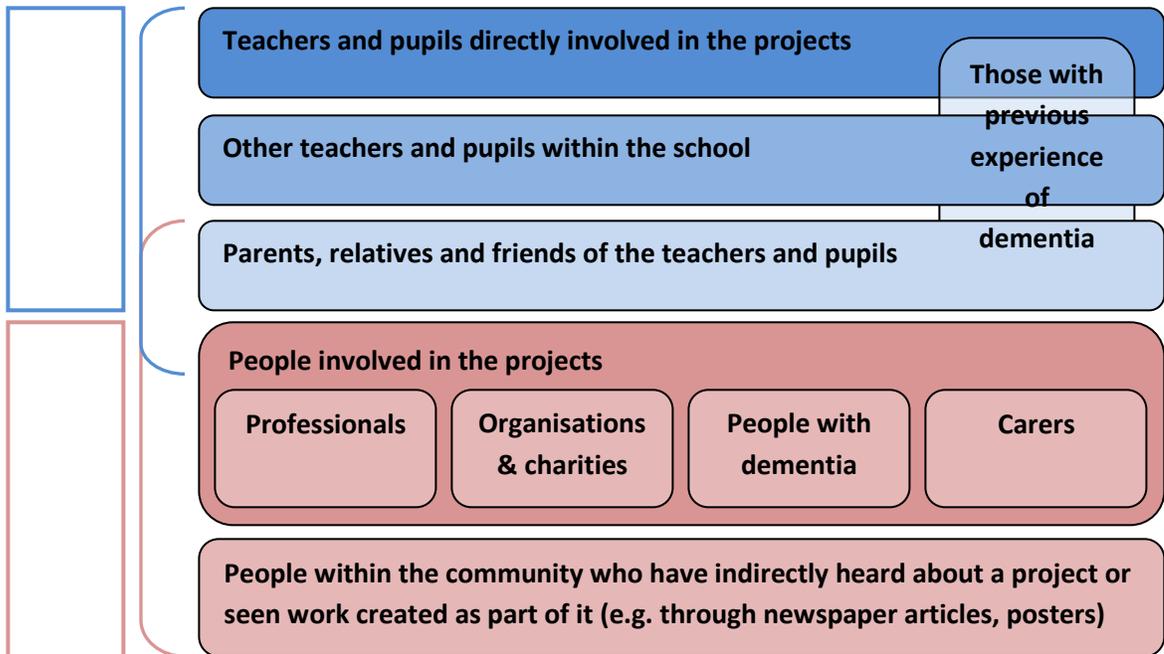


Figure 13: Wider impact of the dementia project

Impact on pupils involved in the projects

Although the anticipated outcome of the project was to raise awareness and understanding of dementia, it was evident that the project also had a secondary impact which extended not only to the wider curriculum but also to pupils' own personal development as shown in Table 6.

Impact related to dementia	Additional impact
<ul style="list-style-type: none"> • Greater awareness and understanding of different types of dementia • Greater understanding and appreciation of the caring role and support available • Appreciation that people with dementia can have a good quality of life • Increased understanding of assistive technology and their benefits for people with dementia and their carers • More awareness of how to help people with dementia • Changed views of people with dementia and more aware of how they are seen by others • Greater confidence in relation to meeting people with dementia, which is enhanced by the opportunity to meet a person with dementia 	<ul style="list-style-type: none"> • Messages around the importance of a healthy lifestyle are linked to reducing the risk of developing dementia • Increased confidence and interpersonal skills which facilitate learning within the wider curriculum • Changed perceptions of older people more widely

Table 6: Impact of the project on pupils directly involved

Wider Impact

The impact of the project on other groups of people involved is highlighted in Table 7.

	Impact of the dementia project
Teachers involved in the project	Improved knowledge of dementia Greater understanding of the importance and relevance of dementia in a school setting
The wider school community	Greater awareness of dementia Parents are able to have conversations about dementia with their children Pupils have a greater understanding of the responsibilities and pressures facing parents or relatives who are in a caring role, either professionally or personally
Carers involved in the project	Being involved in the project helped some carers to see their loved ones in a different way and reconnect with them
People with dementia involved in the project	Taking part in some of the activities was also quite moving for some of the people with dementia involved in the project
The wider community	Community awareness of dementia is likely to have increased due to indirect contact with projects

Table 7: Impact of the project on other groups

Looking to the future

School pupils are the citizens of the future and schools are a key part of the wider community. Therefore, any efforts to create dementia-friendly communities must involve schools and must be sustainable. Inherent dangers in relation to pilot projects are the short-lived effects and waning enthusiasm. That does not appear to be the case with the intergenerational schools project on dementia, and the next phase of the project is already in progress.

Collecting additional evaluation information and feedback about the project often involved meeting and talking to teachers and pupils, and in some cases this took place many months after the schools had actually finished their dementia projects. In spite of this, there was still a high-level of enthusiasm and pupils were still able to talk about what they had learnt in some detail. They were also able to reflect on what they felt about being part of the project and what they got out of it, suggesting that it has had a long-lasting impact on them.

It is also evident that many schools are building on what they have already achieved and intend to continue and improve their projects; identifying the long-term benefits, rather than seeing them as a 'one-off' success. The schools are also keen to incorporate ideas that they have found out about during the course of the project, with some schools becoming more ambitious in terms of what they believe is achievable.

Supporting and sustaining similar projects in the future would be aided greatly by making all of the example resources and activities developed during this work accessible to other teachers through a single, central location. One option for this would be to create a website to house all of this information, which would make it easier for other schools to incorporate dementia into their curricula in the future. This is being considered during the next phase of the project.

Recommendations

Based on some of the main challenges faced by the schools taking part in the evaluation and building on what worked well for them, the following recommendations have been developed as a set of guidelines for how to successfully implement a dementia project:

- The project needs a lead teacher who has time allocated to project planning and delivery. Where possible, the lead teacher should be supported by fellow teachers and administrative staff.
- Teachers themselves need sufficient knowledge and understanding of dementia and access to suitable resources and ideas:

- Resources and activities should be made available to teachers via a website or similar means;
- Providing information sessions for teachers should be considered as an option for improving their knowledge of dementia;
- Teachers should not be afraid to come up with their own ideas or adapt existing work to make it more suitable or applicable for their school.
- Time allocated to the project should be ring fenced within the curriculum to avoid competition from other subjects and events. When planning project timescales known events should be taken into consideration.
- Schools should aim to form links with local dementia organisations, care homes and schools to help with various aspects of their projects.
- Lessons should be interesting and include interactive or practical elements where appropriate to make the learning more 'real' for the pupils.
- Pupils should be given the opportunity to meet people with dementia, carers and professionals where possible and appropriate.

In addition, it is recommended that appropriate support is provided for those involved in any projects undertaken:

- Pupils and staff who may be affected by any of the issues raised during discussions, especially those with family experience of dementia.
- People with dementia and their carers who are invited to take part in activities within the school environment.

References

Alzheimer's Society Report (2012) *Overcoming the stigma of dementia*. London: Alzheimer's Disease International.

Alzheimer's Society (2013) *The Hidden Voice of Loneliness*. London: Alzheimer's Society.

Dementia Today (2012) *Alzheimer's Program has special meaning for Harvard student*.
<http://www.dementiatoday.com/alzheimers-program-has-special-meaning-for-harvard-student>
(Accessed 19/08/2013).

Department for Education (2012) *Citizenship: Programme of Study*.
<http://www.education.gov.uk/schools/teachingandlearning/curriculum/secondary/b00199157/citizenship/ks3/programme> (Accessed 31/07/2013).

Department of Health (2009) *Living well with dementia*. London: The Stationery Office.

Department of Health (2012) *The Prime Minister's Challenge on Dementia*. London: The Stationery Office.

National Institute on Aging (2012) *Global Health & Aging*
www.nia.nih.gov/research/publication/global-health-and-aging/overview (Accessed 19/07/2013).

Sanchez, Mariano (2007) *Intergenerational Programmes: Towards a society for all ages*.
Barcelona: La Caixa Foundation.

Teaching aid developed in previous work (2012a) *Part 1*
http://www.youtube.com/watch?feature=player_embedded&v=bcFxa6qUggw (Accessed 14/08/2013).

Teaching aid developed in previous work (2012b) *Part 2*
http://www.youtube.com/watch?feature=player_embedded&v=AHuK34VzSbg (Accessed 14/08/2013).

Teaching aid developed in previous work (2012c) *Part 3*
http://www.youtube.com/watch?feature=player_embedded&v=jrRZXNYOUSQ (Accessed 14/08/2013).

Teaching aid developed in previous work (2012d) *Part 4*

http://www.youtube.com/watch?feature=player_embedded&v=UU72dbeRumU (Accessed 14/08/2013).

United Nations (2000) Follow-up to the International Year of Older Persons: Second World Assembly on Ageing. A/RES/54/262. June 16.

World Health Organisation (2012) *Dementia: A public health priority*. London: WHO.

YouGov (2012) Dementia survey commissioned jointly by the Alzheimer's Society and Saga Homecare. <http://research.yougov.co.uk/news/2012/05/22/are-you-worried-about-dementia/> (Accessed 12/08/2013).

Appendix 1 – Evaluation detail

Understanding dementia

Basic dementia awareness

Primary schools

As can be seen from Figure 14 the dementia project has had a significant impact on the dementia awareness of primary school pupils, with all pupils having heard of dementia after taking part in the project. This 100% awareness is an increase of 73% in terms of pupils now knowing about dementia.

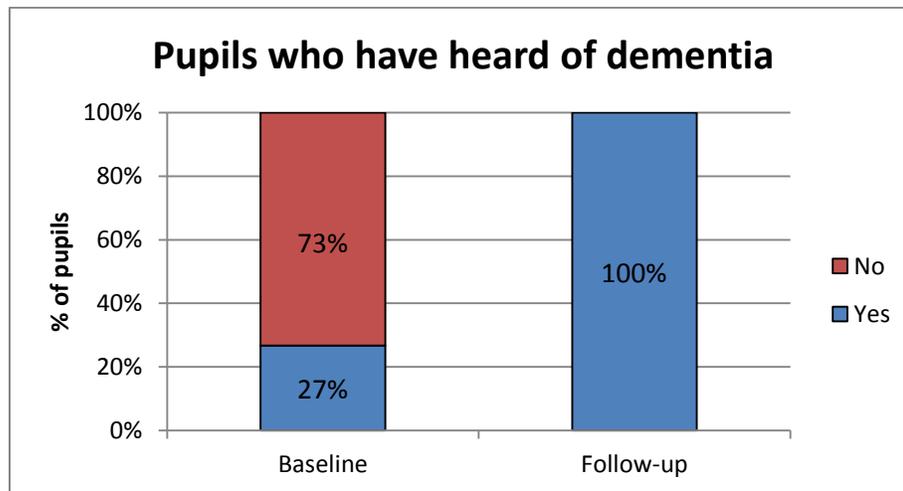


Figure 14: Primary school pupils who have heard of dementia

Secondary schools and colleges

Although the majority of secondary school and college pupils had already heard of dementia at baseline, Figure 15 shows that following the dementia project there had been a big improvement with 97% of pupils now saying that they had heard of dementia (up from 79%).

It should be noted that the responses for some pupils were classed as 'Unclear' as they had either said that they had not heard of dementia or left the question blank, but still said that they had heard of different types of dementia in the subsequent question. If these responses are actually considered to be 'Yes' then the results have improved from 84% at baseline to 99% at follow-up. Although it would be preferable to have 100% of pupils saying that they have heard of dementia and reasons for the negative answers

are not known, allowances must be made for pupils who were ill/absent when certain lessons took place or who may have joined a school part way through the project.

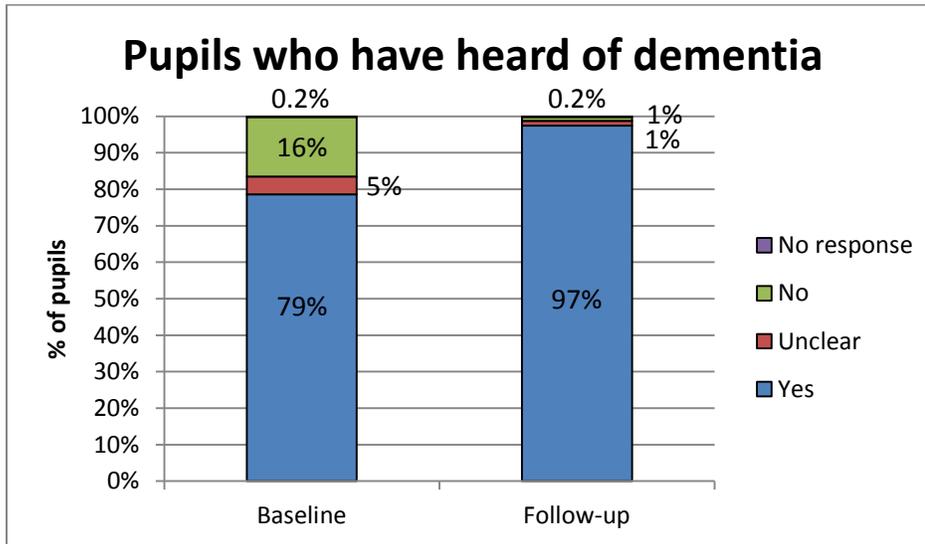


Figure 15: Secondary school and college pupils who have heard of dementia

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

Primary schools

At baseline, comments around what it might be like to have dementia indicated that the only form or symptom of dementia the pupils were really aware of was memory loss or forgetfulness. While the follow-up comments still focused on memory problems, they also included some references to people with dementia having difficulty doing things such as it being hard to read, hard to use technology, hard to get around, and hard to speak which could lead to frustration when people do not understand you. This could be seen as an indication that the pupils have developed a broader understanding of dementia and are aware that it is not limited to memory problems.

Additional feedback from the schools showed that when pupils wrote about what they had learnt from the project, they were indeed aware of and able to list different types of dementia.

“There are many types of dementia such as Alzheimers [sic], lewy [sic] body and other types”

“There are many different types of dementia including vascular, alzheimers [sic] and many others”

(Year 5/6 pupils, Christ Church C of E Primary School)

At both the baseline and follow-up stages, pupils felt that having dementia would be confusing, frustrating, upsetting, tiring and sad, with many pupils at follow-up also saying it would be scary.

Secondary schools and colleges

By the end of the dementia project secondary school and college pupils were also more aware of different types of dementia, with Alzheimer’s Disease remaining the most commonly known as shown in Figure 16. It was encouraging that even the types that were lesser-known at baseline had seen an increase in awareness, with only fronto-temporal lobe dementia remaining at less than 20%.

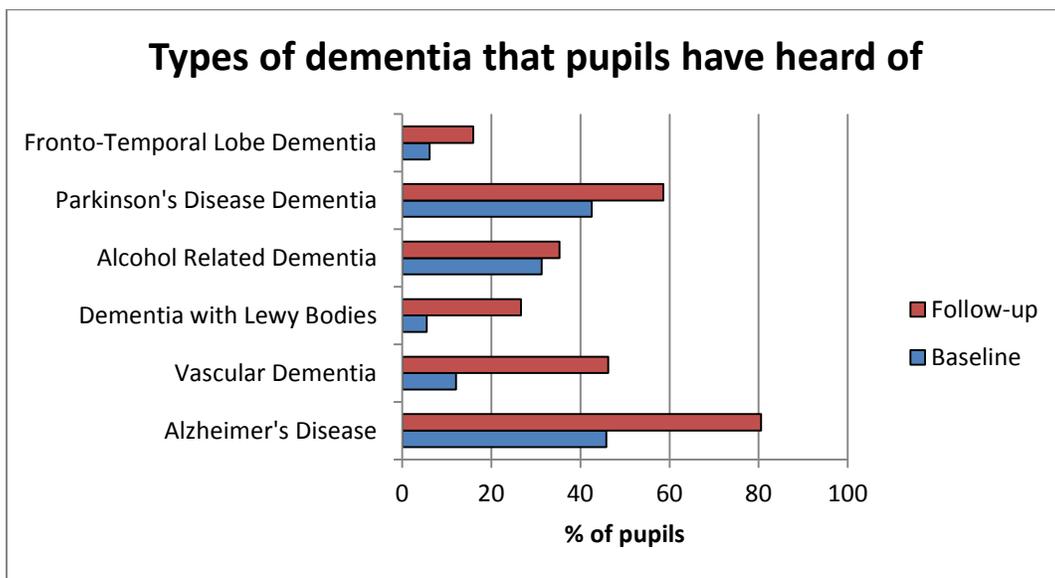


Figure 16: Types of dementia that secondary school and college pupils have heard of

Most pupils understand that dementia is not the same for everyone

Primary schools

At baseline only 6% of primary school pupils thought that dementia affects everyone in the same way, indicating a good understanding that dementia is not the same for everyone. However, it should be noted that two schools did not respond to this question as the pupils did not know what dementia was at the time, meaning that the 6% only really applies to pupils from four of the six schools.

At follow-up 9% of pupils thought that dementia affects everyone in the same way, which at first glance suggests a worse response. However, this follow-up result is across all six schools. When the two schools who did not respond at baseline are excluded, the

result falls to 0%, showing that there has indeed been an improvement in the pupils' understanding in the remaining four schools. The results are summarised in Table 8.

	Baseline	Follow-up
4 out of 6 schools	6%	0%
All 6 schools	-	9%

Table 8: Primary school pupils who thought that dementia affects everyone in the same way

At both baseline and follow-up the pupils used a range of generally negative words to describe what they thought it would be like to have dementia, and the following short poem written about how someone with dementia might feel also focuses on the negatives.

"I stood there all cold and alone. My frustration got to me. Confused I was. I had forgotten my family and friends. These muddled memories will never end. During the course of my life. I saw the best of me. I stood there all cold and alone. My frustration got to me"

(Year 5/6 pupil, Gretton Primary School)

However, it was reassuring to note that one follow-up comment said that it is "tough and scary but you can still live well and be happy with it" and another poem from the same school had a more positive side to it.

"Dementia makes you feel sad and lonely, makes you loose [sic] good memories, but your family will still love you the same. Just listen to your family and they will make you happy"

(Year 5/6 pupil, Gretton Primary School)

Secondary schools and colleges

As can be seen in Figure 17 at baseline only 11% of secondary school and college pupils thought that dementia affects everyone in the same way, indicating that the vast majority saw dementia as being a very individual illness. Although this was already quite positive, the follow-up results showed an improvement with only 8% of pupils now thinking that dementia affects everyone in the same way. This improvement is even more impressive than it initially appears as at follow-up 97% of pupils expressed an opinion compared to 93% at baseline, i.e. pupils were more likely to actively disagree that dementia affects everyone in the same way.

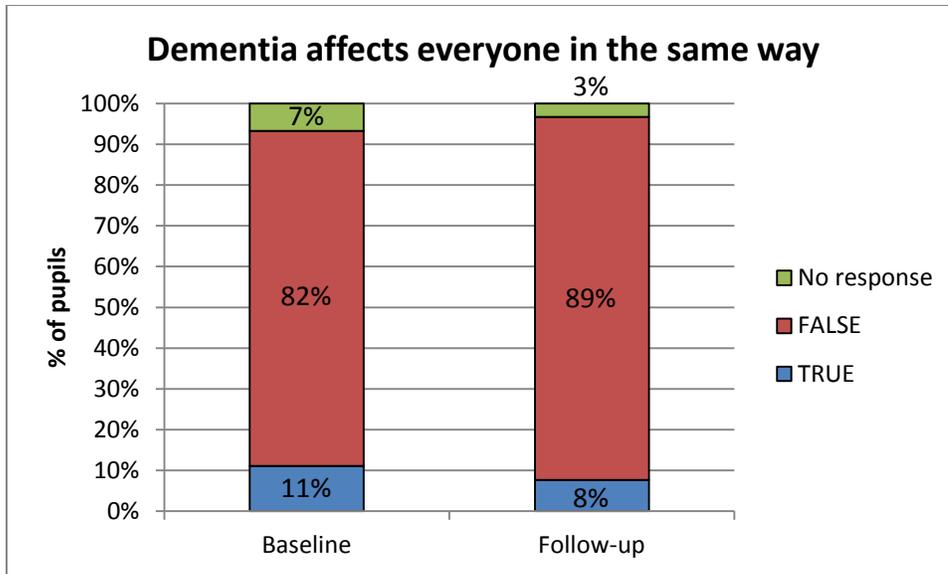


Figure 17: Secondary school and college pupils responding to ‘Dementia affects everyone in the same way’

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

Primary schools

In a similar way to the previous statement, at baseline only 5% of primary school pupils agreed that dementia always happens when you get older, indicating that the vast majority did not think it was a normal part of ageing. However, as before, two schools did not respond to this question as the pupils did not know what dementia was at the time, meaning that the 5% only applies to pupils from four of the six schools.

At follow-up 12% of pupils across all six schools thought that dementia affects everyone in the same way. When the two schools who did not respond at baseline are excluded, the result falls to 0%, showing that there has actually been an improvement in the pupils’ understanding in the remaining four schools. The results are summarised in Table 9.

	Baseline	Follow-up
4 out of 6 schools	5%	0%
All 6 schools	-	12%

Table 9: Primary school pupils who thought that dementia always happens when you get older

Secondary schools and colleges

As can be seen in Figure 18 at baseline only 13% of secondary school and college pupils thought that dementia always happens when you get older. The follow-up results

showed an improvement with only 9% of pupils still having this opinion, and as with the previous question this is made more impressive by having 98% of pupils expressing an opinion at follow-up compared to 95% at baseline.

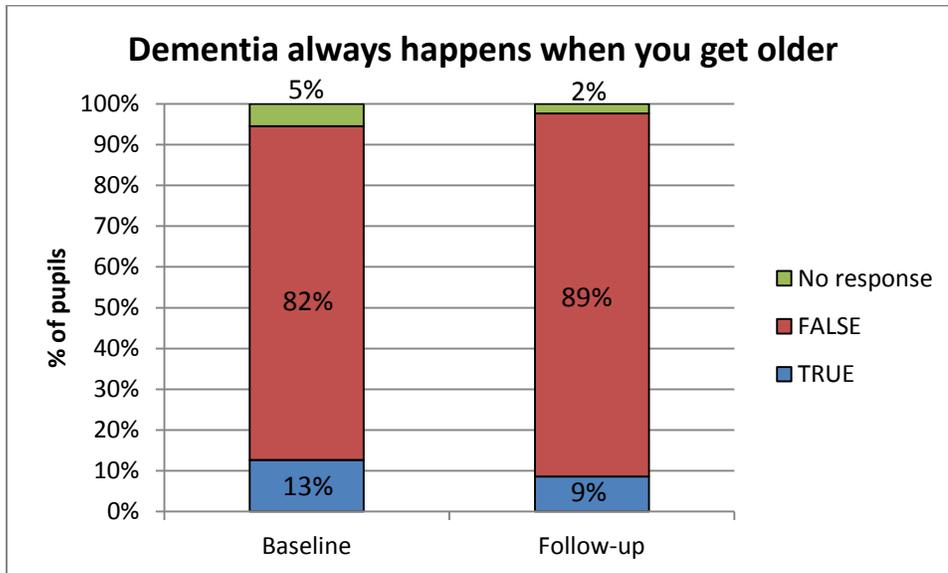


Figure 18: Secondary school and college pupils responding to 'Dementia always happens when you get older'

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

Primary schools

At baseline 17% of primary school pupils thought that there is nothing you can do to improve your life if you get dementia. Although higher than for previous questions, it still suggests that the vast majority feel that people with dementia can enjoy a good quality of life. As before, two schools did not respond to this question as the pupils did not know what dementia was at the time, so this result only applies to pupils from four of the six schools.

At follow-up only 7% of pupils across all six schools were pessimistic about being able to improve your life. Although this is already a big improvement, when the two schools who did not respond at baseline are excluded the result falls to 0%, showing an even greater level of improvement in the pupils' opinions. The results are summarised in Table 10.

	Baseline	Follow-up
4 out of 6 schools	16%	0%
All 6 schools	-	7%

Table 10: Primary school pupils who thought that dementia always happens when you get older

Secondary schools and colleges

Another improvement in attitudes and opinions can be seen in Figure 19, where the percentage of secondary school and college pupils thinking that there is nothing you can do to improve your life has fallen from 16% to 11%.

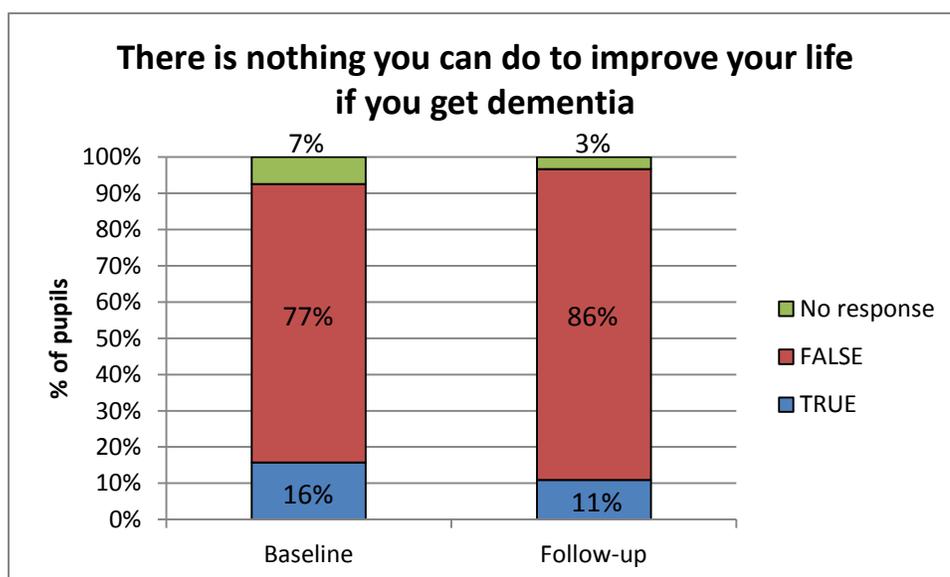


Figure 19: Secondary school and college pupils responding to 'There is nothing you can do to improve your life if you get dementia'

At both baseline and follow-up, pupils displayed an appreciation that people with dementia could enjoy a wide range of activities and have their own preferences just like 'normal' people. "I think people with dementia will enjoy different things. They are not the same and have their own opinion". As comments covered such a range of different ideas the following analysis focuses on where there were changes between the baseline and follow-up responses.

In terms of calm and relaxing activities, at follow-up the pupils put more emphasis on activities that were creative and mentally challenging, as well as activities that were relatively quiet and could be done individually rather than as part of a group. However, pupils also referred to a wide array of physical and social activities, essentially reflecting that people with dementia would enjoy any form of activity.

At follow-up, going on days out was seen as more important, with more emphasis on having fun and enjoying yourself. The importance of seeing and spending time with family was also recognised, as was having friends and company in general. Communicating and having conversations with people with dementia was an important factor, with listening to people featuring almost as much as talking to them.

As far as managing the impact of dementia was concerned, memory games and puzzles were still important, but there were a lot more comments around reminiscence activities, including memory books and boxes. Related to this, many comments talked about animals and pets, playing musical instruments, and singing and dancing, which are likely to be linked to pupils learning about dementia dogs, singing for the brain and using animals and music as parts of therapy sessions. This indicates that the pupils were able to reflect on what they had been taught and appreciate its importance and relevance for people with dementia.

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

Primary schools

At baseline, although knowledge of dementia was limited the primary school pupils were able to suggest a number of ways of helping people with dementia, including practical assistance, memory prompts and reminders, reminiscence activities and generally being nice to them.

The comments made at follow-up were similar as they also referred to helping with everyday tasks, reminders and labels, and *“talking to them about things they can remember”*, but in addition there were many comments relating to the way you should act around people with dementia. For example, speak calmly, be patient, “don’t correct them or tell them they’re wrong or stop them unless there is a safety risk” and “make them feel safe”. These comments indicate a greater awareness and appreciation of how important emotional support can be as well as more practical types of help.

Secondary schools and colleges

At both baseline and follow-up the pupils displayed a good overall understanding of ways to help people with dementia, but the comments at follow-up tended to focus more on improving quality of life at a personal level rather than relying on medication and professional or formal help.

At follow-up communication was seen as a more important area and focused more on *how* to communicate, such as being patient and understanding, and treating people

normally. Care and support was also more important, especially from family and/or professional carers. There was more awareness of the role of support groups and also more emphasis on staying positive.

In terms of helping people with dementia to be active, remaining physically and mentally active was seen as important. Although this was also the case at baseline, more comments focused on this at follow-up. There was also more emphasis on being happy, saying that it was important for any activity to be something that the person with dementia enjoyed and wanted to do.

The role of socialising was more important at follow-up, saying that people with dementia should not be alone but should spend more time with other people. For some pupils this involved spending time with other people with dementia, which is likely to be linked to the increased awareness of support groups as seen earlier.

In terms of limiting the impact of dementia, the main difference between baseline and follow-up was the increase in the number of comments relating to assistive technology and reminiscence activities including memory books, suggesting that pupils were able to appreciate their importance on a much broader scale, rather than just referring to them in the questions around assistive technology.

Caring for someone with dementia

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

Primary schools

As seen in Figure 20, at baseline only a small percentage of primary school pupils knew someone looking after a person with dementia. By the follow-up stage a greater proportion of pupils knew a carer. While it can be suggested that the increase in pupils knowing parents or relatives as carers could be linked to raising awareness of dementia and more conversations taking place between pupils and parents, the other increases are more interesting.

The 'Friend' carer increase came mostly from one school who had worked closely with someone from a care home who was then classed as a friend. The 'Other' carer increase came from more than one school and was a combination of carers coming into school to talk to pupils, attending 'Singing for the brain' sessions and talking to a teaching assistant who is also a carer.

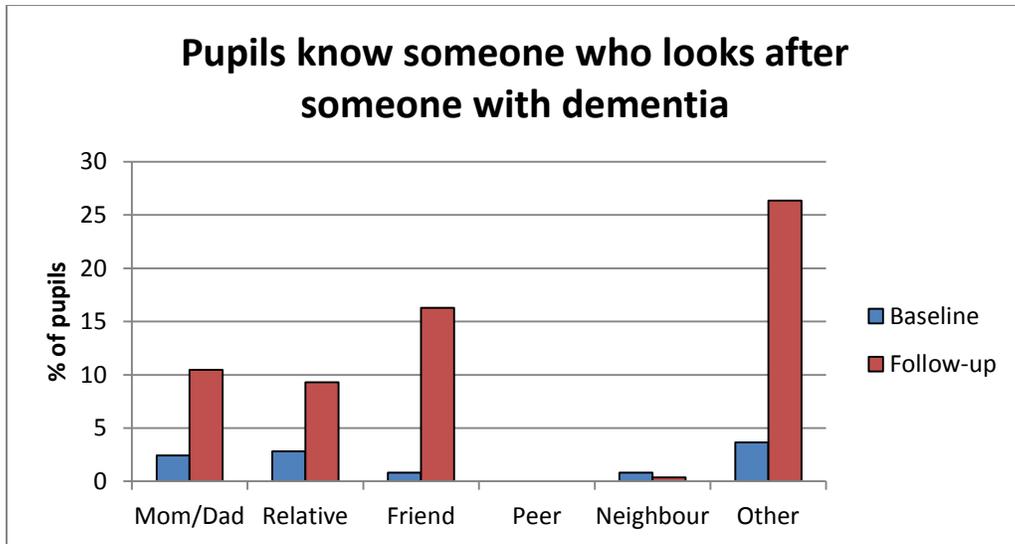


Figure 20: Primary school pupils who know someone looking after a person with dementia

Secondary schools and colleges

As seen in Figure 21, although the majority of secondary school and college pupils already felt that they appreciated how people feel when there is a person with dementia in the family there was still an improvement at follow-up, increasing from 80% to 91%. However, the overall pattern seen in Figure 22 in terms of feelings was generally the same at both baseline and follow-up. In both cases, the more positive feelings – shown in paler colours – were chosen a lot less often than the negative feelings, indicating that the pupils see caring as a mainly negative experience.

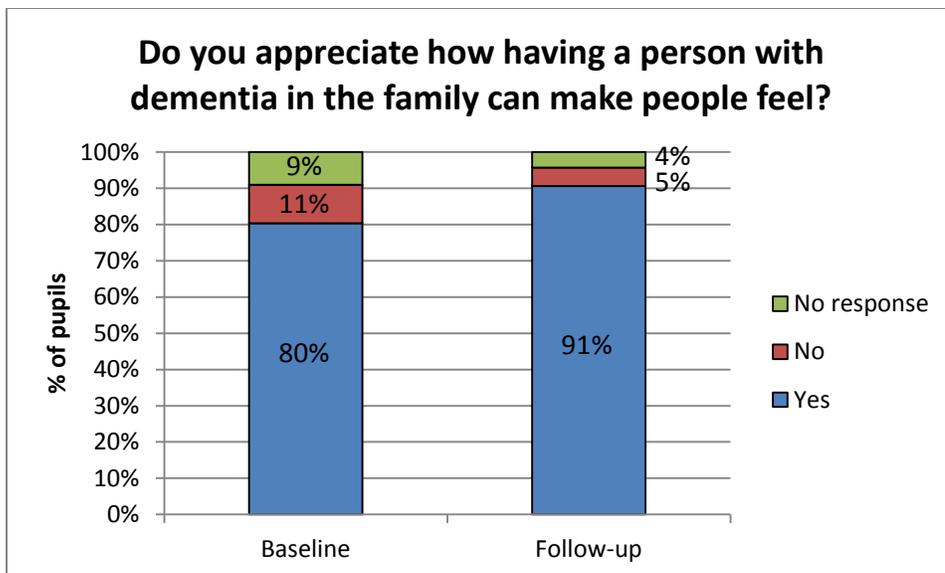


Figure 21: Secondary school and college pupils who appreciate how having a person with dementia in the family can make you feel

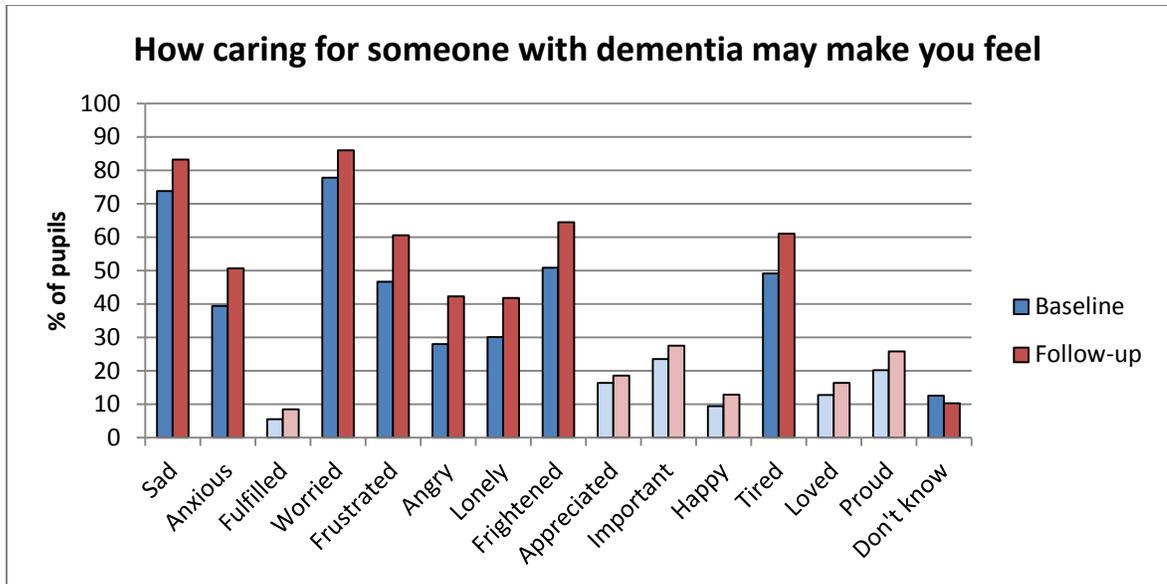


Figure 22: Secondary school and college pupils who appreciate how caring for a person with dementia can make you feel

The responses shown in Figure 23 indicate that the pupils recognise that a range of people could be involved in caring, with neighbours least likely to be involved. The pattern of results was similar at both baseline and follow-up, although it is interesting to see that professionals were less likely to be considered as part of the caring process at follow-up. For example 'Doctors' and 'Hospitals' became less popular, and 'Nurses' only saw a very slight increase.

This could possibly be a reflection on the types of carers that pupils met during the project, but could also reflect a slightly different view of care, focusing more on being involved in day-to-day care and less on providing care in emergencies or on a less regular basis.

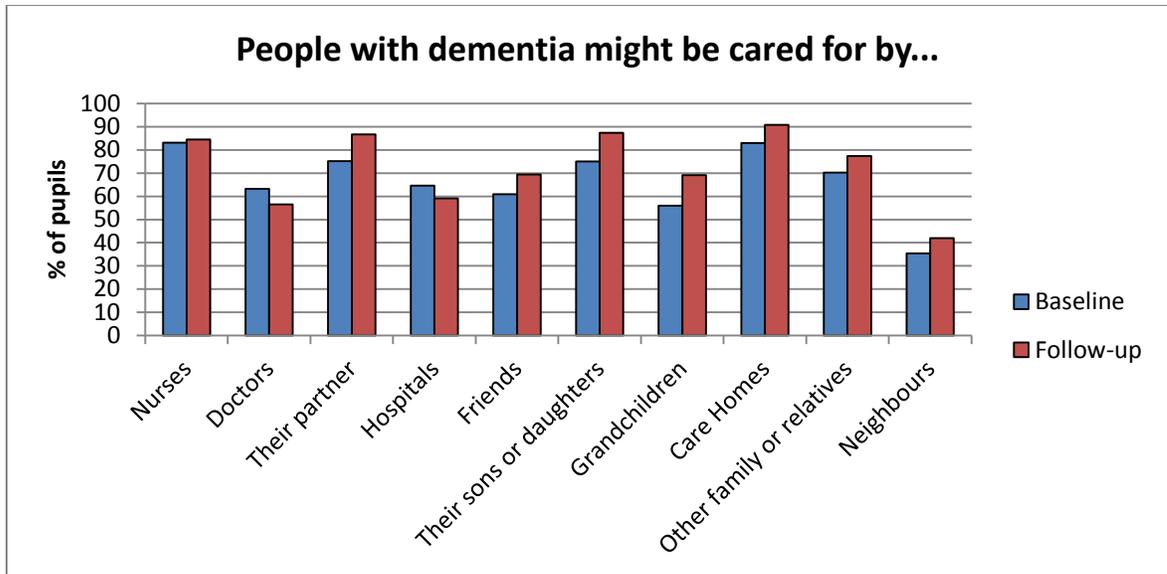


Figure 23: Who secondary school and college pupils think might care for a person with dementia

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 in Figure 20, none of the primary school pupils knew of any peers who were helping to care for a person with dementia.

Conversely, at baseline nearly 1 in 5 secondary school and college pupils (19%) said that they knew a friend who cared for person with dementia. It is unclear whether these are friends of a similar age or family friends from an older generation, but indicates that having an understanding of dementia and the caring role is important to ensure that pupils are able to support their friends.

At follow-up the responses increased to 25% of pupils knowing a friend in a caring role. This slightly higher percentage could in part be due to pupils meeting carers during the project, but could also be due to the increased awareness and openness around dementia resulting in more people admitting that they care for a person with dementia.

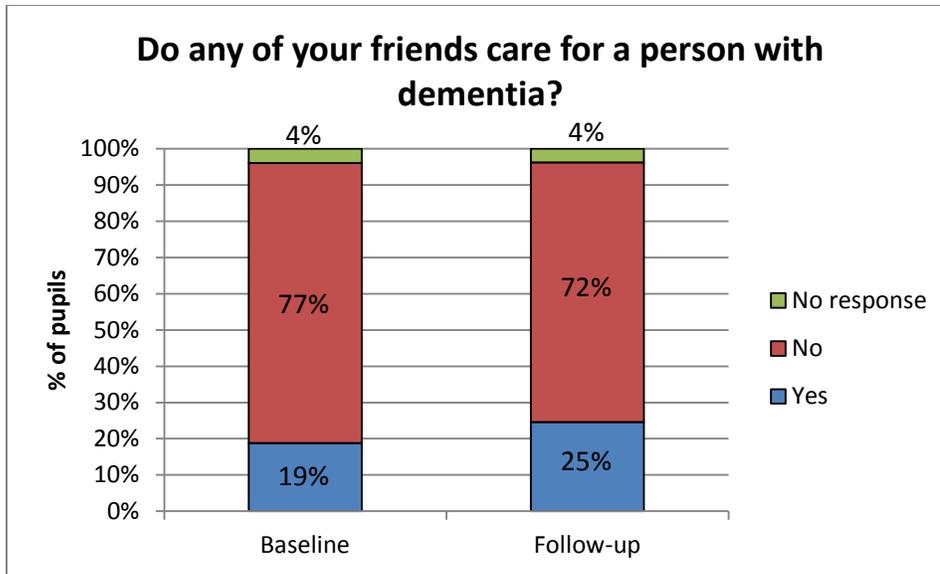


Figure 24: Secondary school and college pupils with friends caring for a person with dementia

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 did suggest that they appreciated how difficult caring can be. However, some pupils were more positive as shown in Figure 25, where it can also be seen that there was a degree of overlap between the baseline and follow-up responses.

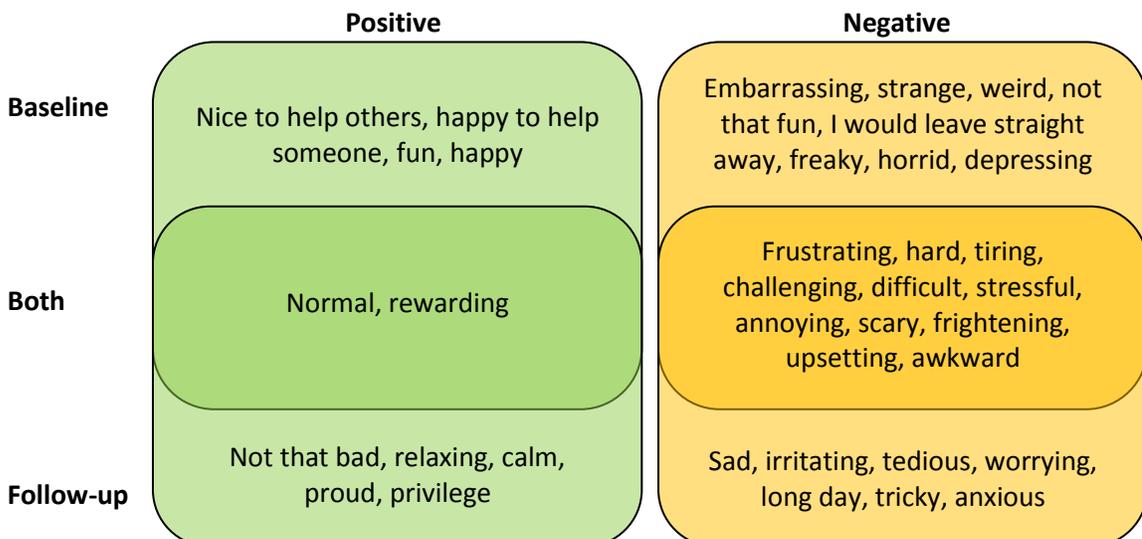


Figure 25: Comments from primary school pupils relating to looking after a person with dementia

Secondary schools and colleges

As seen in Figure 26 at both the baseline and follow-up stages the pupils were very understanding of the situation faced by carers, and were more likely to admire carers than feel sorry for them. This indicates that the pupils have an appreciation of the impact that caring for a person with dementia can have, and also an appreciation of how difficult it may be for individuals and why they deserve respect for what they do.

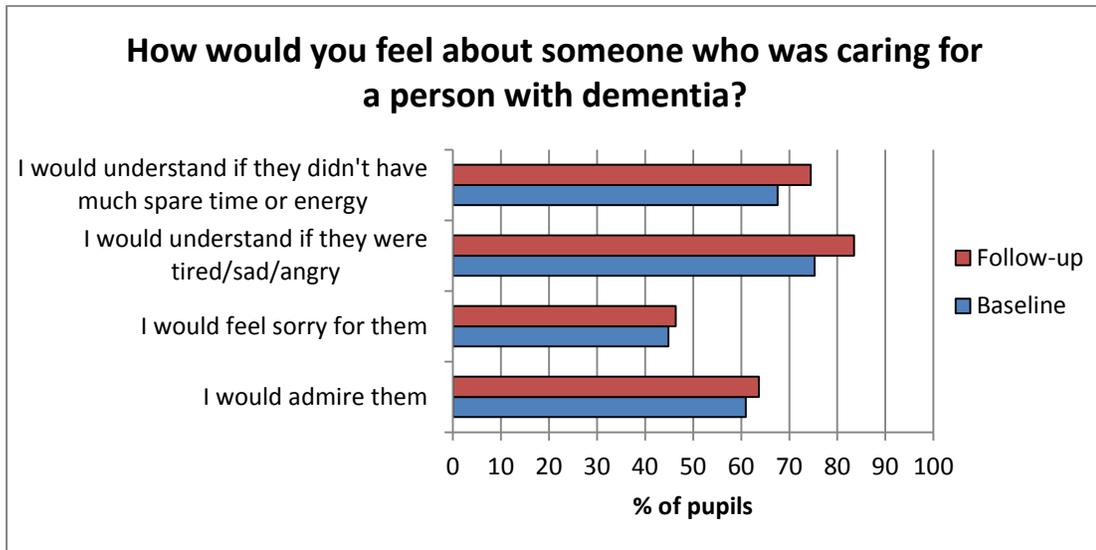


Figure 26: How secondary school and college pupils feel about someone caring for a person with dementia

At both baseline and follow-up, pupils recognised the importance of helping and supporting carers as well as the people with dementia, but were clear that help should be offered rather than forced on people with ‘ask’ and ‘if’ being key words. *“Ask if they needed any support, be there if they need to talk.”*

In terms of rest and recuperation, pupils at follow-up were slightly more appreciative of the need for carers to be given a break, and felt that they needed to be able to relax and have fun during their time off as well as just having a rest. In addition, pupils made more comments around spending time with carers and taking them out for the day.

Providing moral support was also a strong theme at both baseline and follow-up. Pupils already knew about the need to encourage and motivate carers when they were low, and being a friend to them, as *“you could just be there for them if they needed someone”*. By the follow-up there was more emphasis on being understanding of the carer’s situation and being someone they can talk to, suggesting that the pupils were more comfortable with this idea as they knew more about dementia overall.

There was no real change seen around the provision of practical help and support, with pupils at both baseline and follow-up commenting on the need to help out caring for the person with dementia, offering help and support when needed, and helping out around the house. *“You could help carers with everyday tasks (cleaning, shopping etc) as this may be difficult while looking after someone with dementia.”*

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

Primary schools

As seen in Figure 27 pupils were able to suggest a variety of potential sources for information and support about dementia, covering family, professionals and general sources. It was interesting to see that at follow-up there was more awareness of dementia organisations and the importance of carers’ knowledge and experience.

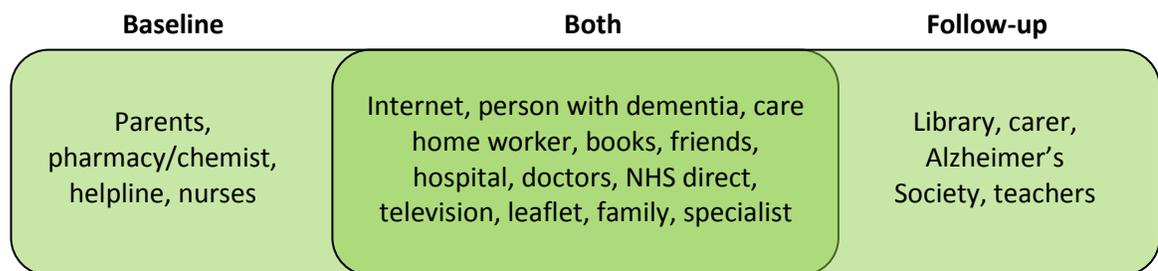


Figure 27: Comments from primary school pupils relating to seeking support and information

Secondary schools and colleges

The responses from pupils are shown in Figure 28 where it can be seen that at both baseline and follow-up Doctors were the most commonly recognised source of information. As with the primary school pupils, at follow-up there was more recognition of the importance of the Alzheimer’s Society, indicating that pupils had become more aware of it and what it can offer. This is likely to be due to many schools working with or having input from their local branch of the Alzheimer’s Society during their projects.

It should also be noted that although teachers and school nurses are not seen as the main sources of information they would be important for 30-40% of pupils, indicating that they need to have sufficient knowledge of dementia to be able to help pupils or signpost them to an appropriate service. This is likely to be out of the normal skill set for the majority of school staff.

Examples for the ‘Other’ sources were essentially the same at baseline and follow-up, covering parents, family, the internet and NHS services.

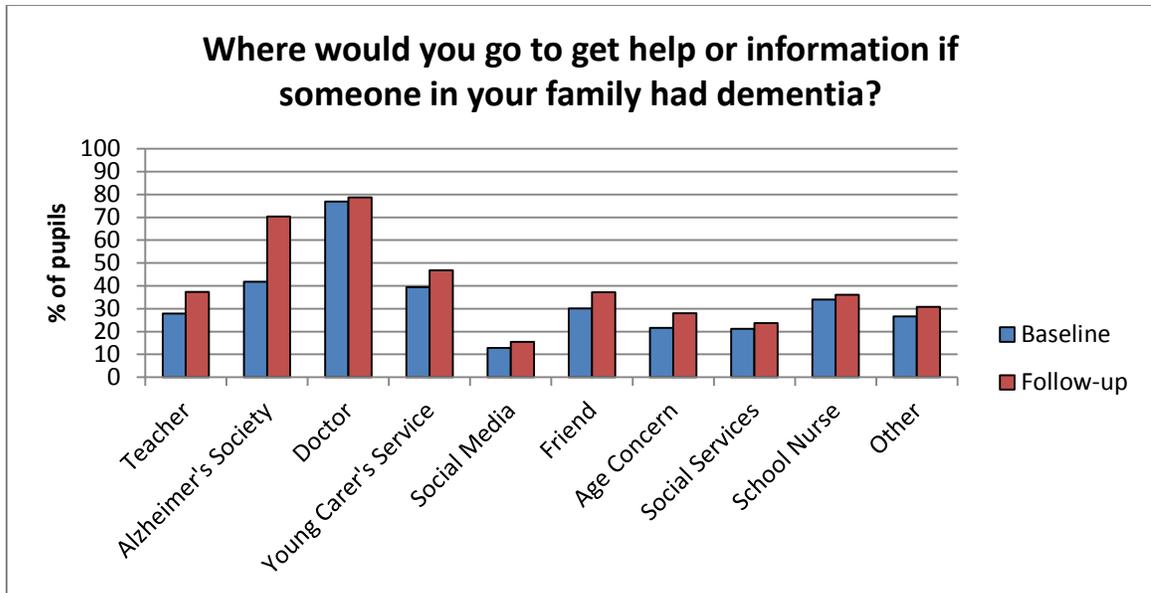


Figure 28: Sources of information and support for secondary school and college pupils

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

Types of assistive technology

Primary schools

Pupils were not asked specifically about assistive technology, but some comments touched on this area when talking about help available for people with dementia. At baseline these comments were mainly relating to making lists, writing things down and having reminders or memory prompts. For example, *“a diary to write down things to remember”* and *“memos to take pills”*.

Although these ideas were repeated in comments made at follow-up, the pupils were able to talk about a wider range of concepts such as *“beepers/alarms to alert others or self to potential danger, talking watch/device, gadgets/assistive technology”* and *“have a phone message recording of a family member telling them what to do, have a panic button”*. This indicates that pupils have become more aware of assistive technology and how it can help people with dementia.

Secondary schools and colleges

In both the baseline and follow-up responses, some pupils said that they had not heard of assistive technology but did actually talk about different examples for other questions. These are represented by the 'Unclear' group in Figure 29, where it can be seen that there was a big improvement overall between baseline and follow-up. Just under half of the secondary school pupils (46%) are now aware of assistive technology compared to 12% previously, or 53% compared to 17% if the 'Unclear' responses are included.

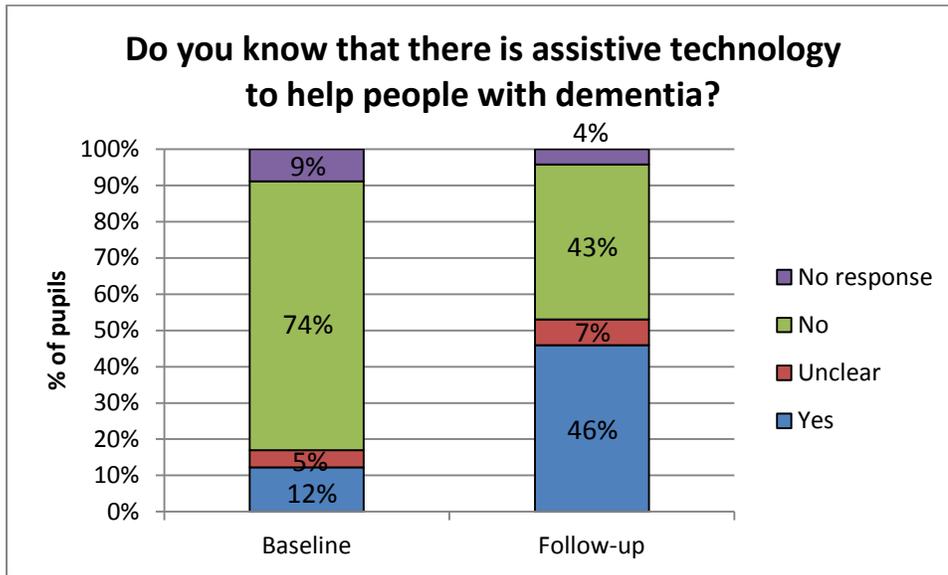


Figure 29: Secondary school and college pupils who have heard of assistive technology - overall

Despite the improvement seen in Figure 29, early responses had indicated that the improvement would be even greater. It was discovered that different schools covered the topic of assistive technology differently, with some schools not really focussing on it at all. By looking at the results for individual schools the impact of using these different approaches can be seen more clearly. In Figure 30 awareness of assistive technology was low across all schools at baseline. Although it improved for each school, the greatest improvement was seen in schools that had a strong emphasis on assistive technology.

For example, Gloucester College had input from a specialist on assistive technology and passed this knowledge on to some of the pupils at Newent Community School. Consequently, awareness in these two schools increased to 100% and 67% (71% including 'Unclear') respectively. In contrast, Northfleet School for Girls did not specifically focus on assistive technology so their improvement was more modest at just 19% (26% including 'Unclear').

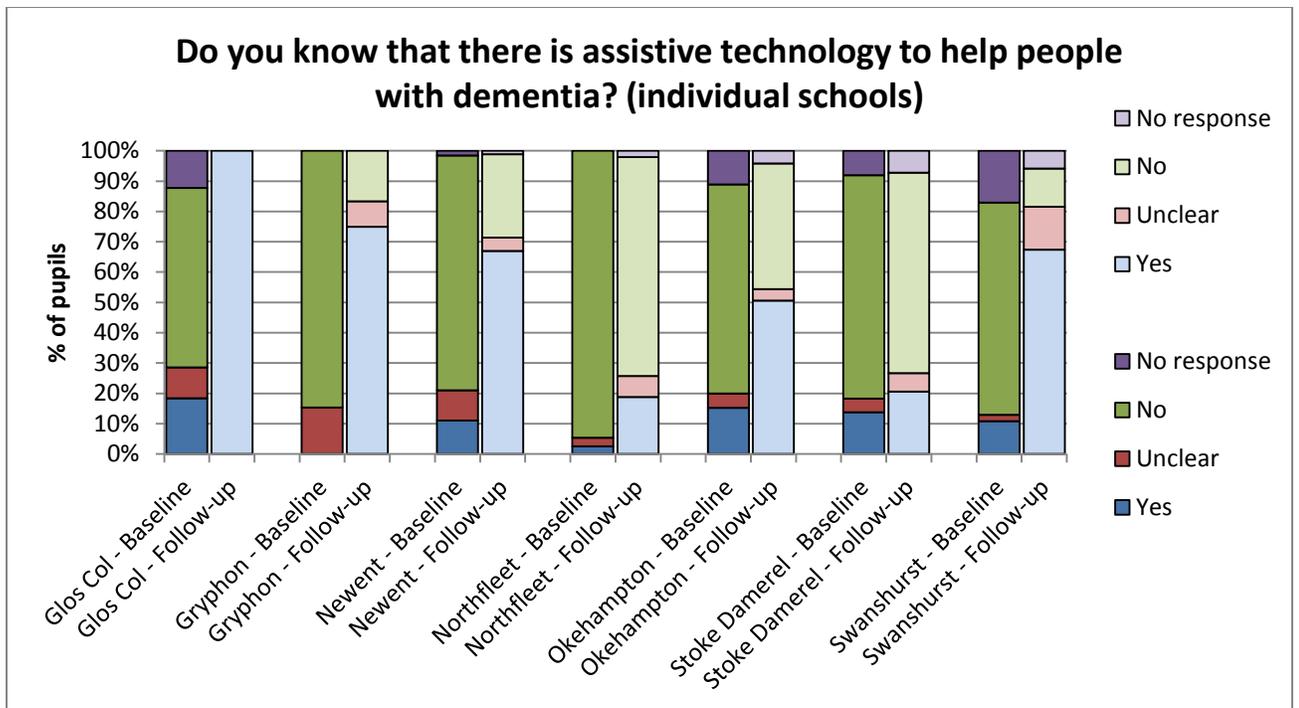


Figure 30: Secondary school and college pupils who have heard of assistive technology – individual schools

From just a cursory glance at the questionnaires it was clear that the pupils’ knowledge and understanding of assistive technology had vastly improved by follow-up as more pupils were able to actually provide an answer for the questions around this area. This is shown in Figure 31, where it can be seen that the blank and ‘don’t know’ responses was a lot lower for each of the three questions looking at assistive technology.

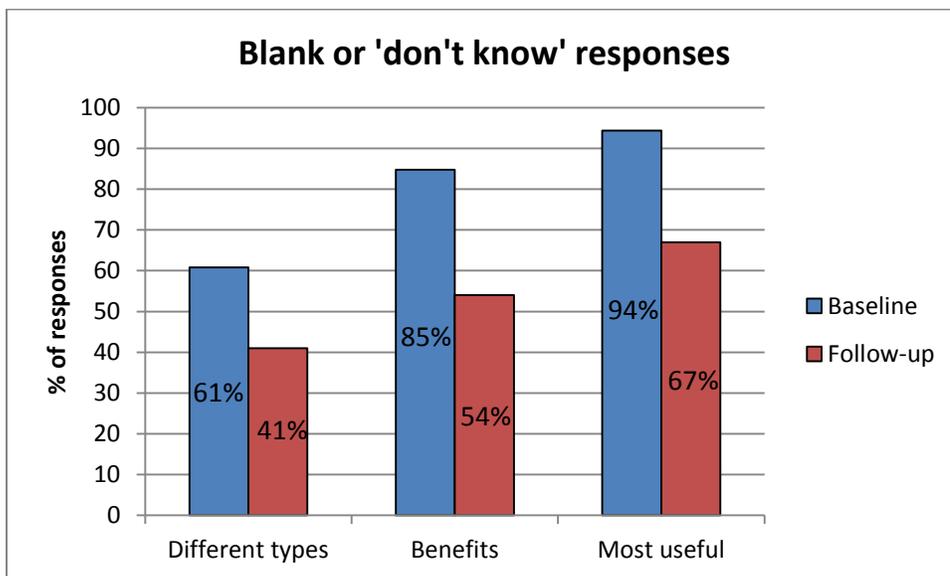


Figure 31: Percentages of assistive technology responses that were blank or ‘don’t know’

In addition to the increased number of 'valid' responses, the follow-up comments were less vague and more focused on dementia and memory problems. Some standard care aids were still being mentioned such as wheelchairs and hearing aids, and some generic examples of sensors and alarms, but there was hardly any mention of everyday technology. This was contrast to the baseline comments which focused mainly on these areas. Even when normal technology was mentioned, it was a specific type, for example telephones were talked about, but in terms of telecare and special ones with picture buttons instead of numbers.

The majority of follow-up comments related to memory-specific aids and covered a much wider range than pupils were able to mention at baseline. They included:

- Timers and alerts
- Trackers and tagging devices
- Buddi bands
- Grouple
- Reminders, especially voice prompts
- Memory book/box
- Pill dispensers
- Colour-coding items
- Organisers and planners
- Talking watch
- Dementia dog
- ODE (scent to help people remember to eat)
- Automatic clocks and calendars
- Locator devices
- Automatic locks for doors
- Devices for monitoring water temperature for bathing
- Automatic switch for turning the cooker off
- Automatically turning taps off to prevent flooding

How assistive technology improves the lives of people with dementia

Secondary schools and colleges

Responses at baseline were limited around this area as pupils were generally unaware of assistive technology overall, let alone its benefits. At follow-up there were more comments around helping people to remember things, find things and remind them about things, which helped to reduce confusion, frustration and stress. *"It makes them feel less helpless"*.

One of the main benefits was felt to be making life easier. For people with dementia, this involved helping them to do things, getting out and about, having fun, socialising, keeping them safe, having more help and support, and being more independent.

Consequently, assistive technology was seen as a means of enabling people with dementia to remain in their own homes for longer.

“it allows them to feel safer at home and it reduces the chance of accidents that could happen”

“it helps them to live as normal as possible”

“it gives them their independence and can stop the need for them to go to a care home”

Pupils also saw how assistive technology could make life easier for carers, as the extra independence for people with dementia means that they *“have to rely less on carers”*. It can provide/trigger help in an emergency, reducing the stress and providing *“peace of mind for carer”*.

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

Secondary schools and colleges

Although as mentioned previously some standard care aids were still commented on at follow-up, the forms of assistive technology that were referred to most commonly were memory-specific:

- Reminders – *“audio reminders because they can be used on a lot of things and they are quite effective as if they hear a familiar voice then they are likely to listen and be reminded”*
- Automatic clocks and calendars
- Dementia dogs
- Pill dispensers
- Buddi band/tracking devices
- Locator devices
- ODE

This indicates that the pupils’ knowledge around assistive technology has improved greatly, enabling them to appreciate their benefits and see how the most useful ones are those that help people with dementia to live as normal a life as possible.

Meeting someone with dementia

Most pupils have met a person with dementia

Primary schools

As can be seen from Figure 32 only 9% of pupils had met a person with dementia at baseline. This was not overly surprising as younger pupils were less likely to have grandparents in the higher-risk age ranges (65+), and parents may be less likely to discuss dementia with their children even if it was affecting grandparents. In addition, as pupils did not really know about dementia at this stage, they would be less aware in general of people having dementia.

By follow-up 65% of pupils had met someone with dementia, with most of this being due to the activities undertaken by the schools which brought pupils and people with dementia together. Not all schools included meeting people with dementia as part of their projects, which is reflected in the remaining 35% of pupils.

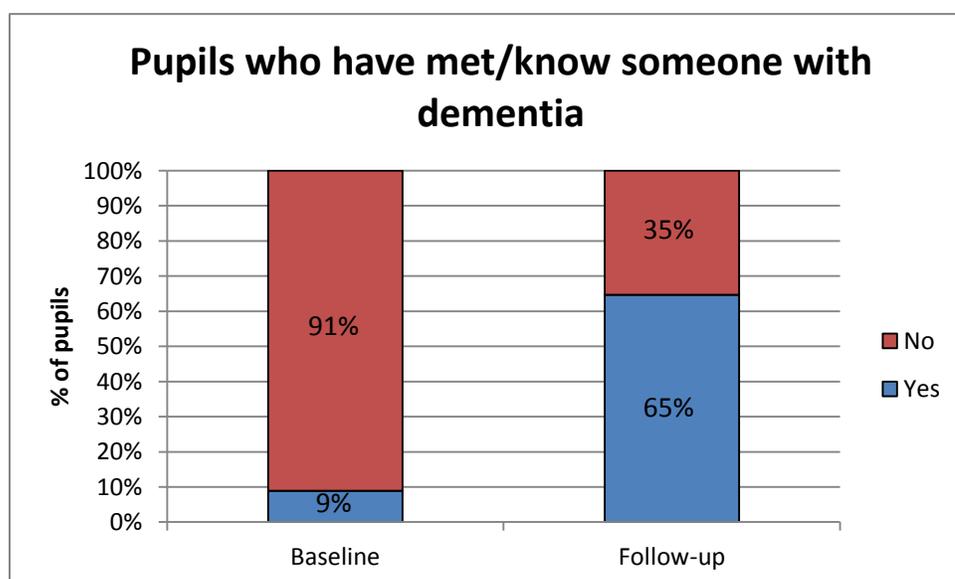


Figure 32: Primary school pupils who have met/know someone with dementia

Secondary schools and colleges

At baseline 33% of pupils had met a person with dementia as shown in Figure 33, but by follow-up this had risen to 51%. As with the results for assistive technology the improvement was not as great as had been hoped, but like the primary schools not all secondary schools and colleges involved meeting people with dementia as part of their projects.

The responses are shown for individual schools in Figure 34, where it can be seen that each school improved which was probably due to increased awareness and more recognition that relatives or other people pupils knew actually have dementia. Unsurprisingly the biggest improvements were seen for schools that did include meeting people with dementia, such as The Gryphon School and Swanshurst School.

It should be noted that the older pupils at Northfleet School for Girls did actually work closely with people with dementia, but were unable to complete follow-up questionnaires due to time pressures from other subjects, hence their level of improvement is lower than it should be.

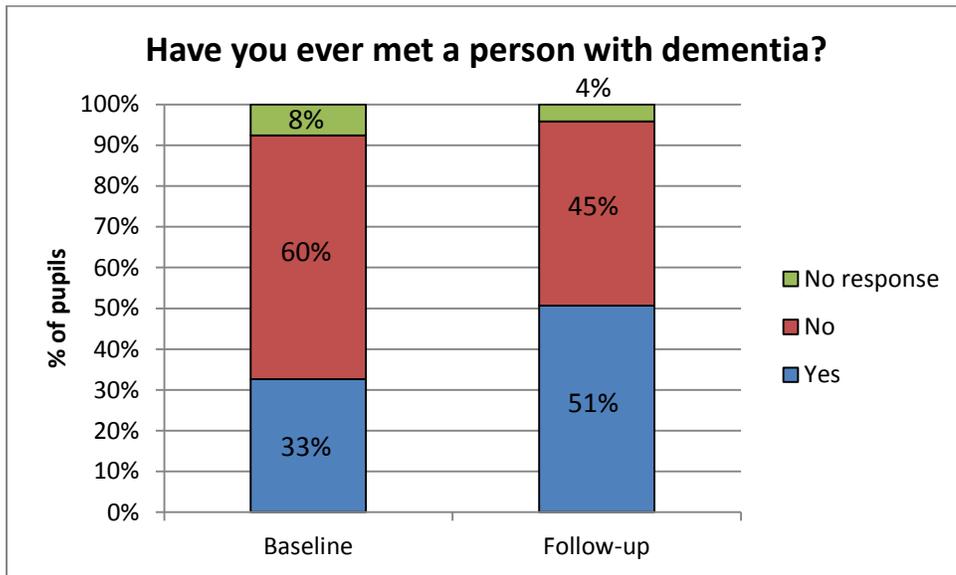


Figure 33: Secondary school and college pupils who have met a person with dementia - overall

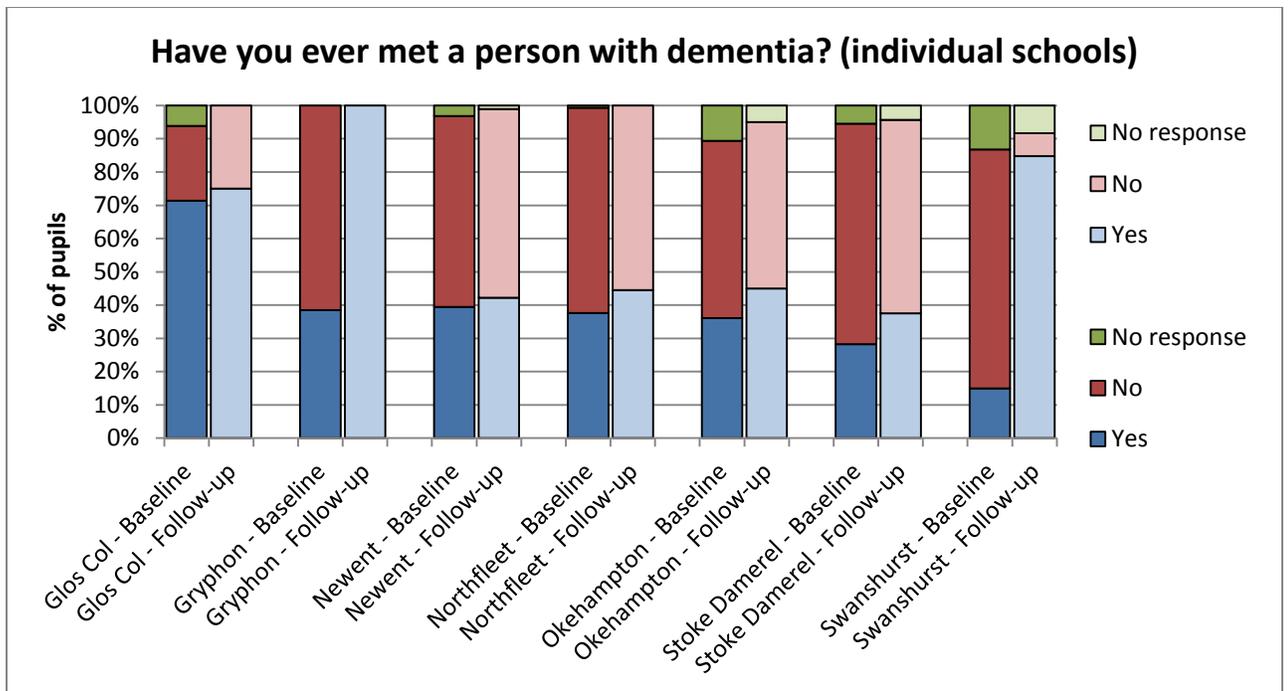


Figure 34: Secondary school and college pupils who have met a person with dementia – individual schools

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

Primary schools

As seen in Figure 35 only 25% of pupils felt confident about meeting a person with dementia at baseline, but by follow-up this had increased to 76%. Before meeting people with dementia pupils said they were “nervous”, “scared” and “worried” but also “interested” and “curious”. After meeting someone with dementia, pupils commented that they were “more confident”, “relieved”, “fine” and “happier because [I] understand more now” although one pupil was “still slightly nervous”. The pupils also said that they were “glad they had the opportunity” to meet people with dementia, and while it was generally a positive experience some pupils said it had been quite sad with one pupil commenting that they felt “sorry for him as he was so young”.

The responses are shown for individual schools in Figure 36, and indicate that although the biggest increase in confidence was seen for schools where the pupils met people with dementia (Bernard Gilpin Primary School, Copplestone Primary School and Curzon C of E Combined) it was still possible for the other schools to improve confidence. This is a good indication that raising awareness and learning about dementia can help to

reduce pupils' fear about the subject, and schools should not feel pressured into involving people with dementia in future projects if they are uncomfortable with it.

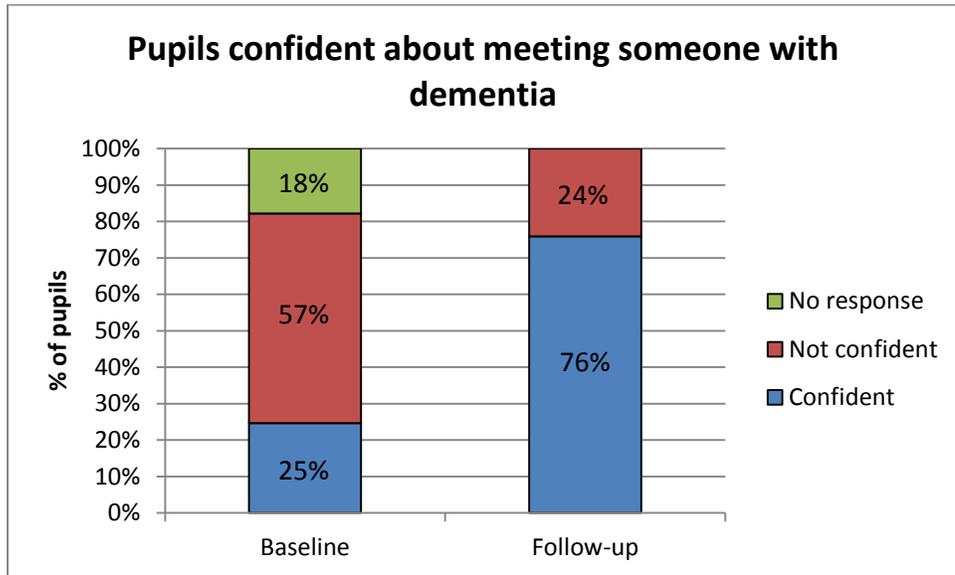


Figure 35: Confidence of primary school pupils when meeting someone with dementia - overall

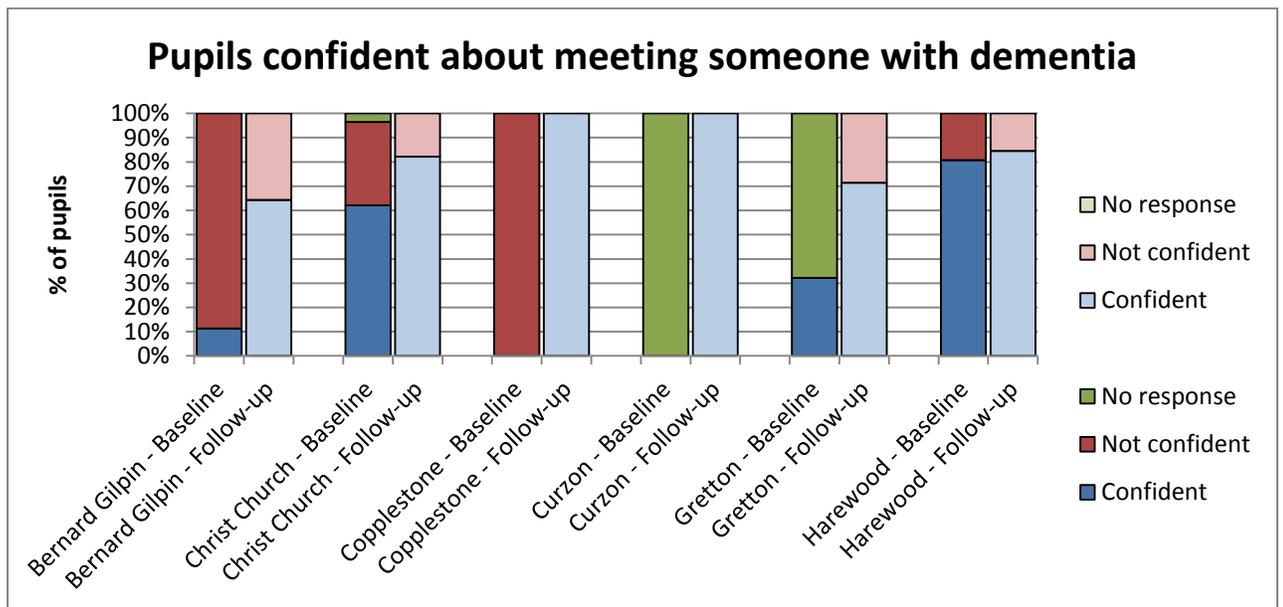


Figure 36: Confidence of primary school pupils when meeting someone with dementia – individual schools

Secondary schools and colleges

The baseline responses shown in Figure 37 indicate that although many pupils felt awkward meeting people with dementia as they 'Didn't know what to do or say', almost as many felt 'OK'. This suggests that dementia was not seen to be a particular issue for

pupils, and it was encouraging to see that very few pupils actually 'Avoided people with dementia'.

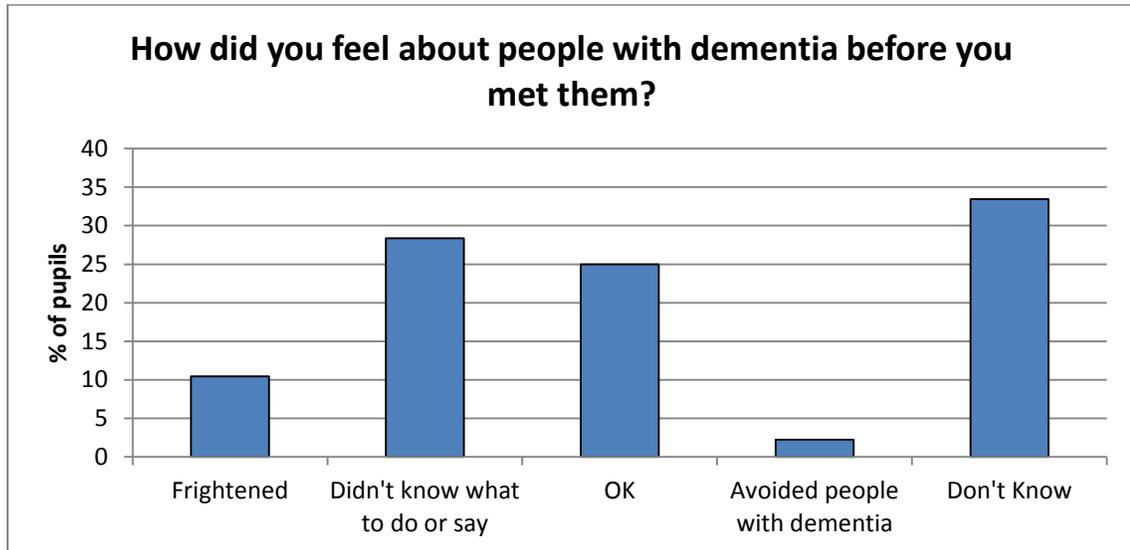


Figure 37: Secondary school and college pupil reactions to meeting someone with dementia – baseline responses

Pupils were asked to rate their confidence when talking to a person with dementia on a scale of 1-5 with 3 essentially representing 'average'. As shown in Figure 38 'average' was the most popular rating at both baseline and follow-up, but overall confidence did increase. By follow-up, more pupils rated themselves in the two highest levels than at baseline (33% up to 41%), and similarly fewer rated themselves in the two lowest levels of confidence (27% down to 19%). This was despite a greater percentage of pupils actually answering this question, as 94% of pupils responded at follow-up compared to 89% at baseline.

Taking part in the dementia project has therefore had a positive impact on pupils' confidence around talking to people with dementia.

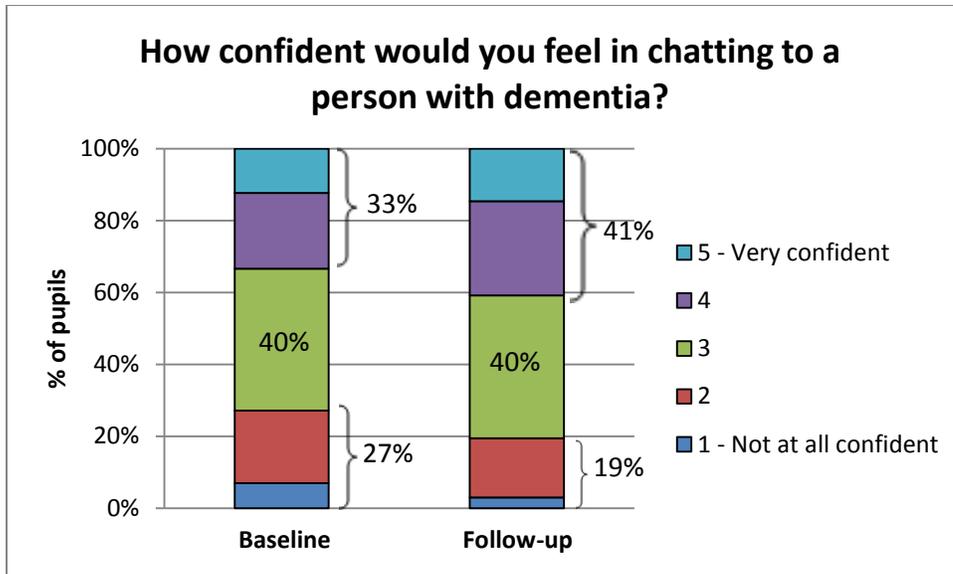


Figure 38: Confidence of secondary school and college pupils when meeting someone with dementia - overall

The responses were analysed separately for pupils who had met a person with dementia and for those who had not, and are shown in Figure 39. It can be seen that pupils who had met a person with dementia were more confident throughout the project, but the biggest improvement in confidence was for the pupils who had not met a person with dementia. These results are summarised in Table 11 which groups together the two highest confidence levels and the two lowest confidence levels.

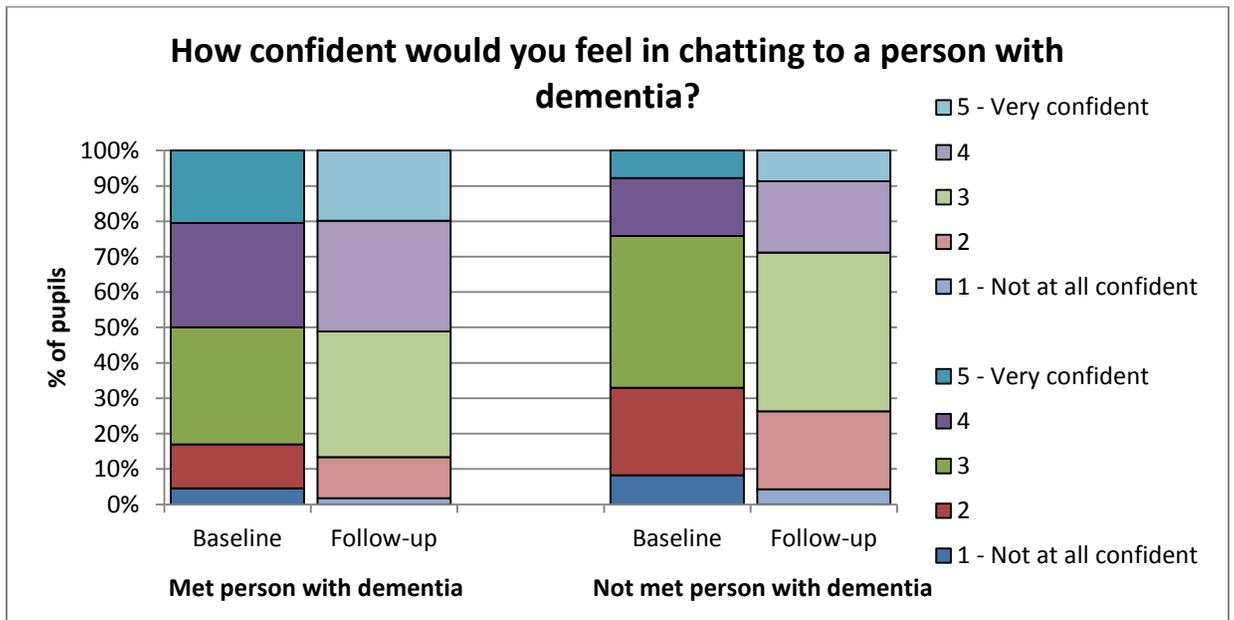


Figure 39: Confidence of secondary school and college pupils when meeting someone with dementia – individual schools

		Met person with dementia	Not met person with dementia
Baseline	Rate 1 or 2	17%	33%
	Rate 4 or 5	50%	24%
Follow-up	Rate 1 or 2	13% (4% reduction)	26% (7% reduction)
	Rate 4 or 5	51% (1% increase)	29% (5% increase)

Table 11: Comparison of confidence when pupil has/has not met a person 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 and colleges

As shown in Figure 40, at both baseline and follow-up pupils felt that other people were most likely to not know how to talk to or act around people with dementia, which may be a reflection on their own feelings as seen previously. The only option to see a reduction was 'OK', making it the least popular response at follow-up. This could indicate that by learning more about dementia pupils have also become more aware of the stigma around it, so are less optimistic about how they think other people see people with dementia.

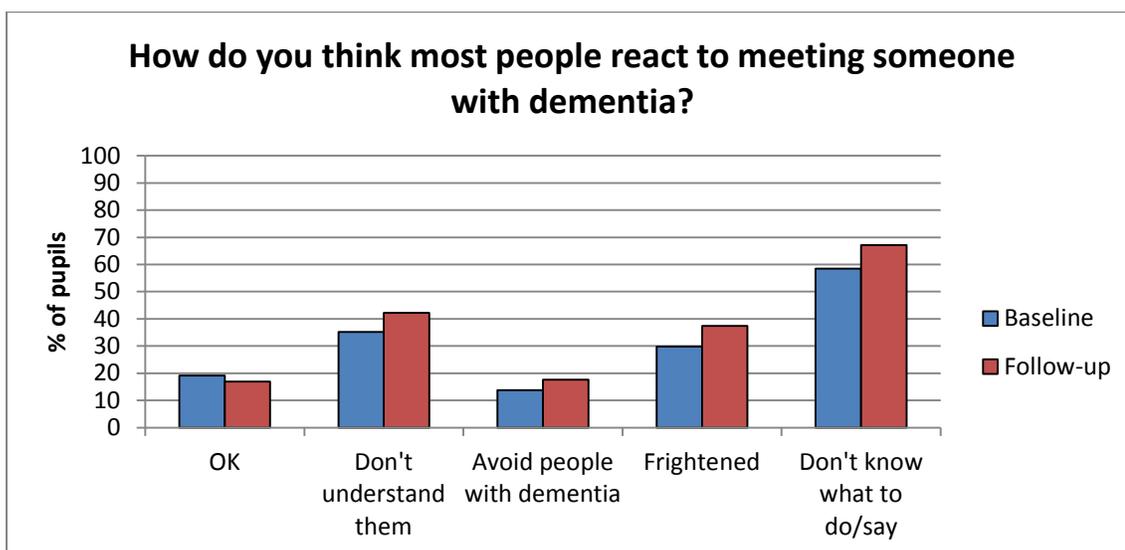


Figure 40: How secondary school and college pupils think general public react to meeting someone with dementia

The comments from pupils at baseline and follow-up were generally quite similar, with the “fear of the unknown” being the main theme. Pupils felt that people “don’t know

much about dementia or they are scared of what they don't know" and consequently "people avoid things they do not understand". This was mainly due to a lack of knowledge about dementia and the feeling that most people have not met a person with dementia before. Reassuringly though, pupils felt that once people knew about dementia they would be ok, and this increased at follow-up "it's not like they're a monster it's just having a chat with a complicated person".

Stereotypical views were mentioned in a number of comments, with people with dementia being portrayed negatively by the media which helped to reinforce stigma and make people think that people with dementia are 'different' when actually they are the same as everyone else. As one pupil said, people *"are not open to the fact that people with dementia have personalities and they are still human beings"*.

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 and colleges

At both baseline and follow-up, pupils displayed a good understanding of how to change the way people see dementia, with the key themes being encouraging people to meet people with dementia and the importance of providing information about dementia to improve understanding. It was however recognised by the pupils that it was also important to provide information on what people can do to help, rather than just what dementia is.

Some pupils were keen to share their own understanding with others *"tell them what you have learnt about dementia as well as how you can improve their lives"*. This tied in with an increase at follow-up around being more open about dementia and talking about it more, and telling people that dementia is nothing to be scared of. As one pupil said, people with dementia *"are still the same as you on the outside just a bit different on the inside"*. This indicates that the pupils' confidence around dementia has increased and it no longer has the 'fear of the unknown' element.

Pupils recognised the importance of learning about dementia at school and some commented that this would be a good strategy for changing opinions in the future, saying that *"doing this project every where [sic]"* and *"teach [about dementia] at school so awareness raised"* would be useful.

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

Primary schools

Although not specifically related to dementia, as baseline pupils were able to suggest that people with dementia might be able to help themselves by keeping healthy, for example *“drink water”* and *“eat the right food”*. Medication and medical help such as pills and check-ups were also mentioned, but the most common comments related to ways to remember things or remind themselves to do things. Some comments also indicated that pupils felt it was important for people with dementia to *“ask for help”* and *“let other people help them”*.

By follow-up, most comments related to reminders and ways of remembering, and while some comments said about keeping your brain active there was no mention of healthy lifestyles. The main area regarding lifestyle choices related to *where* to live rather than *how* to live. Moving to a care home or living with someone else such as a partner or relative were more popular than living alone, although these were seen as positive choices rather than a last option. Even when living alone was mentioned, pupils felt that the person with dementia should still have help from family, friends, neighbours, carers or nurses.

Secondary schools and colleges

At both baseline and follow-up, pupils recognised that people with dementia are able to do a lot for themselves, and can improve their own lives. Leading a healthy lifestyle was just one of the options available to them, *“have a good, healthy and active lifestyle”*. At follow-up there were more comments around the importance of being active, enjoying life and socialising in general, with one pupils saying that people with dementia should *“socialise instead of sitting down”*.

Pupils at follow-up were also more aware of the role that support groups can play for people with dementia, and linked in the benefits of the variety of assistive technology and reminiscence activities that they had learnt about.

It should also be noted that although only mentioned by a few pupils, comments at follow-up recognised the importance of spotting dementia early, saying that people should not *“ignore the signs”* and should *“get themselves diagnosed as early as possible”*. While this had also been raised at baseline, pupils understanding had increased as they were able to expand on the benefits of early diagnosis, saying *“sort*

out wills and finances in the early stages” and “plan ahead once they know they have dementia so they make choices”.

A final indication of the impact of the project is that at baseline only 47% of pupils gave a valid response around this area (i.e. not blank, and not “don’t know” or “not sure”), but at follow-up this had increased to 72% of pupils. This shows that pupils were more confident and willing to give a considered opinion about ways in which people with dementia can improve their own lives.

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

Primary schools

Although at baseline many pupils did not know what dementia was, comments indicated that they were still quite caring and generally wanted to help people. However, only some of the comments related to people with dementia and focussed on helping with memory issues and offering practical assistance. It should be noted that some of the ideas were not necessarily things that the pupils themselves would be able to do, for example *“getting them out of bed”* or *“take the person on holiday”*.

At follow-up the comments were more dementia-focused, but again mainly related to memory problems and practical ways of helping. However, there were also comments around supporting people with dementia, being there for them and adapting how they are with them, such as *“stay patient”*, *“speak calmly”* and *“make them feel safe”*. These suggest that the pupils are more able to appreciate how they could improve the lives of people with dementia.

Secondary schools and colleges

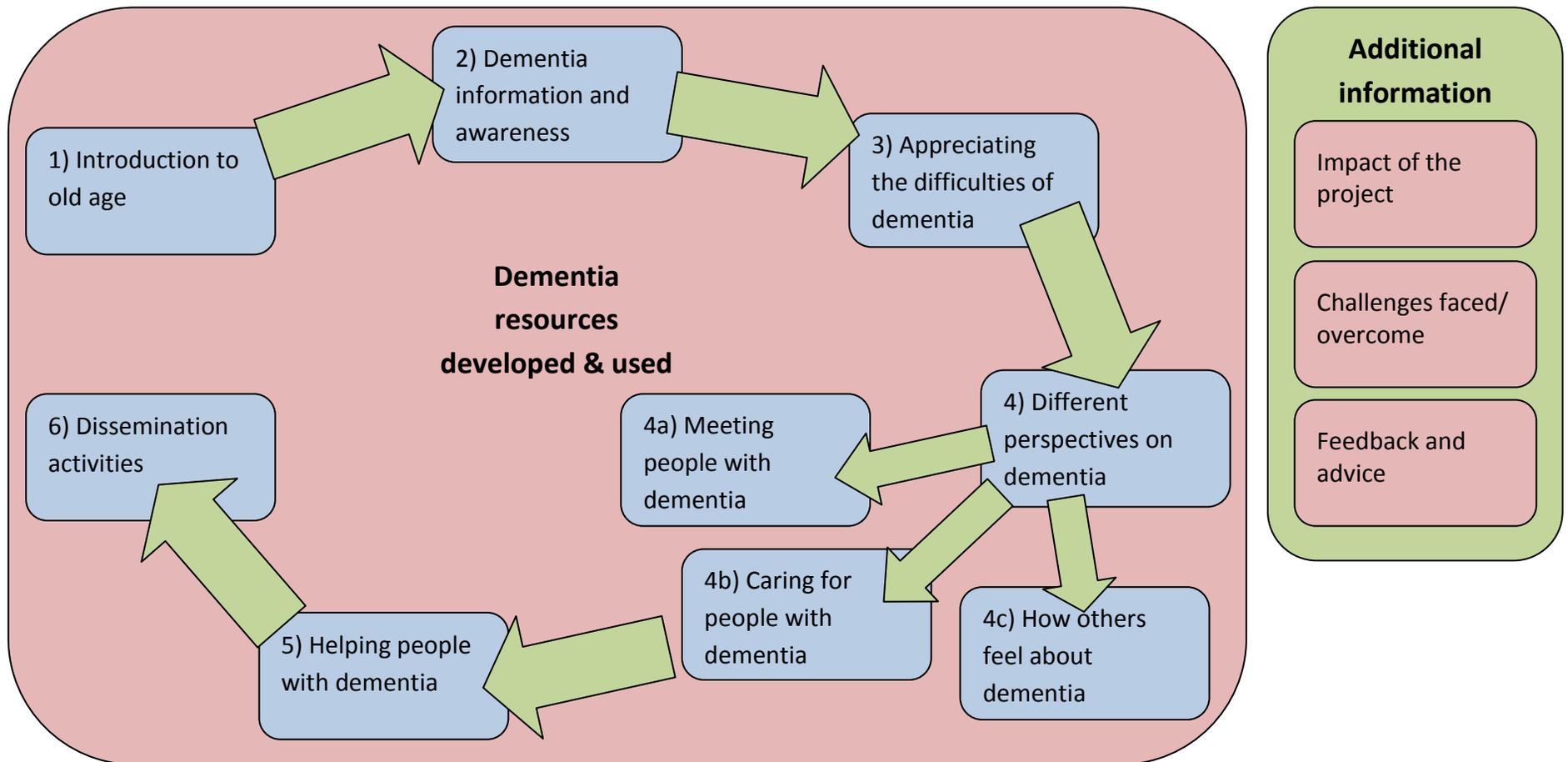
Although pupils at baseline were able to suggest a variety of ways in which they could help people with dementia, the comments made at follow-up were generally more confident and considered, and focused more on ways to help improve quality of life than on getting professional help. This indicates that the by knowing more about dementia pupils had become more comfortable with the idea of actually being the person to help out, rather than needing to get other people involved.

Learning from other areas was also included in the responses, with more mention of reminiscence activities, assistive technology and memory cafes or support groups. There was also a slight increase in awareness of the importance of communication, with pupils also mentioning *how* to communicate with people with dementia, such as not patronising them or contradicting them.

Normality was a feature of comments at both baseline and follow-up, *“treat them normal like any other human. Their brain may work slightly different but their not alien”*. There was also still a good emphasis on helping people with dementia to do what they enjoy, have fun and be happy. The main difference related to this was that at follow-up there was an increase in maintaining a positive outlook and boosting morale, indicating that pupils did not always focus on the negative side of dementia.

Appendix 2 – Resources, activities and information

As can be seen below, the resources developed and used by the schools during the project can be grouped into 6 key areas which enable pupils to be taken through the dementia journey. In addition, the schools also provided information about the impact that the project has had, some of the challenges they faced, and advice for other teachers looking to undertake such a project. This section provides examples of some of the resources and information gathered for each of these areas.



Primary school resources, activities and information

Introduction to old age

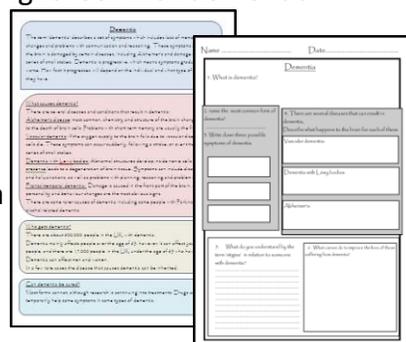
Example activities:

- For homework, get pupils to talk to or interview people from a different generation such as their parents or grandparents. Using something like 'This is me' can be a good start as it gets people to think about what is important to them as an individual and helps pupils to talk to older people in general. (Christ Church C of E Primary School)
- Form an intergenerational choir (Bernard Gilpin Primary School)

Dementia information and awareness

Example resources

- Understanding dementia worksheet covering:
 - What is dementia?
 - Types of dementia
 - Writing a short poem about how someone might feel with dementia (Gretton Primary School)
- Dementia factsheet covering:
 - What dementia is
 - What causes dementia? – types of dementia
 - Who gets dementia?
 - Can dementia be cured?
- Dementia worksheet getting pupils to reflect on what they have learnt and how to improve the lives of people with dementia



Example activities:

- During lessons, getting pupils to carry out their own research into what dementia is and what the symptoms are. This could be on the internet or from leaflets that have been collected and brought in. (Curzon C of E Combined School)
- Provide basic information about dementia in PSHE lessons. (Bernard Gilpin Primary School)
- Study the brain and dementia in Science lessons. (Bernard Gilpin Primary School)
- Question and answer session with a local GP who is also a pupil's parent. (Coplestone Primary School)

- Pupils from other schools coming in and talking about dementia, including acting out how dementia works (normal brains let messages through, but when you have dementia some messages get blocked). (Gretton Primary School and Harewood Junior School receiving information from Newent Community School)
- Hold a debate on dementia. (Bernard Gilpin Primary School)



Appreciating the difficulties of dementia

Example resources:

- Understanding dementia worksheet, in particular the part about writing a short poem about how someone might feel with dementia (Gretton Primary School)

Example activities:

- Memory game – Putting objects on a table, covering them with a blanket, removing one and the pupils have to say what is missing (Newent Community School teaching Gretton Primary School and Harewood Junior School)
- Get pupils to tie their shoes with the wrong hand (Newent Community School teaching Gretton Primary School and Harewood Junior School)
- Imagine what it is like to step off an aeroplane in a foreign country and you have no idea where you are, what people are saying, how to get anywhere etc. (Newent Community School teaching Gretton Primary School and Harewood Junior School)

Different perspectives on dementia

Meeting people with dementia

Example activities:

- Invite people with dementia and their carers in to talk to pupils – in groups or as part of an assembly. (Bernard Gilpin Primary School)
- Form a link with a local care home (Christ Church C of E Primary School)
- Go and sing at a local care home (Coppleshole Primary School)
- Talk to someone from the Alzheimer’s Society about their work and ‘Singing for the Brain’ sessions, learn some of their songs, then visit and take part in one of the sessions. (Curzon C of E Combined School and Bernard Gilpin Primary School)





Caring for people with dementia

Example activities:

- During lessons, getting pupils to carry out their own research into how to look after a person with dementia. This could be on the internet or from leaflets that have been collected and brought in. (Curzon C of E Combined School)
- Invite people with dementia and their carers in to talk to pupils – in groups or as part of an assembly. (Bernard Gilpin Primary School)
- Q&A session with a teaching assistant whose mother has dementia. (Coplestone Primary School)

How other people feel about dementia

Example activities:

- For homework, get pupils to talk to or interview their parents or grandparents to find out what they know and think about dementia. Using something like 'This is me' can be a good start as it gets people to think about what is important to them as an individual. (Christ Church C of E Primary School)
- Use the evaluation questionnaire to find out what parents know about dementia. (Curzon C of E Combined School)

Helping people with dementia

Example resources:

- Read a book aimed at teaching children about dementia and how to help people, such as the Alzheimer's Society book 'It's me Grandma! It's me!' (Curzon C of E Combined School)



Example activities:

- During lessons, getting pupils to carry out their own research into any charities and agencies who support people with dementia and their families. This could be on the internet or from leaflets that have been collected and brought in. (Curzon C of E Combined School)
- Make a frieze of pictures showing how you can help people with dementia. (Curzon C of E Combined School)
- Talk to someone from the Alzheimer's Society to find out about the benefits of activities such as their 'Singing for the Brain' sessions. (Curzon C of E Combined School)
- Carry out role-play activities about how to treat a person with dementia. (Coppelstone Primary School)
- Think about ways to start conversations and reminiscence activities with people with dementia.
- Create a memory box to help with reminiscence activities. (Coppelstone Primary School)

Dissemination activities

Example activities:

- Most schools made local newspapers aware of their projects.
- Add information about the dementia project on the school website. Include a link to organisations such as the Alzheimer's Society. (Bernard Gilpin Primary School)
- Get the students to put on an assembly for the whole school, and invite parents, teachers, governors, relevant people from the local council and people involved in the project to attend. (Christ Church C of E Primary School)
- Get the students to put on an assembly about the project. (Curzon C of E Combined School)
- Record some of the activities you have been doing and share them in an assembly, such as video clips of role-playing. (Coppelstone Primary School)
- Share other activities in assembly, such as the memory box. (Coppelstone Primary School)
- Start activities such as an intergenerational choir or tea dances to keep the connection between pupils and older adults. (Bernard Gilpin Primary School)

Additional information

Example presentations and assemblies:

- Assembly script. (Christ Church C of E Primary School)
- Presentation imagining what it's like to have dementia and basic dementia information.
- Presentation covering what dementia is, communication skills and reminiscence activities

Example project plans and summaries:

- Overview of project plan. (Curzon C of E Combined School)
- Presentation of project work. (Bernard Gilpin Primary School)
- Summary of approach taken by Gloucestershire schools who worked together.

Secondary school and college resources, activities and information

Introduction to old age

Example resources:

- When we get old worksheet, guessing who digitally-aged celebrities are (Swanshurst School)



Example activities:

- Form a link with your local Age UK group and get pupils to do an activity like bowling with older people who may or may not have dementia (Stoke Damerel Community College)

Dementia information and awareness

Example resources:

- Understanding dementia lesson plan (Swanshurst School)
- What do you know about dementia? Worksheet (Swanshurst School)
- Dementia awareness lesson plan (Northfleet School for Girls)
- Dementia awareness lesson plan (St John's Catholic Comprehensive School)



Example activities:

- Dementia specialists visiting school and talking to pupils (Newent Community School)
- Whole campus awareness raising and fund raising (Gloucestershire College)
- Song writing competition (Stoke Damerel Community College)
- Project on the effects of dementia (Stoke Damerel Community College)
- Money raising activities (Stoke Damerel Community College)
- Writing statements, feelings and questions about dementia on luggage labels and hanging them on artificial Christmas trees (Northfleet School for Girls)



- Create videos, posters and leaflets to raise awareness (Stoke Damerel Community College)

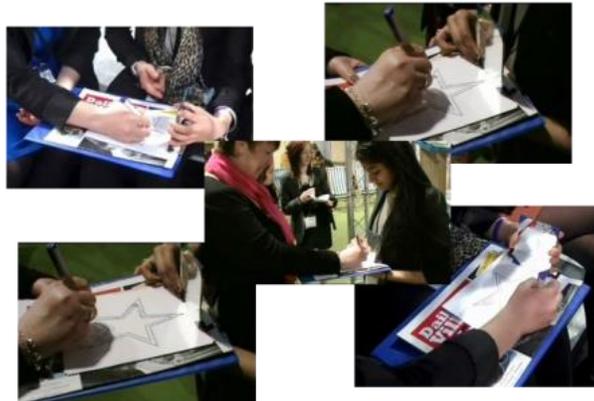
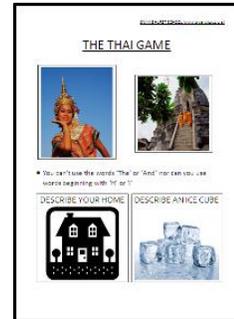


- Watch dementia-related films as part of a 'dementia afternoon' (Okehampton College)

Appreciating the difficulties of dementia

Example resources:

- The THAI game – describing an object without using ‘the’, ‘and’ or words beginning with ‘H’ or ‘I’ (Swanshurst School, Newent Community School)
- The star game – drawing round the outline of a star but only from looking at its reflection in a mirror (Northfleet School for Girls)



- My Grandfather, My Grandmother DVD

Example activities:

- Distraction – trying to read a book whilst wearing gloves, goggles and listening to loud music (Northfleet School for Girls)

Different perspectives on dementia

Meeting people with dementia

Example resources:

- Meeting those working and living with dementia lesson plan (Swanshurst School)

Example activities:

- People with dementia visiting school and answering questions from pupils (Swanshurst School)
- Work with people with dementia to develop life story books (Northfleet School for Girls)



- Work with people in care homes to create memory boards (Stoke Damerel Community College)
- Develop links with a local memory cafe (The Gryphon School, Okehampton College)
- Visit a local care home (The Gryphon School)
- Go to a 'Singing for the brain' session (The Gryphon School)

Caring for people with dementia

Example activities:

- Question and answer session with staff who have been affected by dementia (Newent Community School, Okehampton College)
- Invite carers and care workers to come in and talk to pupils (Newent Community School, Swanshurst School, The Gryphon School)
- Develop links with a local memory cafe (The Gryphon School, Okehampton College)

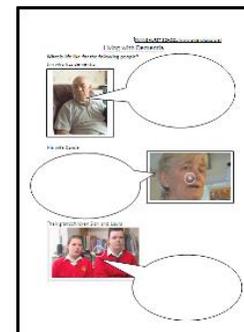
How other people feel about dementia

Example resources:

- Living with Dementia worksheet (Swanshurst School)

Example activities:

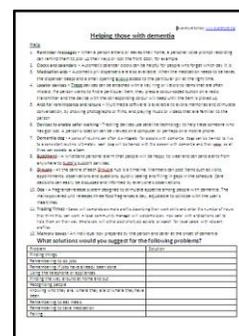
- Writing statements, feelings and questions about dementia on luggage labels and hanging them on artificial Christmas trees (Northfleet School for Girls)
- Interview parents and older family members and write about it (Stoke Damerel Community College)
- Write a play and music about the effects of dementia (Stoke Damerel Community College)



Helping people with dementia

Example resources:

- Helping those with dementia – assistive technology worksheet (Swanshurst School)
- Helping those living with dementia lesson plan (Swanshurst School)
- BME planning and provision of dementia services lesson plan (Northfleet School for Girls)



Example activities:

- Invite people from different professions and organisations to come and talk to the pupils (The Gryphon School, Swanshurst School, Newent Community School, Northfleet School for Girls)
- Invite a specialist in assistive technology to come and talk to pupils (Gloucestershire College)
- Get older pupils to teach what they have learnt about assistive technology to younger pupils (Gloucestershire College, Newent Community School)
- Fund raising activities (Gloucestershire College, Stoke Damerel Community College)
- Create memory aids such as a 'memory jogger' card game or memory sticks with reminiscence activities (Stoke Damerel Community College)
- Create a memory box or dementia scrapbook (Northfleet School for Girls)

Dissemination activities

Example activities:

- Teach other pupils in order to share knowledge (Gloucestershire College, Newent Community School, Harewood Junior School, Gretton Primary School)
- Create dementia champions or ambassadors within the school (Swanshurst School, Okehampton College, Northfleet School for Girls)
- Present posters at different events and talk about their development in front of an audience (Stoke Damerel Community College)
- Hold a tea party to share Life Story Books with people with dementia (Northfleet School for Girls)
- Put on a play about the effects of dementia (Stoke Damerel Community College)
- Perform a song about dementia as part of a dementia awareness evening (Stoke Damerel Community College)

- Design posters and displays around dementia (Newent Community School, Stoke Damerel Community College)



- Create a dementia mural for the Alzheimer's Society (Stoke Damerel Community College)
- Hold an afternoon tea party for the local community (Okehampton College)
- Hold a competition to write a slogan for a mug (Newent Community School)
- Cover the subject in assembly and present what has been done in the project, preferably inviting back external people who have been involved (Northfleet School for Girls, Newent Community School)
- Present the project at appropriate events (Swanshurst School, Stoke Damerel Community College, Newent Community School)



Additional information

Example presentations:

- Understanding dementia presentation (Swanshurst School)
- Understanding dementia presentation (Northfleet School for Girls)
- Dementia presentation (Newent Community School)
- Dementia presentation (The Gryphon School)
- How dementia affects someone presentation (Newent Community School)
- Challenging stigma presentation (Newent Community School)
- Meeting those working and living with dementia presentation (Swanshurst School)
- Helping those living with dementia presentation (Swanshurst School)

Example project plans and summaries:

- Project summary (Newent Community School)

Project/lesson summary (The Gryphon School)